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# LDN low dose naltrexone

# **201 Personal Testimonies**



Produced by LDN Research Trust for International LDN Awareness Week 18-24 October 2010



Is low dose naltrexone (LDN) benefiting these conditions?

Multiple Sclerosis Ankylosing Spondylitis Crohn's Disease Hepatitis B & C Chronic Fatigue Syndrome Fibromyalgia Cancer Rheumatoid Arthritis Peripheral Neuropathy Hashimoto's Thyroiditis Goitre Psoriasis

# Over 200 testify

"Yes it is"

We hope you will too

Background to the 2010 edition...

### In 2009 we brought you '100 Reasons Why'.

### In this 2010 edition

### we present you with over 200 testimonies

Headers of stories first featured in 2009 remain shaded in 'bright blue'

Headers of stories new to this 2010 edition are shaded in `light blue'

Updates were sought from 2009 contributors:

We asked the question

'Are you still taking LDN, and is it still benefiting you?.

42 responded, some email addresses had lapsed, and for unknown reasons, some contributors did not respond.

STORY NUMBER	CONTENT	CONDITION	PAGE
	2009 Edition – 100 Testimonies		
	2010 Edition – 101 Testimonies - new	w to this 2010 edition	
	LINDA ELSEGOOD of LDN RESEARCH TRUST		10
	TESTIMONIES		
1	Adrian R, UK	Multiple Sclerosis	11
2	Adrienne H, UK	Multiple Sclerosis	12
3	Alan H, UK	Multiple Sclerosis	12
4	Aletha W, USA	Psoriasis	13
5	Alexandra M, USA	Multiple Sclerosis	16
6	Amanda B, UK	Multiple Sclerosis	17
7	Annmarie B, UK	Multiple Sclerosis	18
8	Art H, USA	Multiple Sclerosis	22
9	Atif A, Scotland	Multiple Sclerosis	24
10	Audrey H, UK – NB significant update	Multiple Sclerosis	25
11	Bentley L, USA	Parkinson's Disease	29
12	Beth W, USA	Multiple Sclerosis	32
13	Bev K, USA	Multiple Sclerosis	36
14	Bill R, USA	Multiple Sclerosis	37
15	Bill Z, USA	Crohn's Disease	40
16	Bob Lawrence, MRCS LRCP, UK	Multiple Sclerosis	41
17	Brenda M, Northern Ireland	Multiple Sclerosis	54
18	Brenda P, USA	Multiple Sclerosis	54
19	Bridget B, New Mexico	Ankylosing Spondylitis	58
20	Bruce A, UK	Multiple Sclerosis	60
21	Bruce R, USA	Multiple Sclerosis	61
22	Cam P, USA	Multiple Sclerosis	61
23	Carol L, USA	Multiple Sclerosis	62
24	Carole, USA	Multiple Sclerosis	63
25	Cheryl M, Australia	Multiple Sclerosis	65
26	Chris M, USA	Hepatitis C	66
27	Christian C, UK	Multiple Sclerosis	68
28	Christine H, UK	Multiple Sclerosis	70
29	Christine K, UK	Multiple Sclerosis	71
30	Christine L, Ireland	Multiple Sclerosis	73
31	Christine R, UK	Multiple Sclerosis	75
32	Claire S, UK	Multiple Sclerosis	76
33	Clare F, France	Multiple Sclerosis	77
34	Colin T, UK	Multiple Sclerosis	79
35	Connie A, USA	Diabetes, Hashimoto's	80
		Disease, Hypertension	
36	Cristina G, UK	Multiple Sclerosis	83
37	Crystal N, USA	Multiple Sclerosis	84
38	Daisy Z, UK	Multiple Sclerosis	86
39	Daniel B, USA	Crohn's Disease	88

40	Darlene N, USA	Systemic Lupus	91
		Erythematosus (SLE)	
41	David C, USA	Stomach Cancer, Tumors	93
42	David M, USA	Multiple Sclerosis	94
43	David N, UK	Multiple Sclerosis	95
44	Davinia W, UK	Multiple Sclerosis	96
45	Deanna V, USA	Multiple Sclerosis	97
46	Deidre A, Hong Kong	Cervical Cancer	98
47	Denis T, USA	Chronic Inflammatory	101
		Demyelinating	
		Polyneuropathy (CIDP)	
48	Denise G, USA	Multiple Sclerosis	102
49	Di M, Australia	Myalgic Encephalomyelitis	103
		(M.E.)	
50	Dianne W, Australia	Multiple Sclerosis	105
51	Didem K, Turkey	Multiple Sclerosis	106
52	Donette G, USA	Ankylosing Spondilitis	108
53	EF, UK	Multiple Sclerosis	109
54	Eileen P, Ireland	Multiple Sclerosis	110
55	Elise K, South Africa	Multiple Sclerosis	111
56	Elise P, Panama	Multiple Sclerosis	112
57	Ellen D, USA	Multiple Sclerosis	113
58	Emily J, USA	Multiple Sclerosis	117
59	Eva H, USA	Rheumatoid Arthritis,	119
		Dermatomyositis	
60	Fabienne B, UK	Multiple Sclerosis	125
61	Farah C, UK	Multiple Sclerosis	125
62	Francie S, USA	Multiple Sclerosis	127
63	Gary C, Australia	Primary Lateral Sclerosis	128
64	Gemma Y, UK	Multiple Sclerosis	131
65	Geraldine O, Ireland	Multiple Sclerosis	134
66	Ginger M, Canada	Multiple Sclerosis	135
67	Greta T, UK	Multiple Sclerosis	136
68	Hannah G, UK	Multiple Sclerosis	137
69	Helen O, UK	Chronic Fatigue Syndrome	138
70	Huw E, UK	Multiple Sclerosis	139
71	Jackie B, USA	Cancer, Hashimoto's Disease	141
72	Jan A, UK	Multiple Sclerosis	141
73	Jane W, UK	Multiple Sclerosis	142
74	Janet T, UK	Multiple Sclerosis	143
75	Janne, UK	Multiple Sclerosis	144
76	Jay D, UK	Multiple Sclerosis	145
77	Jayne T, USA	Multiple Sclerosis	146
78	Jean M, USA	Multiple Sclerosis	148
79	Jeanette M, UK	Multiple Sclerosis	150
80	Jeanette M, USA	Multiple Sclerosis	151
81	Jeannine E, USA	Multiple Sclerosis	151
82	Jeni S, UK	Psoriasis	152
83	Jennifer F. USA	Multiple Sclerosis	152
84	Jennifer F, Australia	Ankylosing Spondylitis	155

85	Jill G, UK	Multiple Sclerosis	157
86	Jody J, USA	Fibromyalgia	158
87	John D, Ireland	Non Small Cell Lung Cancer	159
88	John M, Australia	Multiple Sclerosis	160
89	John O, UK	Multiple Sclerosis	161
90	Jon C, UK	Multiple Sclerosis	161
91	Jon S, UK	Multiple Sclerosis	162
92	Jonathan D, UK	Multiple Sclerosis	163
93	Joyce C, USA	Hepatitis B	165
94	Judy H, USA	Fibromyalgia	171
95	Kacey J, UK	Multiple Sclerosis	175
96	Karen G, UK	Multiple Sclerosis	178
97	Karen H, USA	Rheumatoid Arthritis	182
98	Kathryn R, UK	Multiple Sclerosis	186
99	Kathy R, UK	Multiple Sclerosis	187
100	Kelli B, Australia	Multiple Sclerosis	187
101	Kim S, UK	Multiple Sclerosis	189
101	Kristie S, USA	Multiple Sclerosis	191
102	LarryGC, USA	Multiple Sclerosis	191
105	Laura, UK	Multiple Sclerosis	193
101	Laura W, Ireland	Multiple Sclerosis	198
105	Leslie J, USA	Multiple Sclerosis	200
100	Linda C, USA	Multiple Sclerosis	200
107	Linda Elsegood, UK	Multiple Sclerosis	201
108	Lisa C, UK	Multiple Sclerosis	202
110	LISA C, UK	Multiple Sclerosis	210
110	Lynne M, Scotland	Multiple Sclerosis	214
111	Maija H, Finland	Chronic Fatigue Syndrome/	215
112		Myalgic Encephalomyelitis	210
		(M.E.)	
113	Malcolm W, USA	Multiple Sclerosis	217
114	Margaret S, France	Rheumatoid Arthritis, Small	226
		Carcinoid Tumour	220
115	Marie D, Australia	Multiple Sclerosis	235
116	Marjorie S, USA	Frontotemporal Dementia &	236
		Parkinson's Disease	250
117	Mark J, UK	Multiple Sclerosis	236
118	Mark S, UK	Multiple Sclerosis	237
119	Mark W, UK	Multiple Sclerosis	237
120	Marna M, USA	Ulcerative Colitis, Primary	239
120		Sclerosing Cholangitis (PSC)	235
121	Martin P, Germany	Multiple Sclerosis	248
122	Mary B, UK	Multiple Sclerosis	251
123	Mary L, UK	Multiple Sclerosis	251
123	Maurey G, USA	Multiple Sclerosis	251
125	Michael G, UK	Multiple Sclerosis	252
125	Michelle X, UK	Multiple Sclerosis	256
120	Mike M, UK	Multiple Sclerosis	250
127	Nathan K, USA	Multiple Sclerosis	258
120	Nettie E, New Zealand	Peripheral Neuropathy,	259
123			233

		Hashimoto's Thyroiditis, Goitre	
130	Nikolaos P, UK	Multiple Sclerosis	26
131	Noreen M, USA	HIV	26
132	Pami, USA	Breast Cancer	26
133	Pat P, USA	Multiple Sclerosis	26
134	Patrick R, UK	Multiple Sclerosis	26
135	Pat U, USA	Multiple Sclerosis	27
136	Paul B, USA	Crohn's Disease	27
137	Paul C, UK	Multiple Sclerosis	27
138	Paul S, UK	Multiple Sclerosis	27
139	Paul W, UK	Kidney Cancer	27
140	Paul W, USA	Multiple Sclerosis	27
141	Peta S, UK	Multiple Sclerosis	27
142	Peter S, UK	Multiple Sclerosis	28
143	Philip M, Australia	Sjogren's Syndrome	28
144	Pierre, Belgium		28
		Ankylosing Spondylitis (AS)	
145	PN, UK	Multiple Sclerosis	28
146	Rachel C, UK	Multiple Sclerosis	28
147	Rachel R, USA	Crohn's Disease	28
148	Ray F, UK	Multiple Sclerosis	29
149	Raynor H, UK	Multiple Sclerosis	29
150	Rebecca S, UK	Multiple Sclerosis	29
151	Richard, UK	Multiple Sclerosis	29
152	Richard P, UK	Multiple Sclerosis	29
153	Roger W, USA	Parkinson's Disease	29
154	Ross S, Australia	Renal Clear Cell Carcinoma	29
155	Sal A, Australia	Multiple Sclerosis	29
156	Sally D, UK	Fibromyalgia	30
157	Samantha B, UK	Transverse Myelitis	30
158	Samreena K, UK	Multiple Sclerosis	30
159	Sandra B, UK	Multiple Sclerosis	30
160	Sandra J, UK	Multiple Sclerosis	31
161	Sandra L, UK	Multiple Sclerosis	31
162	Sandra R, USA	Sjogren's, Rheumatoid	31
		Arthritis, possible	
		Autoimmune Hepatitis; with	
		Lupus Symptom History	
163	Shana S, USA	Multiple Sclerosis	31
164	Shane ANON, UK	Multiple Sclerosis	3
165	Sherri R, USA	Multiple Sclerosis	3:
166	Sherri W, USA	Multiple Sclerosis	3
167	Silvia L, UK	Multiple Sclerosis	3
168	Simon C, UK	Multiple Sclerosis	32
169	Sterling R, USA	Hepatitis C	32
170	Steve W, UK	Multiple Sclerosis	32
171	Steven F, UK	Multiple Sclerosis	32
172	Steven N, UK	Multiple Sclerosis	33
172	Sue G, UK	Multiple Sclerosis	33
175			
1/4	Sue G, UK	Multiple Sclerosis	33

175	Sue T, USA	Multiple Sclerosis	334
176	Suzanne H, UK	Multiple Sclerosis	335
177	Tamar C, UK	Multiple Sclerosis	336
178	Tami M, USA	Multiple Sclerosis	337
179	Tammy, USA	Multiple Sclerosis	337
180	Tanja H, USA	Multiple Sclerosis	339
181	Terri H, USA	Autism	341
182	Tim D, USA	Fibromyalgia	342
183	Tim W, UK	Multiple Sclerosis	344
184	Tina D, USA	Multiple Sclerosis	345
185	Tina E, USA	Cytomegalovirus & Chronic Fatigue Immune Deficiency Syndrome (CFIDS)	346
186	Tina F, UK	Multiple Sclerosis	347
187	Tracie Q, USA	Multiple Sclerosis	350
188	Trish B, UK	Myalgic Encephalomyelitis (M.E.)	355
189	Trish K, Australia	Multiple Sclerosis	356
190	Trish P, USA	Multiple Sclerosis	358
191	Trisha C, UK	Multiple Sclerosis	359
192	Vicki F, USA	Multiple Sclerosis	363
193	Vickie A, USA	Multiple Sclerosis	367
194	Vickie J, Canada	Multiple Sclerosis	369
195	Wanda L, Canada	Multiple Sclerosis	370
196	Wendy – ANON, UK	Multiple Sclerosis	371
197	Wendy L, Australia	Autism, Colitis	371
198	Wendy L, UK	Multiple Sclerosis	376
199	Zillah B, UK	Multiple Sclerosis	378
200	Zoe K, UK	Crohn's Disease	381
201	Zora T, West Indies	Multiple Sclerosis	383
	ACKNOWLEDGEMENTS		
	International LDN Awareness Week eBook 2010 Jayne Thomas Sherri White John Donnelly		385
	International LDN Awareness Week eBook 2011 Jayne Thomas Sally Darin-Brame Suzanne Harvey		
	International LDN Awareness Week 2009		

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386

an old drug a controversial treatment patient testimonies of success across a wide range of diseases linked by immune system dysfunction but

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International LDN Awareness Week 18-24 OCT 2010 http://www.ldnresearchtrust.org

Birmingham LDN Aware Conference 23rd October 2010

please also support

THE INTERNATIONAL LDN PETITION RESESARCH INTO LDN FOR MS

www.thepetitionsite.com/1/sign-support-the-campaign-for-research-trials-in-low-dose-naltrexone-for-multiple-sclerosis

International LDN Awareness Week ebook by

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We are all volunteers at the Trust No one gets paid, and the trust receives no funding

Linda & Leo



"I work towards the day when everyone's able to access LDN easily, wherever they live in the world... and that day is getting closer." July 2009

10

YOU SHOULD **KNOW ABOUT** 

LDN

Low dose naltrexone

201 Personal Testimonies

Produced by LDN Research Trust for International LDN Awareness Week 18-24 October 2010

# My sincere thanks to all who contributed

#### Adrian, UK

April 2005 - Secondary Progressive Multiple Sclerosis (SPMS)

2006 - LDN

I was diagnosed with Relapsing Remitting Multiple Sclerosis in April 2005.

My symptoms got gradually worse over a period of two years, then I had a bad relapse and my Neurologist sent me to hospital.

After an MRI and a lumbar puncture, the Neurologist gave me the news that my MS was probably Secondary Progressive, and I was discharged within a week.

My wife found the Multiple Sclerosis Society website shortly afterwards, and I started to use it daily. During a conversation with a man called George, I heard about LDN and started to research it further.

I thought this drug might help me, and I desperately sought a way of getting it. The usual channels, that is; doctors and neurologists; didn't want to hear about it, so I contacted someone off the website and spoke to them, and she kindly gave me Linda Elsegood's number.

Linda gave me all the information I needed, and it was finally sorted out about 3yrs ago.

Since starting on LDN, my life has changed for the better. I no longer experience relapse after relapse. The fatigue has improved, and I've started to feel well again. I've even started to drive again, after 8 months of being unable to.

During one of my earlier relapses, I'd lost most of the use of my left hand, but one night about 3 months after I started on LDN, I felt a strange feeling, like an explosion in my fingers, and suddenly, I'd regained almost all the use of my hand.

Since starting LDN I've had no relapses. I have had a few bad viruses, but I've fought them off and returned to being as well as I was before.

I truly believe my i.s. now functions very well. I now walk, with crutches, and I'm able to drive a manual car. I have independence, and I can get out when I want, and no longer spend months being housebound.

All this improvement started with LDN, and coupled with my now weekly visits to an MS therapy centre, I'm feeling as well as I have in years. It's true that I get the odd bad day, but it's only a day not 8 months!

### 2

#### Adrienne H, UK 1977 - Multiple Sclerosis 2004 - LDN

I was diagnosed with MS in my late twenties, some 32 years ago.

Having secondary progressive MS now, my condition continued to deteriorate and I am now 'wheelchair-bound', unable to weight-bear.

I was getting worse and worse at an ever-increasing rate. During my HBO session at my local MS Therapy centre five years ago, I was talking to a fellow member who had just started taking Low Dosage Naltrexone (LDN). Her positive experience -- being able to walk instead of using a wheelchair -- inspired me to ask my doctor if I could be considered to take LDN, showing him the research that had been done on the drug.

### 3

#### Alan Harvey, UK 1997 - Multiple Sclerosis 2004 – LDN

I had numerous problems before I was diagnosed, but as I was fit and active playing tennis at a high standard I discounted them. Things came to a head when my left leg became very heavy after a hard set, by the time the second set was over I had great difficulty playing at all, my GP arranged an MRI scan and consultant appointment.

I saw the consultant before my scan, he examined me and said he was 95% sure what was wrong with me but would wait for the scan result. I asked for the diagnosis and was amazed when he said I had MS. The scan confirmed his diagnosis.

It's difficult to remember exactly what happened 12 plus years ago when I was diagnosed, but I do remember researching MS and being terrified reading the information I found.

During the year after diagnosis I spiralled downwards and finally hit rock bottom with a crazy failed suicide bid!

As I could not play tennis anymore I was introduced to bowls, and that game saved my life. I found I could compete with able-bodied players on a nearly level playing field. In fact I have played for England in the Para Olympics.

Over the years I was given no medication except Procarin. I've tried most alternatives, such as 'Goodshape's' formula and numerous vitamins. Don't know if any of them worked as I was still progressing downwards, but I tried them anyway.

Then I read a report on LDN about 5 years ago and contacted Dr Bob Lawrence to try it.

The results were amazing!! All my symptoms improved and my fatigue disappeared. Before LDN, I could only play 1 bowls match, then go to bed. Now I can play 2.

I am now nearing my mid 60s, and I can do most things others of a similar age can do, even though I have MS. My GP is amazed, but still will not prescribe.

#### UPDATE March 2010

Yes, I'm still taking LDN, though it's a little more difficult to obtain than last year.

Bob Lawrence had been my prescriber since I started taking it, but because of 'stupid government legislation' he cannot send it to me directly.

So I now send Bob the order and he faxes to the States and they post it to me, and it arrives within a few days. Someone in government must have a master plan, but who knows how this lot manage to get out of bed in the morning, let alone run a country!

On a brighter note, LDN has given me back my life. I will keep taking it, even if I have to fly to America.

### 4

Aletha W, USA 1977 – Psoriasis August 2008 - LDN

I've had dry patchy spots on the back of my scalp since my teenage years.

My earliest recollection of their development was while I was in French class. I began scratching at spots that were itchy. Within a few short months I was doing this with increased frequency, scratching and picking away at the dry skin almost unconsciously throughout the day.

The dry, itchy spots seemed to move around from one spot to the next, and the severity would also vary week to week. My persistent scratching sometimes resulted in open sores where scabs would then form.

The dry, scaly patches were hidden beneath my blond hair and though no-one could tell I had Psoriasis just by looking at me, I was a typical teenager, and so very selfconscious and concerned someone would notice it. When all of my friends played with each other's hair (as teenage girls do regularly), I'd decline so it wouldn't be discovered.

Once in a while the dry, flaky areas would creep down just below the neckline, and this would keep me from putting my hair up. I'd also wear light-colored clothing so the flaking wouldn't show up on my clothes, and I found myself constantly looking across my shoulder to check if anything was noticeable or needed to be brushed off.

Over the years I tried various shampoos, creams, deep conditioners etc. Doctors would prescribe medicines, special shampoos, or tell me to simply stop scratching. This of course was not an option as the itching was too strong a temptation and it had become an automatic thing for me to do.

I was also very careful in selecting new hairdressers. Once I explained my condition to a new hairdresser and felt comfortable with him/her, I'd stay with them for a long while regardless of whether I liked how they did my hair. In my 30th year, my husband's secretary told me she did hairdressing on the side. She was such a kind person and I loved her hairstyle, so I decided to give her a try.

When I got to her house we were talking away and I completely forgot to warn her. She shampooed my hair and began to comb through it. It had been a particularly bad month and the scaling and redness was very prevalent. She gasped loudly and stepped back lifting her fingers from my scalp.

I quickly explained and told her about my struggles with this ailment. She finished up my haircut and asked me if it was contagious and if she should sterilize her hands. I left humiliated and crying all the way home. I also worried she might talk to others at my husband's work.

Not long after turning 40, I found out about Low Dose Naltrexone (LDN) while researching treatments for my husband who'd been recently diagnosed with Multiple Sclerosis. I'd read many inspirational stories about how LDN had eased symptoms, halted disease progression, and given people their lives back. It was explained to me that LDN tricks one's body into producing a ton more endorphins, which somehow up-regulate the immune system, and; once the immune system has what it needs, it seems to better remember how to behave.

Of course, I spent countless hours gathering as much credible information on this drug treatment as I could find because I wanted to be absolutely certain it was a legitimate treatment option for my husband.

When I first began my research, I joined the official Low Dose Naltrexone (Yahoo) chat site that was set up by Dr. David Gluck and his son Joel. Chatting with others that were using this drug and gathering information on this drug gave us the courage to give it a try.

In the end, the personal stories were what convinced us this drug was worth trying, but apparently it was not enough for US to be convinced it was legitimate, for we then had to struggle to find a doctor to prescribe it.

Thankfully, the LDN ended up being just what my husband needed. His MS symptoms went away in rapid succession, and his feeling of well-being returned. Our decision could not have been more right.

As my husband was doing quite well taking LDN, I decided to get more involved in the LDN chat site so I could help others, share information I'd gathered, and tell my husband's story as encouragement, particularly for those who had too little support from health professionals or loved ones. Through the chat site I learned about many others' experiences, and about how LDN was helping their huge range of ailments.

One of the ailments I was hearing about was cancer, and there was a lot of cancer in my family. After my husband had been on LDN for over 3 years I asked his doctor what she thought about my trying this drug as a cancer preventative. I also told her about the psoriasis on my scalp.

A compounding pharmacy in Florida had made a topical formulation of LDN, and they were trying it for skin cancer. The doctor thought we should give that a try first.

I applied the topical formulation once a day for over 4 months, but there was no improvement and it almost seemed to make the problem worse. I'd had such high hopes it was extremely disappointing. I gave it away and asked the doctor to forget about the psoriasis, telling her I just wanted to try LDN in the capsule form as a cancer preventative. She agreed and I began taking 4.5mg LDN in the capsule form.

Although I'd heard a few successful stories regarding LDN and Psoriasis, I wasn't expecting it to benefit mine because the LDN topical formulation hadn't done anything for me. Three months passed. I didn't notice any difference in my psoriasis but figured it was worth continuing for cancer prevention.

Then, just after my 3rd month of taking LDN, I was at a large continuing education class that I attend annually. I was late to class so I needed to sit in the back row. In the middle of the class I noticed a few people reaching their fingers up to their head to scratch.

Then it dawned on me...

I had not scratched my head once during that day. As the days went by I noticed I didn't have any dry spots anymore... for the first time in over 25 years! I was elated! I could now feel at ease in company and not constantly worry about who could see the back of my head, or what color of clothing I had to wear to hide the fall-out!

By December 2008 my psoriasis 'receded' and it's been kept well under control by my 4.5mg nightly dose of LDN.

I say 'receded' because initially there was no trace of Psoriasis, and I was thrilled; but it has returned occasionally since then. When it appears, it's smaller, milder, and barely noticeable to anyone except me. It just pops up in a small spot somewhere for a short while, usually in response to periods of increased stress, insufficient sleep, or poor diet. Who'd guess?

In the past 2 years I've missed taking my LDN a couple of times, for maybe one or two days, but that hasn't caused any adverse change.

Apart from the psoriasis, I'm pretty healthy. I've rarely been sick in my life and even when I was, it was just the odd cold or two. Since starting on LDN, I sometimes feel as though a little something is coming on, but it never develops any further than that.

The interesting thing about LDN is that it's helped me to identify a few dietary triggers I may not otherwise have noticed: If I don't eat sweets, dairy, and bread, everything goes well. They're okay occasionally, but if I eat them on a regular basis my Psoriasis can pop up.

I take a number of supplements and a few antioxidants. I haven't noticed any particular improvement since starting on any of them, but that's not why I take them. I see them

more as a maintenance programme. Sometimes I forget to take them for a week or so but there's no adverse effect.

My psoriasis has never been physically debilitating, but it was mentally debilitating.

I was also worried about the potential for the psoriasis to develop into psoriatic arthritis further up the track. I'm so glad I found LDN.

### 5

#### Alexandra M, USA November 2006 - Multiple Sclerosis January 2007 – LDN

I'm nearing 60 years old. I was diagnosed with Multiple Sclerosis in November 2006. I had had a number of falls, and in 2005, I broke both of my wrists in a fall.

Unlike some people I've read about who were frustrated that they couldn't get a diagnosis, I avoided trying to find out what was wrong with me. I believe I knew it was something serious and simply didn't want to find out. The falls, dragging of my right foot and limp and slight numbress in my fingers, however, had been ongoing for several years. I also was experiencing fatigue.

At my family doctor's suggestion, I went to the Virginia Mason Center in Seattle. That's where I was diagnosed. At the time of my diagnosis I was in my mid 50s. My diagnosis was definite MS, most likely 'primary progressive'. I have never had a 'relapse', and the symptoms I have do not go away or abate, so this makes sense to me. I was told that I had lesions on my spine, one high up, and that there appeared to be virtually no impact on the brain.

So-called autoimmune diseases seem to run in my family. My father, who died in his early 90s, was diagnosed with RRMS when he was in his 40s. My youngest sister was diagnosed with myaesthenia gravis. There also have been problems with depression.

The neurologist suggested I try Copaxone. I have excellent insurance coverage, but I still wasn't comfortable with the cost. Also, I hated the site reactions, and I questioned the theory behind the drug. I didn't really like the idea, but did try it for a few days. After a lot of research on the internet I discovered people talking about LDN.

At the time of my diagnosis I was experiencing a fair amount of fatigue. I was also feeling very stressed and 'down' as a result of the diagnosis. I noticed that I was beginning to have bladder urgency, and also had to get up several times in the night to urinate. Not long after my diagnosis I had a lot of numbness in my right foot, and it seemed that the tightness (MS hug) was increasing in my arms. (The dexterity in my right hand is compromised slightly, and I have general weakness on my right side.) At the time, to put it bluntly, I was terrified.

I felt that I was headed downhill. I asked my GP if he would prescribe LDN, and I took information from the internet with me. He said he would have no problem doing so, and I

began taking it in early January 2007. Almost immediately, my bladder problems improved. I did initially notice increased stiffness in some of my muscles, but I had read this could happen, so I decided to ride it out.

My mood improved a lot right away. Was it because of the LDN, or because I felt I was on the right track? I don't know, but the emotional improvement was significant. For about 25 years now I have had daily exercise – seven days a week – that began with 20 minutes of brisk walking, then went to 30, then 40 and is now 50 minutes. Several years ago, I began meditation with a goal of meditating daily. In practice, it's now more like several times a week. After starting LDN, it seems that I am able to do much more and have more energy. Is it from the LDN or because I'm trying harder?

When I first started taking LDN I did have very vivid dreams. I think my dreaming is still somewhat affected. I did notice some sleep disturbance at first, but that has passed.

I had read that improvements from LDN could be subtle and that the main hope was for a halt in progression. I also learned that it's a long-term process and that the biggest impacts might take years. My plan all along was to give it at least five years, no matter what. I believe my progression has stopped and that I have had major improvements.

My intuitive sense is that LDN had SAVED me. I thank God for Dr. Bihari and all the other pioneers, and I thank all those who tell their stories on the internet so that people like me have a guiding light. I am SO GRATEFUL that this drug exists.

I will keep taking it... I am not cured, but I am happy. And, I feel that my condition is as good as possible under the circumstances.

I take the LDN at bedtime. It is formulated with lactose. Initially I obtained it from a local compounding pharmacy, but it has since greatly reduced its services, so I now get my prescription filled at Irmat Pharmacy in New York City. I told my doctor I had no way of proving that my improvements resulted from LDN, and he suggested I stop for a while to see whether I got worse. I am not willing to do that!

### 6

#### Amanda B, UK 2005 - Secondary Progressive Multiple Sclerosis (SPMS) 2006 - LDN

I was diagnosed with Secondary Progressive MS 4 years ago and I did not know about LDN until 3 years ago at which point I started to get it prescribed.

Before LDN I was suffering bladder problems fatigue and brain fog but since taking the LDN all of that has stopped.

Over the past few weeks I have been having a lot of pain with my back so I have had to come off my LDN as I have had to take Co-Codamol for the pain but today I have

noticed that for the first time in 3 years I have got a cold so today I have decided that the LDN has kept colds at bay.

I wish I had known about LDN at the beginning, but the medical profession did not know anything about it.

#### Annmarie B, Wales 1972 – Multiple Sclerosis October 2007 – LDN

In 1969, I had a TB vaccination. I was only in my teens, but from that time, my health became erratic.

I continually felt 'wrong'. In my first year sixth, I was absent from school for weeks at a time and whilst I managed to take my 'A' level examinations, my results were disappointing. Everyone, including myself, believed that it was stress-related.

I went to college but once again seemed to be making regular visits to the doctors. Eventually, I was given tranquillisers - as once again stress was diagnosed. I managed to finish my first year but only a couple of days into the summer vacation, symptoms flooded in fast and furiously. My handwriting was practically illegible: I couldn't hit the right notes on the piano; I couldn't walk in a straight line, drink from a cup; parts of my body were numb or had 'pins & needles' - and I was talking with a slur.

At the end of the summer (1972), I had a lumbar puncture and was diagnosed with MS. I was given a course of cortisone injections and no other treatment. At the time I had a few minor symptoms, but nothing that stopped me from working - including running my own business and having 2 children - a time I felt really well. For many years, I was never fully convinced that my diagnosis was correct.

I went back to full-time work when my son was 8 months old, in March 1988. I'd been working long hours and didn't realise I was pregnant for a 2nd time, until I had a miscarriage. I really wanted to spend more quality time with my 3 year old son, so I semi-retired from work in 1990. Not long after, my mother-in-law was diagnosed with bowel cancer, and passed away in December 1992 (within a year of the birth of our daughter).

In 1993, I had a car accident and suffered whiplash. I had problems with legs from that time, increased fatigue, broken sleep etc. In 1996, I had an MRI scan which confirmed lesions, but we did not know if they were from the original attack in 1972 or were more recent.

In 1997 I had another car accident: My car hit an oil patch and careered off the road hitting a fence. Unfortunately, a concrete post was behind the fence. My car ricocheted back over the road and landed in a garden. I was concussed and suffered whiplash again!

The period between 2003 and 2004 was a particularly bad time. My mum had a major stroke. Visiting and caring for her involved travelling to Birmingham every weekend for a year. She passed away in June 2004 and my dad passed away 5 months later, from a broken heart. Then a very good family friend passed away 5 months after that from prostrate cancer, and our dog was run over in May 2005.

I was very run down and tired, and I couldn't seem to improve and get well.

In November 2005 I had my 2nd ever relapse - with symptoms that were worse than when I was first diagnosed!! I was unable to walk for a time and had real problems with my left leg especially. I attended an MS Clinic in Cardiff and was assigned an 'MS nurse', but was discharged by June 2006, with no follow-on treatment - but I wouldn't have accepted any anyway!!!

At the time I had brain fog and very bad balance, was unable to walk more than a few steps without help, had extreme fatigue, and after standing for a time found that I was doubling over unable to hold myself upright, etc, etc. I know that I wasn't as poorly as others I saw at the MS clinic but I did feel that I was being sent away until I was!!

All my nurse offered was a blue badge (which I accepted) and a walking stick (which I did not!!). Seemed to me, she had a shopping list and was just ticking it off as I deteriorated. I could do that myself!! I felt I was being left to get worse.

Over the following year or two I was extremely depressed, frightened, and felt very alone. I continued deteriorating and felt there was no hope, and that I would soon be in a wheelchair.

I had a shoulder operation in September 2007. While I was recovering I began checking out MS on the internet and I fell upon LDN. When I found the link to Dr Bob Lawrence, I rang him, had a long chat, and the following week my husband took me to Swansea. I spent 2 to 3 hours with him talking about anything and everything concerning LDN, MS etc. There was no downside as far as my husband and I were concerned, and I started taking LDN at the beginning of October 2007.

My local doctor won't prescribe LDN, but she's watching me very closely. As I continue to improve, I can't see how she can hold out indefinitely.

I also take the vitamins, minerals and other supplements Dr Bob suggests. I found a brilliant physio (originally for my shoulder) who is now helping me to re-pattern my brain to walk better and I've recently joined a T'ai Chi class. I eat healthily - but misbehave quite often.

I can honestly say that from the first LDN tablet I took, my problems and symptoms started to alleviate. I know this doesn't happen for everyone, but it's been 7 months and I'm feeling fantastic - a different person from the sad, depressed being who visited Dr Bob all those months ago!! Perhaps it's because wasn't taking anything else before I started on LDN, or because of Dr Bob's supplements, or maybe both.

I have to sing praise to both Dr Bob and Joyce, his right-hand woman!! I've emailed them most days and always had a same-day response - it's easier than ringing and getting the engaged tone. Dr Bob and Joyce are there to help and advise whenever, whatever - even when it's not connected to LDN!!! It really helps knowing Dr Bob takes LDN because he too has MS ... he is somewhere to hang your hat!! In fact, if I lived

closer I'd gladly be going there every day to look after them whilst they look after all of us!!

The effect of LDN has been extremely subtle over the time I've been taking it. Just this last week, I've realised that the pains in my left leg are subsiding, slowly but surely. I've even worn shoes with a heel the last couple of days - haven't done that for over 5 years!!

I haven't gone back to bed during the day these last 3 months - in fact, we've just acquired a puppy, so I've been getting up between 6 and 6.30am every day!! I'm not doubled-over anymore after I've been standing. My walking improves with each day, and I am now confident enough to take Syd (the puppy) for a walk without someone to hold on to.

LDN has changed my life - it's stopped me from being frightened and has given me hope for the future - and I know it will continue to. I intend to run again and I haven't done that for 15 years!!! Everyone with an auto-immune disease should know about LDN!!

Not every day is good!!! I reckon that in any one month, I have a 'wrong' week but it's nothing in the grand scheme of things. I think of it as a time of transition - my body readjusting and realigning to the subtle changes brought about by LDN.

Update - 25 September, 2008: At the end of July, I had a fantastic hypnotherapy session with Ted Heath who, to-date, has worked with over 300 people with MS. What a fabulous couple of hours! What a positive experience! What a lovely man! I was convinced that counting back from 100 was no problem. I managed 97!! He repatterned my walking, gave me various triggers for different problems and gave me exercises to strengthen my muscles - all that and took delivery of a parcel whilst keeping Syd (our dog) amused!!

Well, in August we went to Rome for 5 days and I organized four 3-hour walking tours for the family - giving me an enormous mountain to climb if I did them, but knowing that I didn't have to if I felt unwell. Before I relate the outcome, I have to admit that I went well-armed!!

I completed all 4 tours - one of the Coliseum and Forum, a walk along a section of the Apian Way and around the Catacombs, a city tour and a tour of the Vatican and Sistine Chapel!! Admittedly, I had some funny moments, but then I either took a breather or hung on to hubby, son or daughter - whoever was nearest! But, importantly, I didn't slow the group down, so was I pleased with myself, LDN and especially Ted!!

About 2 weeks ago, I had another of my funny weeks when things just didn't seem right, but then up another notch I went. A couple of days ago, I walked around 2 supermarkets without the trolley that over the last 4 years I've needed to hang on to as I couldn't propel myself forward. More often than not, my daughter has had to pull me along on any necessary shopping trips whilst guiding me so that I don't bump into anyone - she's in her teens and an absolute treasure!!

I was out visiting our son who is now renting a house and in his 2nd year at uni. I asked if he thought my walking and balance had improved. He had, but didn't want to jinx me by saying anything!!!

Also, this week I was out walking Syd with my husband, and we both noticed that I no longer have to hang on to his arm. I can walk again unaided.

I've just taken Syd on a walk by myself. I didn't stop once - pretending to admire a flower, tree etc whilst waiting for my legs to start moving again. I walked there and back just like everyone else does. I'm ecstatic!!!!!!

So, my balance and walking have improved amazingly in the 3 months since writing 'my story' and my sleeping is phenomenal - rarely waking in the night to toilet trot and asleep as soon as my head hits the pillow - and it's a restful sleep. In fact, my husband describes me as 'dead to the world' in seconds.

To sum up, it's now been 4 years since I had my second ever exacerbation, which left me bedridden for a time. I spent the next 3 years getting more and more depressed and convinced that I would soon be in a wheelchair.

In September 2007, a sorry figure visited Dr Bob and Joycie and after a good few hours talking decided there was no down side to taking LDN.

One year later with the help of LDN, GABA, other supplements, a reasonable diet, Dr Bob's good counsel with trusty Joycie and not forgetting the amazing Ted, I now have a life to look forward to.

The best decision ever!!!!

I'd love to keep you posted and if there's ever anything I can help with, please let me know.

Update - 25 March 2009: I can't believe it's been 6 months since my last update - which means 18 months have gone by since I started taking LDN.

The one major change in my regimen is that I began taking LDN 4.5ml liquid instead of tablets in February 2009, when new legislation meant I could no longer get my tablets from Dr Bob Lawrence. This has surprisingly been a positive move - I've found both falling asleep and having sleep that is even more restful has been the outcome!! My only problem with the liquid has been practical - using the syringe supplied with the liquid - much too fiddly, with most of the liquid that should be in the syringe dribbling down my fingers. But, that is easily solved - I now use a teaspoon!!

I've also been a little remiss and not taken my minerals and vitamins religiously - it always happens in the dark dreary days of winter when everything seems such an effort. But, now the sun is shining and the days are getting brighter and longer, I should have the impetus to behave again!!

I continue to hiccup along the way - it happened again a couple of weeks ago - lots of pain in my left arm, side and leg, even interrupting my sleep. I've found that I can lessen the pain if I'm well wrapped and snug, and then I sleep through – a simple solution that is working. Over-the-knee socks are worth the investment too!!!

The left side 'stuff' has been around since I was first diagnosed in 1972 but the emphasis has changed over the years. In 1972, I had pins/needles/electric shocks in my left arm - often lying on it so that I could get to sleep but nothing in my leg.

Since the mid 90's I've had niggly pains/shocks around my left hip sometimes cascading into the front of my upper leg.

About six years ago (during a stressful period in 2003), it all started to become more pronounced and travelled through my left arm, around my left hip and then into the front of my left leg all the way down to the top of my foot.

My left leg always feels extremely cold - I always think of a slab of wet cold fresh fish!!

Dr Bob Lawrence suggested taking Malic Acid about a year ago, which does help enormously with the pain. Now its intermittent - if I try to hurry, it becomes more pronounced so I just don't hurry :-)

I've always felt my body, especially waist down, belongs to two different people - normal sensation in my right side, stuff and nonsense in my left!!

My test for years, as I don't have a fish slab, is to lean my legs against the outside of the toilet, obviously in succession - it's cold, smooth and almost feels wet!!!! Right side fine, left side goes haywire, like an electrical storm. Am I barmy !!!! One day, there'll be no storm.....

Having said that, my walking continues to improve, albeit small steps only - but I do have to be mindful otherwise I trip where there's nothing to trip over!!

I've had a couple of massages that have really helped and also invested in a set of pedals - not a bike with a seat, just pedals, and I sit on an upright chair - quite a contraption but it works!! At the moment I'm not using any resistance but intend to introduce it gradually. I've had maybe 2 sessions of physio since Christmas, compared with before Christmas when it was practically once a week. Sometimes, I even walk Syd, my dog, from the house to the local park rather than driving there.

So, once again, my update is positive and I'm still enthralled with LDN!! I'm also really looking forward to the 1st LDN European Conference in Glasgow at the end of April. I'll be there waving my flag!!!

### 8

#### Art H, USA 1988 - Multiple Sclerosis 1994 – Secondary Progressive Multiple Sclerosis (SPMS) March 2005 – LDN

I was diagnosed with multiple sclerosis in April of 1988.

I was very messed up for two years after the initial attack. I couldn't walk straight, and was actually blind for a few weeks. I never thought I would recover and become independent again. I was very depressed, and briefly considered suicide.

I gradually pulled out of the attack with the help of IV Solumedrol and oral Prednisone,

which is all the doctors had to offer back then. CRAB, Novantrone, and Tysabri meds were unheard of.

I made a full recovery and was symptom-free until around 1994. It was as if I never had MS. I wasn't under the care of a neurologist, which, in hindsight, was a mistake. 1994 is when I started seeing him again on a regular basis.

I was originally diagnosed with Relapsing/Remitting type MS, but the neurologist upgraded it to the next level, which I think is called Secondary Progressive Multiple Sclerosis.

1996 was a very rough winter here in New York. There was a major blizzard, followed by snowfall after snowfall. I work as a maintenance supervisor for a real estate company and part of my job is to see that the snow is removed from their properties. It was a very stressful winter for me both mentally and physically. My MS returned with a vengeance, and my neurologist put me on Avonex, which I took for over three years.

I eventually developed antibodies against interferon meds so my neurologist put me on Copaxone for over three years. He also had me on six treatments of Novantrone. I had many, many IV Solumedrol/Prednisone taper-offs in between all of this. Nothing was holding the MS off. Nothing.

He then wanted to put me on Betaseron and I asked him why, as I thought I was immune towards interferons. He said, "Well, we have to try something". He also thought about putting me on Tysabri, right before it started killing people and was pulled from the market. It was then I realized he was only experimenting on me and really didn't have definite answers.

I am 6'7" and weigh 240 lbs, but I broke down and cried in his office.

Fortunately, his nurse saw me and suggested I look into LDN, even though the neurologist was against it. She is my special angel.

I have been on LDN since March of 2005 and shudder to think where I'd be without it. Among other things, it has helped my blurry vision, improved my balance, increased my bladder control, and given me a general sense of well-being. If that weren't enough--and perhaps best of all--it has completely halted the progression of my disease.

Besides taking 4.5 mg of LDN every night, I also take supplements daily and sometimes, occasionally. I try to avoid eating foods containing gluten, casein, sugar, corn, soy, legumes, eggs, red meat. The foods I try to eat are fresh wild fish, organic chicken, brown rice, and fresh raw organic fruits and vegetables. I believe highly in the benefits of Coconut Oil and Stevia. I try to walk as much as possible, light stretching, ride my exercise bike, deep breathing and lift moderate weights.

I am still taking 4.5mg LDN every night. I get my capsules via mail order from a compounding pharmacy in Florida. The cost is approx \$25.00 a month.

I have experimented with dosing times and skipping doses, but find personally, I am better off with my usual every night dosing schedule, taking my LDN exactly at 10pm now instead of 10.45pm.

My multiple sclerosis has not progressed as far as I can tell. My eyesight is less blurry, fatigue level improved, little numbness in my face, bladder control is okay, although I have an occasional accident in bed while sleeping as I don't always empty my bladder before bed. Thinking is sharp and so is memory.

I do have problems with two herniated discs in my spine and will be going for steroid injections soon. The discs cause me more problems than does the MS. LDN has solved that problem. I work full-time as a maintenance supervisor for a real estate company. It is very stressful.

I still follow a restrictive diet free of sugar, gluten, casein, red meat, eggs, corn and legumes to the best of my ability. When I was first diagnosed with MS back in 1988 I thought my life was over. LDN has given it back to me.

It is a crime LDN is not more widely accepted. So many people who could benefit from it are being denied it's healing powers and I think the biggest reason is greed and money.

### 9

#### Atif A, Scotland November 2005 - Multiple Sclerosis November 2008 – LDN

I am in my late 20s, and I was diagnosed with MS in November 2005.

My MS symptoms started way back in 2000, which was my first year of University. I used to get the 'craziest symptoms', which always used to show up around exam time.

I remember the worst time was in May 2004 when I became cross-eyed, and the right side of my face became numb!! I used to always be paying visits to doctors to explain the numbness and try to find out why it was happening. I'd be given an appointment at the hospital to get CAT scans and blood tests, but once again, no result would be obtained.

The doctor would tell me to try and stay calm and "pray to God"!! In November 2005 I had a Lumbar Puncture, and was diagnosed...FINALLY!! The doctors at the Southern General told me that it was the 'Relapse Remitting' type of the disease, and that I would be started on treatment very soon.

I was given the Interferon injections, which I had to take deep in the muscle. The interferon was not having much of an affect though, so the dosage was increased to 3 injections a week. Life on that treatment was painful. I found myself not only having to fight the painful symptoms of MS but also having to take other drugs to combat the side affects of the Interferon!!

Life for me had come to a stop. I knew that there had to be an answer to this illness somewhere. I used to do the research on the internet on a daily basis to try to find a solution. Around the same time, I was attending the 'newly diagnosed' group at the

Southern and we had a talk by Dr Gilhooly about this drug called naltrexone, taken in low doses (LDN). I spoke to the nurse after the talk. She was extremely sceptical and said it was just lies.

So I dismissed thoughts of LDN, but still continued on with the research. It was in November 2008 when I started researching LDN again, and the effects of this drug. I then discovered an article written by Dr Bob Lawrence on the positive affects of LDN. At the end of the article was a telephone number. I dialled the number and spoke to Dr Lawrence. I found out that Dr Lawrence himself had MS and was on the LDN. He told me that I had nothing to loose and that if it didn't work I could always go back on the Interferon.

I started the LDN treatment at 9:30pm that night, beginning on 3mg. That very night, at around 11:30pm, I started getting sensation in my fingers!! Even though I was experiencing the full sensation on my hands, I still could not believe it.

My initial thoughts were that this has to be a placebo type affect. Surely no drug of such success can be unheard of. The very next morning when I got out of bed and took my first steps, I realised this WAS the answer I'd been searching for!!! I could walk around a lot easier.

I spoke to Dr Lawrence on a weekly basis and he told me to increase the dosage slowly to reach the amount that my body could handle. I now am taking the maximum amount, 4.5mg every night, and I feel almost as if I am CURED!!

My prayers have been answered, thank God. LDN has virtually no side affects of any kind, and it's had such a positive impact on my life. I've got my life back together again. I can enjoy sitting out in the sun without pain. I can work out in the gym for long periods of time and work up a sweat without pain. I can think more clearly and I'm performing a lot better at university. I haven't had to take any more painkillers because the pain has vanished!!

I was lucky to find out about LDN, come across Dr Lawrence's number, and be given it through my GP. I'm also one of the lucky who achieve better than expected results with LDN.

But there must me many more people out there that are still living life on Interferon and other drugs. Please let LDN be made available to all that need it.

#### Audrey H, UK 1997 - Multiple Sclerosis March 2007 - LDN

There's not much to my story really. I am in my late thirties now, but I've had MS since I was young (when I had diplopia for a few weeks). I also had burning sensations in my

legs. In my early 20s I had a lumbar puncture and MRI. As it was during the late 1980s, the doctors thought it better not to tell me, even though they wrote in my medical notes that they 'suspected' MS.

Throughout my twenties I had relapses, but I wasn't diagnosed until I ended up in tears in front of a compassionate GP. He sent me for another MRI, and then the two MRI's were compared. MS was confirmed.

Throughout my thirties my relapses got progressively worse and despite following a healthy diet I got to the point where I couldn't see, couldn't stand up, and was falling over - mainly because of balance problems. I had fatigue that prevented me walking very far. I couldn't even peel a carrot, and was generally feeling suicidal and hopeless. During this time, I never tried any other drug.

I seemed to be on a steep decline. I had five relapses with no intermission and no short breather. The last went on for six months. I wasn't sure what was happening but my MS was really progressing.

If I went for a walk it was like the plug was pulled out after a short distance. My energy was zapped. I could barely walk and had very, very little energy to do anything or go anywhere. I would awaken as if I had done a marathon the day before. My right hand would keep me awake at night from nerve damage - it had been numb for six years.

One of my relapses just six months prior to LDN left me unable to drive, with difficulty walking, talking, eating and preparing food. I had terrible fatigue. No energy and no ability to make something to eat - with no one to help, including my husband. I found it difficult to go to the toilet to empty my bladder. I dropped whatever I touched literally.

My balance became bad and I would constantly fall over. I would go into remission, only to have another relapse straight away. I had double vision and needed an eye patch. I sprained my ankle 5 times because I couldn't see. I had problems with cognition, no clarity of thought – often called 'brain fog' by others with MS. Then I had a bladder infection and I had to take antibiotics and both my legs went numb and stiff with spasticity.

Then I found out about LDN. My neuro and two local GPs would not prescribe LDN, but fortunately, a Harley Street GP came through for me. At the time of starting LDN, I had spasticity in my legs and general fatigue. Within a matter of days I felt like a new woman. It was as though I had been given my life back. The spasticity left, and the fatigue lifted.

I noticed a difference within a few days. I began three days before I had an appointment with my MS nurse. I actually walked to the hospital - something I definitely couldn't have achieved before starting. It must have been 1 mile at least. My mood was much happier and I noticed a difference from the word go. I found myself dancing to the radio and realised my fatigue had disappeared.

I saw my GP and he noticed my walking was much better. The previous time I saw him I was walking with a stick. Today my right hand (which suffered from nerve damage and numbness) feels markedly better.

This is one of my diary notes: 'I have been taking LDN for a month and already I have virtually no symptoms including previous bladder retention. My energy is amazing. I am

sleeping the whole night through. Yesterday I got up in the morning, walked the dog, and went for a 1km swim. I went for a strenuous bike ride, walked the dog, made lunch, tidied the house, walked the dog again, went shopping, picked up my husband from the station, walked the dog yet again, and still had enough energy to make something to eat. I find if I plan, I can still spend the day somewhere like St Albans or Windsor and still find energy to drive home, walk the dog and socialize. The most noticeable difference is the reduction in numbness, pins and needles, bladder retention, sleeping the night through, energy levels and probably more. All in the first month.'

Taking LDN has helped me get back on my feet and build up my strength sufficiently to stop my rapid decline.

On the way to my second appointment with the GP who originally prescribed my LDN, I got off the train at Marlebone and ran all the way to Harley Street. I remember running down the platform at the station and beating everyone to the barriers. I thought that was pretty good considering I'd spent six months incapable of much at all not that long ago.

I originally paid for the LDN myself, but later went to my own GP and asked if she would prescribe LDN. She said, "Wow you look fantastic", and prescribed it for me. Two male GP's at the same local practice had previously turned me down.

I've now been on LDN since March 2007, 16 months. Despite a short exacerbation, which wasn't as severe as previous relapses, I'm still active and full of life. My only side effect is constipation, which I've had since starting LDN. Nothing I've tried seems to help. Over a long time this may result in other problems, but who knows. Also, I noticed if I take my LDN at bedtime, I can have nightmares, so I experimented with taking it a bit earlier, and it worked - no more nightmares.

I now have a border collie who is extremely active and keeps me busy. More than anything LDN has given me hope.

**Update – January 2009**: I've had diplopia for as long as I can remember. When I look to the far left, right, up or down. If I do exercise it gets a bit worse. I saw my optician recently and he thinks I had it as a child, just didn't notice. I haven't had a relapse and it's been like this the whole time I've been on LDN.

I am trying to be careful with diet and lifestyle but Christmas is a difficult time of year. I've just had a birthday celebration and I was as good as gold. I ate pigeon and venison. I had an Elissa test and it revealed I had a problem with most proteins. The only proteins I eat at home are hemp seeds and quinoa.

The constipation problem disappeared soon after starting on the Best Bet Diet (BBD), and I got rid of my nightmare problem by taking my LDN a bit earlier at 10.00pm instead of 11.30pm.

I have just joined a gym for three months so I hope to make the most of it. I don't think my border collie is going to be too pleased!!

**It's now July 2009**... I never did go to the gym and I didn't continue with the BBD. My Elissa test told me to exclude everything I was eating but to give up so many foods would be impossible. I now eat everything, gluten, dairy and the odd glass of wine.

My health has been good and I didn't have a cold all winter until May. I don't feel like I have MS. I am even attempting to have a baby, something I never thought I'd hear myself say. I'm closer to the end than the beginning of my childbearing years, so it's a bit late, but I am putting my trust in the LDN.

#### UPDATE February 2010

I've been taking LDN now since March 2007, almost 3 years.

I ran a five kilometre race in December 2009 for the first time in my life. They are organised locally every weekend. It took me 31 minutes. Amazing, considering how I was pre LDN.

I will have had MS for 29 years in June and because I am 99% symptom free my neuro says I am a benign case because I haven't progressed to the point where I need to use a wheelchair after all these years.

Prior to starting LDN I felt I was moving into secondary progressive stage when 17 yrs of being in remission stopped and a prolonged period of relapses began.

I have not been taking any supplements regularly now for months, except flaxseed oil (Omega). Flaxseed in it's natural form is a food and I take Flaxseed oil, derived from that food daily - on rice or a cooled baked potato.

I went back to my vegan diet just before Xmas. I eat ANY food except foods that contain something derived from an animal. There are several reasons for this:

1. I hate all the animal slaughter in the world and I would be adding to it if I ate meat.

2. After my Elissa test, all the foods I was intolerant to were the animal derived foods (uncanny!).

3. I read 'the China Study' recently. It stated a high protein, high fat diet is the cause of all the major diseases in the world today.

4. Whenever I have had an MS exacerbation, it has been after bingeing on cheese, milk chocolate or ice-cream, which I admit I have done to excess at times.

For three months last year from October I started drinking wine again after not drinking it since my twenties. A small glass every single night slowly led to two glasses and then more. I stopped this apres dinner activity outright when I nearly didn't manage to walk to my bed one night. I now no longer partake in my husbands apres work relaxation technique.

I am 99% symptom-free when I follow a strict vegan diet, but I'm still heat intolerant if I have a long hot bath, so I avoid hot baths. I felt the detoxification I was doing may have caused me to wake up in the morning a few days ago with some numbness in my leg but this disappeared as soon as I got up and has not happened since.

LDN has made me feel so good that I don't feel I need the supplements and although I'm not committed to every supplement people recommend, I am still making progress.

I do agree with the bit from the BBD that says not to have dairy and soy but I do eat other legumes, which they don't recommend. I don't agree with the rest.

For most of my twenties and the first half of my thirties I was strictly vegan. I only started

eating animal products about six years ago. I found it difficult to give them up, however, reading 'The China Study' has really helped me to mentally commit.

I've been on LDN now for three years. My MS was at its worst 3-3.5+ years ago, but has improved so much in the last three years.

I rarely ever eat processed foods, if possible. I try not to eat sugary cereals, cakes and biscuits because of hidden animal fats. I drink mostly water or freshly prepared juices and avoid foods that contain palm oil. I drink Rooibos tea and the very occasional coffee.

With the news of the research into CCSVI I have felt in the past that having hot and cold showers has always helped me, which would make sense if I had CCSVI. The hot and cold water would force the flow of blood through the veins. This is my theory.

As at February 2010, I'm only taking Flaxseed oil, no other supplements. On 9 February I commenced a 14-day Detox using Nutrigold Detox supplement, plus a five-food diet. The allowed foods include brown rice (which I sprout first), carrots, apples, lentils, onions and garlic.

The detox plan involves AM body brushing, hot water and lemon. Breakfast and lunch are from allowed foods, plus 2 capsules of Nutrigold's Colon Support Formula and 2 capsules of Nutrigold's Detox Support Formula. Snacks are fresh juice carrot or apple (or combination) mixed with 28g Bentonite Clay with 2 Detox Support Formula. Dinner consists of allowed foods plus 2 Detox Support Formula.

I am on day 6 of my 14-day detox but when complete I plan to start Dr Gray's Colon Cleanse which could be interpreted as a continuation of the detox. I would like to do the colon cleanse for up to 5 months. I'll have to wait and see how I go.

I credit my present state of well-being to LDN and returning to a strict vegan diet just before Xmas 2009, and eliminating alcohol straight after Christmas. I'm hoping my recent Detox strategy and planned Colon Cleanse will help with the few remaining symptoms, primarily heat intolerance.

### 11

#### Bentley L, USA 1992-1993 - Parkinson's Disease October 2004 - LDN

Bentley Lyon was diagnosed with Parkinson's (PD) almost 19 years ago. Our family never could have imagined where our choice to join him in his fight for recovery from PD and stroke would take us. I was 11 years old when I first saw Bentley playing Dixieland Jazz banjo, he was funny and a great musician. From the moment we met, I knew my mother, Bentley, and I would spend a lifetime together.

You might say Hall of Fame Wrestler, Bentley Lyon, is obsessed with life. The first Californian to become All American, Bentley is a Renaissance man. In High School he

was both Student Body President and Co-Captain of his High School football team. He became the first NCAA Wrestling Champion (1952) west of the Rockies from the University of California at Berkley and graduated with a BS in Forestry. He served as a Marine in the Korean War. During his career with the U.S. Forest Service, he learned to speak four languages and was sent all over the world to unusual places during extraordinary times. Upon retirement, he started a new career as a published mystery suspense author.

Bentley has always challenged himself. In the 1960's, he combined his love for the outdoors and exercise by running in the early mornings before going to work. Eventually he started marathon-ing, and at age 45 he ran the Boston Marathon in 2 hours 51 minutes and 26 seconds. We now joke that he is continuously preparing for the biggest marathon of his life.

May 14, 2004, Bentley suffered a massive hemorrhagic stroke during the second lead placement in a double-sided deep brain stimulation (DBS) surgery for Parkinson's. Due to the severity of his condition, he never had the second surgery to install the battery packs and turn on the stimulators.

Right after Bentley's stroke we realized that if we did not step in, he would die. The hospital staff was overwhelmed and understaffed and hoping for help from family or friends. Bentley's new life now required assistance 24 hours a day.

When you tell a physical therapist or doctor that your loved one has Parkinson's and a stroke, they are kind and helpful, but they know the statistics are not on your side. Bentley survived the ICU and Brain Trauma units, a nursing home and a second hospitalisation with us by his side. After six weeks, we brought him home to recover in a loving, familiar environment. Our fight for Bentley's recovery from Parkinson's and stroke was just beginning.

October 2004, Bentley's PD continued to progress using the standard forms of treatment. We thought that he had survived the stroke only to die from Parkinson's complications. A dear friend's patient persistence paid off, after months of assuring us that even though LDN was not a Parkinson's medication, it could help.

LDN is an opioid antagonist (it blocks opioids from the opioid receptors in your body) that tricks our biological systems into restoring homeostasis (i.e., the body's normal equilibrium). This is a remarkable drug in that it mobilizes the endorphin system for repair and prevention of disease. The FDA has approved Naltrexone for the treatment of alcoholism and opioid addiction.

However, when used at much smaller doses (approximately one tenth of the dose used for the treatment of addiction), it can help in alleviating pain, muscle tension, and other physically debilitating symptoms that occur with Parkinson's, Multiple Sclerosis, Arthritis, Crohn's and many other diseases: - Dr. Ian Zagon, Professor of Neural and behavioral Sciences at Pennsylvania State University's Hershey Medical Center. (www.fred.psu.edu/ds/retrieve/fred/investigator/isz1)

We decided to try this off label usage of a Food and Drug Administration (FDA) approved drug called Naltrexone, in low dose form or LDN (http://www.lowdosenaltrexone.org). It certainly seemed safe and at this point Bentley's very life was at risk if his breathing continued to worsen, and his neurologist did not seem to have any other suggestions.

It was miraculous, within four days of starting LDN we went from desperation to total elation at how quickly his body was responding to this generic medication that his neurologist had almost refused to prescribe. We could not believe that no doctor had ever suggested we try this drug that cost less than a \$1.00 a day with minimal side effects.

We wondered what if we had known about LDN prior to Bentley's failed DBS surgery. As we watched the muscle tension that was affecting Bentley's breathing, causing tremendous stiffness and pain disappear, we knew we only had LDN, our dear friend and our wonderful family doctor to thank for saving his life. We called our friends and said we were using a miracle drug that everyone should know about and they said a few days was not long enough to make these declarations.

We observed Bentley over the next eight months, as we slowly lowered his Parkinson's medications from 10 Sinemet 25/100, 3 Permax .25mg, 2 Artane 2mg., to 4 to 5 Sinemet 25/100, no Permax, 1 Artane and 4.5mg LDN, almost a 60% reduction which he still maintains today five years later. We called our friends again and again, urging them to tell their relatives and friends about LDN. Over the last five years we have seen LDN help these same friends with Lupus, ankylosing spondylitis, cancer, MS and Parkinson's.

We only requested that each person we took the time to share LDN with, would do the same. It has been amazing to see how far reaching this one on one sharing and patient persistence has spread the knowledge of this incredible therapy. We have gone out as a family to speak to PD support groups, but realized that if some of these people could not get the support of their doctors or family they would not be able to use LDN until it becomes a more traditionally prescribed medicine. It is astounding to see how quickly this patient Internet movement is happening.

Due to the progressive stroke symptoms from his weakening left side, we decided to try Hyperbaric Oxygen Therapy (HBOT) October 2005 in conjunction with LDN. After the first treatment, Bentley was happier and more relaxed. After five weeks of treatment his speech had improved, he could eat without choking and his skin began to clear from dermatitis from PD and other irritations due to paralysis.

According to a recent study published in the American Journal of Physiology-Heart and Circulation Physiology, (http://ajpheart.physiology.org) hyperbaric oxygen treatments increases by 800% the number of stem cells circulating in a patient's body. Stem cells, also called progenitor cells, are important players in repairing the body after injury and in tissue regeneration. Stem cells exist in the bone marrow and are capable of changing their characteristics to become part of many different organs and tissues. When a body part is injured, stem cells are mobilized and provide the cells necessary for the healing process to occur.

Hyperbaric oxygen therapy (HBOT) provides an important trigger or stimulus for this mobilization. "This is the safest way clinically to increase stem cell circulation, far safer than any of the pharmaceutical options," said Stephen Thom, MD, Ph.D., Professor of Emergency Medicine at the University of Pennsylvania School of Medicine, lead author of the study. "This study provides information on the fundamental mechanisms for hyperbaric oxygen and offers a new theoretical therapeutic option for mobilizing stem cells... We reproduced the observations from humans in animals in order to identify the mechanism for the hyperbaric oxygen effect."

We spoke with Dr. Harch (www.hbot.com), the world's foremost authority on the use of HBOT for neurological applications. He is currently running a clinical trial treating our soldiers from this Afghanistan and Iraq wars for PTSD and Traumatic brain injury using HBOT. He told us that it is simply amazing how much our brains can recover from brain injury. Dr Harch's book, The Oxygen Revolution: Hyperbaric Oxygen Therapy: The Groundbreaking New Treatment for Stroke, Alzheimer's, Parkinson's, Arthritis, Autism, Learning Disabilities and More, is One of the most important and insightful medical books in 40 years. -Vance Trimble, Pulitzer Prize winner. Dr. Harch and his wife Juliette Lucarini's kindness and encouragement gave us the understanding and strength to continue using this amazing therapy with LDN for Bentley's daily fight for recovery.

Although we continue to investigate additional treatment options like stem cell therapy, we believe that LDN has saved Bentley's life, and in combination with HBOT, his general health, swallow, breathing, cognition, tone, movement, rigidity, balance continue to improve. These two miraculous therapies and our existing regimen of proper nutrition, hydration, rest, exercise and careful medication management enable us to live the best life possible while working towards a cure for Parkinson's.

Destiny Marquez, USA Bentley's daughter http://health.groups.yahoo.com/group/healingparkinsons

### 12

#### Beth W, USA 1984 - Multiple Sclerosis June 2007 - LDN

I experienced my first MS symptoms in my early 20's, several years before the birth of my first child. I went to a physician to investigate them, but he was dismissive of my complaint. For example, when I tried to explain the sensation of an electric current running up and down my spine, he dismissed it as 'silly'.

Unfortunately, that experience encouraged me to consider myself a bit of a hypochondriac, and it wasn't until years later when a neurologist told me the symptom was called Lhermitte's Sign, and that it was an early indicator of MS, that the symptom was validated.

Without going into too much detail, my MS symptoms began to increase during my first pregnancy. I experienced numbness in my feet, legs, and fingers, and I fell a few times. I tripped over my own feet and repeatedly dropped things. My obstetrician sent me to a neurologist but the neurologist told me my symptoms were pregnancy and hormone related.

At the time I was mildly frustrated with all these new and strange sensations, but I didn't dwell on them... until four months after my son was born and I lost the vision in my right eye (retrobulbar neuritis, accompanied by a lot of pain). That is the first time the words

Multiple Sclerosis were mentioned to me, but surprisingly not by the neurologist, but by an Ophthalmologist. I was officially diagnosed with MS in 1984, just months after my first child was born.

At that time there were no specialised medications for MS so my doctor prescribed prednisone, and my vision eventually improved to 'almost' normal. After my eyesight improved I chalked the whole episode up to a 'fluke' and did a good job of trying to forget about it. (Denial... do you think?)

Over the next few years, though, new symptoms emerged which eventually led to my seeing Neurologist(s). I had a spinal tap and a few MRI's over the following years, and they verified the earlier diagnosis. But still, it took me a while to digest and accept the diagnosis.

Back then, other than trial medicines, there were no treatments or meds available to me during my relapse-remitting years. I was not 'bad' enough to be considered for any trials. I will say I feel fortunate that most of the exacerbations I experienced were sensory with discomfort, but not real 'pain', and I still count my blessings every day for that.

For many, many, many years I had the 'MS hug' (I'm really glad they finally gave that a name!!), plus a variety of what I referred to as general nuisance symptoms and weird sensations that were always coming and going, like; spasticity, smelling things like burning wood in the middle of the night, falling, tipping over like a weeble but falling down, feet and hands not co-operating, and not being able to recall everyday words ('brain farts' as I called them). The symptoms could, at times, be quite humorous. After all, if you couldn't laugh at it you'd cry... better to laugh.

I felt I had to hide my disease from my employers, but finally I had to 'fess up', or be accused of having 'liquid lunches'. I staggered a lot, even more so in the afternoons when I became exhausted. My speech was also affected and I began to slur my words. If I was tired it was even more difficult to enunciate so my speech was even more slurred. Rumours were flying that perhaps I had a 'problem'.

My progression was slow but inescapable. Over the years others often noticed a change, a sign of progression before I did. I think it was because I was becoming too tired really, to pay attention. I won't even 'go into' how I felt about the reactions I got from employers, and even some friends. Things do change when you decide to share your little secret.

I used Copaxone for a few years, after it became available in the late 90s and early 2000s, but I had already progressed to secondary, Primary Progressive MS with continued relapses by then. I tried Rebif but did not tolerate it well. I left my full time job and started working from home freelancing when things became too difficult. Walking and standing continuously were increasingly exhausting and I was suffering badly from fatigue. I was fortunate to have a skill set that allowed me to work at home. I'm a graphic designer and thankfully, I'd built up a freelance clientele over the years.

No longer after, I started using a cane most of the time. Working from home helped, because it allowed me to rest during the day when I needed to, however; I became uninsurable when my cobra insurance ran out. I had to discontinue all meds for financial reasons. Provigil had helped a great deal with the fatigue but it was too pricey for someone without insurance.

Then my parents saw an article in the local 'Daily Home' newspaper. My dad saved it for me. It was about a fire-fighter in Alabama called Bill. He had been terribly affected by MS and had been wheelchair bound, with many more problems than I ever had to deal with. He had been using LDN with success, and was trying to raise money for clinical trials to prove it worked. He had what sounded like miraculous results within months of starting LDN.

I researched the drug on the internet for a few months and then after trying to find a neurologist to prescribe it (to no avail), contacted the reporter that had written the story on Bill. I asked if I could contact him to discuss LDN and find out who prescribed it. He was kind enough to invite me to call him, which I did.

We spoke on the phone for quite a while. He was a delightful man to speak with. He stressed that LDN doesn't work for everyone and it is not a 'cure' but had worked for him. My interest was one of sceptical curiosity at first, but then my thoughts soon turned to... "I should try to be more proactive about my situation and at least look into this drug that I could actually afford without insurance."

I had tried other things over the years; evening primrose, different combinations of vitamins and diet, but had not seen any results. I was somewhat intrigued, but not counting on anything. I made an appointment with the neurologist that Bill had used. I really was not expecting any noticeable results because it sounded too good to be true. While I am an optimist, I am also a realist.

The neurologist was so kind... she said she'd write me the prescription but cautioned that she had no reason to believe it would actually work and encouraged other approved meds (unaffordable for me) and physical therapy. She was very honest and thorough.

I had the LDN prescription filled at a compounding pharmacy and started taking it in June 2007. I started at 1.5mg the first week, every night at bedtime. When I started noticing what I thought might be a slight improvement, I increased to 3mg. I wasn't dwelling on the drug or looking for improvement. I just thought, "it can't hurt".

But... within 10 - 15 days I started noticing that I was able to walk a little better. I noticed I could manage the slight incline of my driveway when I went to get the mail, without looking like a staggering drunk. Also, I didn't need to run my finger along the walls in hallways to keep my balance and be able to walk a straight line (as I had done for YEARS).

I noticed I could get up out of a chair easier, and in and out of a car. I wasn't stumbling as much. I could walk to the grocery store... and along ALL the aisles. All these things used to exhaust me. I had increased energy - not all at once, but progressively. I still had to pace myself and not overdo it, but as long as I didn't overdo it I could definitely notice improvement.

And I don't mean a slight improvement... I mean major improvement. When you slowly lose certain functions over a long period of years, you forget what you have lost. You find work-arounds. Then when you regain functions within a few weeks, it feels absolutely amazing, like someone turning on a 'little light at the end of the tunnel'. Now I can walk a lot farther and do a lot more than I've been able to do in the last 10-12 years.

I have always tried to be a 'glass half full' kind of gal. But I look back now and realize

that as happy as I am today, I was rather miserable and pretty depressed before LDN. I hated to admit defeat, but I felt I had 'lost' the battle against MS and was resigned to possibly winding up in a wheelchair.

I used to think I'd been so very fortunate to have had so many mobile years that I wasn't going to feel sorry for myself. But now, I realise I was reflecting 'back' on my life whilst at the same time prepping for an 'oh well, it could have been worse', end. I'm happy to say I now look forward to the future.

There was a period of time after I relocated when I had to go off LDN until I found someone in my new location who would prescribe it. In just a matter of weeks I started relapsing and feeling like my old MS-ey self. After getting back on LDN after just a week and a half without, I was feeling better again and now, feel very close to my 'normal'.

I don't know why LDN works for me and frankly I don't care. As long as I can continue to take it, I feel like I have a 'quality of life' I would otherwise not have.

I'm certainly not 'cured'. I'm not 100% of the person I was before I had MS, but I am certainly in much better shape both physically and mentally than I would ever have hoped to be, prior to learning of and taking this medication.

I would like to take this opportunity to encourage more doctors and patients to research this little miracle drug. My number 1 frustration has been with doctors who 'shut down' when you ask about LDN... unwilling even to discuss it at all... especially MS specialist doctors because they are the ones who should be aware of what's going on across alternative treatments, and should be open to discussion on what works.

It troubles me so when they say that they haven't ever even heard of LDN, because I know many of them have, but deny it.

I would also like to thank my family... my father especially for re-re-re-nag-re-rereminding me about the article on Bill until I took the initiative to find out more about LDN.

There are always friends and family who offer suggestions or treatments they have heard about, and unfortunately, you tend to lose faith after having read about so many alternative and new treatments, and having tried so many that didn't work or weren't within your reach, from bee-stings to hyperbaric chambers to acupuncture, vitamins, etc...

To those of you out there still considering LDN... by all means remain sceptical, but don't overlook LDN. Give it a shot. I pray your results are similar or better than mine. Stay as hopeful and positive as you can... and don't forget to laugh.

## 13

#### Bev K, USA 2004 - Multiple Sclerosis 2005 - LDN

My husband was diagnosed with MS in 2004. He had not long turned 40. He was diagnosed fairly soon after his first definitive symptom, which was Nystagmus. MS was confirmed after a brain MRI and a lumbar puncture.

Of course we were shocked, and right away the Neuro advised him to begin Avonex. We were given all the info - a huge folder of paperwork. When we took it home I spent a couple of days going through it all and finding out how much it would all cost. Living in the US with no health insurance is a scary thing. I'm British and was used to the NHS, not without its problems, but compared to living with no health providers at all, it seemed wonderful by comparison.

When we found out the Avonex would cost us over \$1,000 a month, we were horrified. How could anything cost so much! THEN, I started to hunt online for an alternative. I found out that Avonex and indeed all the injectable MS drugs, were not only expensive but fairly ineffectual. My husband always laughs at me for being online so much and using the computer to research so many different things. When I came across LDN and we started talking about it, he changed his tune!

I wish now that I'd started to make notes of the whole process, as my memory is not so great on how we progressed after that. I know I found the Yahoo LDN group and asked a lot of questions and found info to print up and take to the Neuro.

We told the Neuro that before my husband would try the Avonex, he wanted to try LDN. It was a treatment we could afford, and it was obviously less invasive that an injection each week. We left the info with him and returned a few weeks later. He said he'd rather my husband start on the Avonex, but agreed to him trying the LDN for a while.

We had to tell him how to fill out the script (we still do actually!) and we sent the script off to Skips Pharmacy in Florida.

He started off with the first batch of LDN at 1.5mg, and within a month was at his present dose of 4.5mg. I think he's missed one pill once in the whole four and a half years.

We still battle occasionally with the Neuro. Now he says my husband probably has 'benign' MS and that's why he's still so well. It's not true, but whatever works for him! Have to be gentle with the Neuros!

My husband has had a brain MRI each year since diagnosis. No new lesions have appeared since he started on LDN. Many of the lesions he had have either gone or are inactive. He's had no new symptoms and no relapses. He still has some cognitive issues, and a little balance problem. When he's stressed or tired his Nystagmus kicks in a bit, and he has periods of fatigue.

It costs us under \$70 for a three-month supply - one pill at bedtime each night. He's had no colds or flu or any of the 'things that go around' that I always get - his immune system is superb!

He works as a stonemason every day. It's a physically demanding job and he's outside in the elements all day. It's hot because we live in California. He's now in his late 40s and as strong as an ox!

LDN is not a cure. It hasn't repaired any of the damage he got before he was diagnosed. But he hasn't got any worse and for us, that is fantastic. I know he will never stop taking it - regardless of any other drugs that may appear in the future.

The neurologist works at UCSF where some limited clinical trials were conducted recently. When we ask the doctor how many other patients he has on LDN, he's cagey about it and I can see he doesn't really want to talk about it. When we're in the waiting room we see people in wheelchairs, with walkers, shuffling and limping along. It's maddening and heartbreaking all at once. I want to go and talk to them all and tell them to check out LDN. I want to slip a note into their pockets. I want to shout out, 'LOOK at my husband, SEE how well he is'.

I recently got diagnosed with Fibromyalgia and plan on starting LDN soon too. I also have Hashimoto's Hypothyroid so am hoping for some good results.

I am passionate about spreading the word as I know many others are, so hopefully there will be power in numbers, and eventually it won't be such a battle to get our healthcare providers to open their minds to LDN.

#### **UPDATE March 2010**

My husband has been taking LDN for MS for just about 5 years now. No disease progression, either in his demeanor or showing on his annual MRI. He`ll be on it forever!

## 14

## Bill R, USA

1998 - Relapsing Remitting Multiple Sclerosis (RRMS) 2002 - Secondary Progressive Multiple Sclerosis (SPMS) July 2005 - LDN

I'm nearing 60. I was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) in 1998, and upgraded to Secondary Progressive (SPMS) in 2002. My chief symptoms are (were) extreme mixed sleep apnoea, chronic obstructive pulmonary disease (COPD), inability to walk, total deafness in my left ear, and inability to concentrate for any period of time.

I have been treated with Avonex, Copaxone, and Rebif of the ABCR drugs,

chemotherapy (Cytoxan, plasma exchange, as well as many, many sessions of IV steroids (Solumedrol).

As of June 2005, I was on oxygen 24/7, wheelchair bound, having a flair of my MS on an average of once a month, and doctors had told me that my breathing difficulties, caused by the MS, would ultimately result in my demise.

I had also ballooned in weight to 289 pounds. Two of the top neurologists in Birmingham consulted and agreed that, while continuing on Rebif, I should begin taking a week of IV steroids every three months, regardless of my condition.

I did not feel that the steroids were offering enough positive results any longer, and I did not want to take any more. I asked if they would mind my getting an alternate opinion from another neurologist. They agreed.

My new neuro re-ran all of the standard MS tests, including magnetic resonance images (MRIs). After studying the results, she suggested I stay on the Rebif and see what the next two months showed with regard to flares or episodes, then to probably go back on chemotherapy. I asked her, at that time, if she would prescribe a drug therapy I'd read of - Naltrexone - in low doses (LDN).

I had read a great deal about LDN and talked to a number of MS sufferers who had improved with the use of LDN. She said she had never prescribed it but had also read a lot about it. She agreed to prescribe it.

I began around the first of July 2005 with 1.5 mg of Naltrexone taken in one dose per day for the first week. I then increased to one 3.0 mg dose per day. I stopped taking the Rebif at the same time.

While I did not notice any symptom improvement for the first three months, I also had NO flares either. But, after around three months I began to notice small improvements - my breathing was improving - I could take time off from the oxygen for extended periods of time - the strength in my legs and arms was improving - I began to be able to take short walks with a walker - then was able to take longer walks - then upgraded from my wheelchair to a cane - then actually walked to the bathroom without assistance! My sleep began to improve as well.

My improvement continued incrementally. When I went for my six-month check-up with my neuro, I did not even take my cane, and I blew away my neuro by ace-ing all the tests.

I couldn't drive a car for four years. I am now driving again and I'm walking without any aid or assistance. My weight has dropped to 232 pounds. I hope to get back to my target weight of 195 pounds by year's end.

I attribute my miraculous improvement to LDN, attitude, faith, and my new neurologist's willingness to prescribe LDN for me.

The only real dietary change I have made is to make water my primary liquid of choice.

I recently had surgery for an unrelated problem. I was half expecting to get an MS flare up but am very pleased to say I didn't and recovery is on schedule. After my check-up next week, I'm planning to begin an exercise schedule involving walking, lifting light weights, and abdominal exercises, and I might even get started on some long overdue yard work!

I wish to acknowledge and thank Dr Bernard Bihari for his groundbreaking work. Clearly I was on a downhill slide before I learned of his Low Dose Naltrexone (LDN) drug therapy.

I realize that money and profits are the motivation for initiating studies to have LDN approved for treatment of MS, as well as ALS, Alzheimer's, Parkinson's, HIV, AIDS, Cancer, etc. With that in mind, and knowing that the standard treatment for MS, the ABCR drugs, all cost insurance companies and/or patients in excess of \$1000.00 per month, I do not understand why insurance companies are not initiating these studies themselves.

I also do not understand why, if the 'Mission Statement' of the National MS Society is to 'find a cure for MS,' THEY are not funding these studies.

#### UPDATE: July 2007

I continue to do very well on LDN. I cannot know how long my good fortunes in health will continue, so I am trying to make the most of it while I can. I am doing landscape consultation for our city, finishing a backyard landscape project of my own that I began last summer, and I'm doing some landscape design work for a local contractor.

I still talk to people from all over the country about LDN and do volunteer work here, too. By the way, last summer, while working on my backyard, my ladder tipped over, and I badly dislocated my left ring finger. It was in a cast for a couple of months. I built the fence, the pergola, and planted all the shrubs! Though it has taken me much longer than it once would have, I never thought I would be able to undertake such again. I'm planning on attending the conference in Tennessee this October (2007).

#### UPDATE: July 2008

I continue to do well on 3mg of LDN daily. It has been three years since my last exacerbation (before LDN). I still find it hard to believe how much my quality of life has improved because of LDN.

#### UPDATE: July 2009

I continue to do well on LDN after almost four years.

I added 2000iu of D3 per day. Our community has started a three and a half acre community garden to help those who need food. I have the pleasure of heading up the project and work in the garden an average of five hours per day. To date, we have distributed almost five hundred pounds of fresh vegetables.

I began taking D3 before the first of the year, after reading up on it. I began with 1000iu and increased to 2000iu in May 2009. None of this was based on doctor recommendations...just going with what I feel. As far as high fiber diet, I pretty much eat what I want to. I am spending a great deal of time in the garden, sweating, working, and 'taste-testing' peas, beans, squash, okra, tomatoes, eggplant, cucumbers, cabbage, collards, and corn, and GALLONS of water. :-) I have also lost about twenty-five pounds in that garden. I want to lose about twenty more by summer's end.

While LDN is NOT a cure for MS, it has afforded me the opportunities to do things that I never thought I would be able to do again. One of those opportunities has been to spearhead the community garden here in my home town. Even with the improvements I have experienced through the use of LDN, I was not sure I could endure the rigors involved in working this three and a half acre vegetable garden.

I do have to be careful, take lots of breaks, drink LOTS of water, and 'delegate authority', but I am very proud of what we have accomplished thus far. I owe a large part of my own personal success in the garden to LDN. As of June 29, 2009, we had given away over 600 pounds of vegetables and sold over 250 pounds at a very reduced rate. We expect to double that production by season's end. We are planning to add another acre and a half for next year, PLUS add up to 75 six-by-ten-foot raised garden beds to lease to individuals for their own garden plots. They will lease for \$5.00 per year, including drip irrigation and on-site assistance.

This is by no means all 'my' project. The success of this garden has come from the hours and days of hard work by many whose only desire is to help others. LDN has allowed me to join in, too. :-)

### Update February 2010

I am having some numbness and tingling in my legs and fatigue issues; but I continue to be able to walk without assistance and carry on a relatively busy volunteer program. I'm also President of local Beautification Council, Tree Commission, and Leadership training program, and Head Gardener for our local 3 and 1/2 (Now 5!) acre Community Garden.

After hearing of risks associated with D supplementation, I'm going to stop taking the 2000iu of D-3 for a while to see if it could have been a catalyst for recent adverse health changes.

# 15

### Bill Z, USA 2006 - Crohn's Disease early 2007 – LDN

Three years ago I was diagnosed with Crohn's Disease and was very miserable. I was put on a couple of drugs - Asacol and another one, but I can't remember its name. They did very little for my Crohn's Disease and were fairly expensive.

I did considerable research on the latest experimental approaches to treatments and found the work of Dr. Jill Smith at Penn State. I reviewed her studies and decided I wanted to try naltrexone. My Physician was not aware of her research although her work was published in several professional journals, which my physician apparently had not read!

My physician was not readily willing to prescribe naltrexone as he said it was 'experimental'. I convinced him that it was my life and I would not just sit back and do nothing. Eventually he did prescribe it and after 100 days, I was in remission.

That was nearly three years ago now, and I have not had any symptoms of Crohn's since! Of course I believe it to be a miracle drug!

I have visited with a few other Crohn's patients and have been surprised at their difficulty in getting their physicians to prescribe naltrexone.

I did learn from a client that his brother could not stand the effects of his Crohn's and took his life... so sad...

I hope this info is of assistance to others.

# 16

## Dr Bob Lawrence MRCS LRCP Dietary Research Ltd, UK 1986 – Multiple Sclerosis 2001 - LDN

My first symptoms of auto-immune disease actually started long before the onset of the MS. This was an acute onset of lumbar back pain during the summer of 1967, my final year in college. At that time, I was just 26 years old and attending Plymouth Technical College while taking three 'A' level examinations. These were in preparation for entry into Bristol University as a medical student.

I was otherwise very fit, active, and capable of either walking or running many miles. As a poverty-stricken student it was economically often essential to walk to and from the college each day. At other times, I would regularly walk ten miles or more, either for pleasure or simply visiting friends, some of whom lived several miles from my home.

The back pain was the first indication of the often relapsing-remitting nature of autoimmune disease as the pain would simply occur or disappear completely without any apparent logic or reason.

It was later that same year that I was to suffer a tragic road accident when, whilst riding my motorcycle, I was hit by a careless driver who turned right suddenly without checking his mirror. I was thrown against a lampost, seriously damaging both legs.

Due to this injury I was forced to remain in hospital for five months, which obviously delayed my planned entrance to Bristol University Medical School in September. A year later, in 1968, I was still walking with a full leg calliper when I began attending lectures in my chosen subject at Bristol.

My subsequent progress through medical school was often difficult due to the obvious

disabilities resulting from the injuries and it was this constant level of pain that finally contributed to my eventual failure at the final examinations in 1973.

Undaunted however, I and several other of my equally unhappy, and unsuccessful, student friends immediately applied to attend the examinations in London for the external degree of MRCS LRCP, a joint examination held by the Royal College of Surgeons and the Royal College of Physicians. This I completed and passed in March 1974.

On Starting my first pre-registration job as a doctor in Merthyr Tydfil, South Wales, I soon found the work quite demanding due to my poor walking ability and an average working week of 100 hours.

In response to this increasing level of stress I soon developed a further recurrence of the back pain, now obvious as ankylosing spondylitis (AS), with recurring thoracic and lumbar pain. In December of that year I bought my house in Swansea and, with my wife, Pauline, and two young sons, took up residence in the quiet residential area of Treboeth.

It was during the latter part of my employment at this hospital that I also developed an acute inflammatory condition of my right eye. Late one evening, I happened to run into the Sister in charge of the ophthalmic outpatient department.

With years of experience in ophthalmics she immediately recognised the condition as serious and promptly called the on-call ophthalmic physician. He quickly confirmed the diagnosis as uveitis, an inflammatory, auto-immune condition of the eye, known to be associated with the occurrence of ankylosing spondylitis.

The sight-saving treatment for this was the immediate and regular use of steroid eyedrops, applied every hour, plus the use of atropine eye-drops twice daily, which caused the pupil to dilate, making vision blurry and indistinct. This treatment was continued for about three months before the problem was completely resolved.

This problem further confirmed the prior diagnosis of ankylosing spondylitis due to the common association between these two conditions.

After completing my first six-month post in general medicine at Merthyr Tydfil I transferred to Neath General Hospital where I was to conduct my efforts in the art of general surgery. The surgeon in charge of this surgical unit was known to be somewhat eccentric, driving an ancient 1936 Rolls Royce. He was also a notorious tyrant who expected his junior doctors to be present on the wards at all hours, both day and night. Needless to say, this continuing level of stress gave rise to further bouts of back pain associated with the AS.

My next job, starting in August 1975, was as Casualty Officer at Singleton Hospital, Swansea.

This was busy, but not with the level of stress previously experienced in General Surgery. At times the work was intense, with several hundred patients being seen each day, all attended by just three doctors. It was during my duties at this task that I experienced what may now be considered as my first symptom of MS. This was the sudden onset of a divergent diplopia, or double vision.

I was subsequently seen by an ophthalmologist, who, without offering any explanation of why this might have occurred, simply gave me a small card with two separate images, on one side a picture of a cat, and, about three inches away, on the same side of the card, an image of a tail. The aim of the exercise was to focus the two images so that they coincided, placing the tail on the cat.

This amusing little exercise kept me busy for the next three months before the diplopia finally resolved, with normal vision re-established as a single image once again.

I completed the job at Singleton in February 1976, when I decided to try my hand at anaesthetics. After being shown the various techniques involved in inducing anaesthesia I was considered safe and fit to start my own anaesthetic list within just one week.

I continued this work until 1978 when I decided to transfer to General Practice, starting work in a small practice in the Brynmawr valley, in Gwent. I left this post early in 1979 and I made use of Aircall, working mainly at night or at weekends, when regular GPs chose to use this emergency cover instead of attending the calls themselves.

Eventually, I found a longer-term post at a practice in Clydach, one of the outlying districts of Swansea. Having the convenience of a local post I was at last able to take advantage of the opportunities to do some gardening and also some restorative work around the house. I decided to take on the task of renewing the concrete of the driveway and an area at the back of the house.

Anyone who has ever used ready-mix concrete knows that the mix sets very quickly so it was a frantic race against time trying to complete the task before it all went hard. This was the time when I noticed the first real sign that I now recognise as MS. One half of my right thumb had suddenly become numb.

I initially attributed this to the demands of my heavy days work but, as time went by, within a few days, the other half of the thumb had also gone numb. Next was the first half of the first finger, then the numbness of this finger became complete, then the next finger was affected, then the next. Within about ten days the whole hand had become quite numb.

I did initially assume that this would eventually resolve itself, but it has only been since starting the LDN, in 2001, that the hand begun to regain its normal sensation.

I later noticed, when completing another section of the concreting, trying to carry bags of cement from the boot of the car, that I was no longer able to lift the bag as I had been able to do so many times before. I became seriously concerned when I had to ask a neighbour for assistance to carry the bag from the car to the back of the house.

During my time at this current post it was an occasional benefit when all the doctors in the practice, a total of four, were able to take advantage of the generosity offered by many of the drug company reps. This often involved lunch, a large steak, which I enjoyed with relish. I did begin to notice however, that following the meal, within about twenty minutes I would experience a dramatic increase in back pain.

The journey back to the practice to complete the remainder of the days work was also found to be an acutely painful experience as every minor jolt or bump in the road sent spasms of pain down my spine.

After this initial observation it did not take long to realise that this pain was only occurring after eating beef, in one form or another. It also became equally apparent that on those occasions when I chose either chicken or fish, the pain simply did not occur.

This was not a surprising revelation to me as I had suffered recurrent migraine since a child and I had become aware that certain foods were instrumental in initiating the migraine attack. Some examples of such foods I had come to recognise as chocolate, oranges, or cheese.

I decided to investigate this observation more thoroughly and, while browsing in a local bookshop (this was long before the later and convenient access to the internet), I discovered a book, which discussed this very same principle.

This was entitled, 'Diet for Life, A Cookbook for Arthritics'. Written by Mary Laver and Margaret Smith, the book described how avoiding certain foods could improve symptoms of arthritis. Mary Laver had apparently suffered with rheumatoid arthritis for several years and had developed a dietary regimen which she found effective in eliminating her symptoms.

The foods which it was considered necessary to avoid included all of those that I had found detrimental in both migraine and the back pain I had experienced.

Needless to say, I bought the book and followed the advice offered. As anticipated, while following this advice, the pain resolved and ceased to be a problem.

Early in 1981, after completing my year at this practice, I applied to attend for an unpaid attachment to the local Maternity Unit at Mount Pleasant Hospital, Swansea, the purpose of which was to gain sufficient experience to qualify for my obstetric certificate, required to carry out obstetric work in general practice.

After completing the required thirty deliveries I was awarded the appropriate certification to conduct this work, but I was never to make full use of this qualification, as subsequent job opportunities seemed to become increasingly rare and even more difficult to find. I reluctantly returned to Swansea to face a series of further locum posts, which were to continue into 1982.

At that time, late in 1981, I had noticed an article in one of the many free medical newspapers, which referred to the opportunity of a career in the Royal Fleet Auxiliary, a fleet of civilian manned merchant ships, maintained and provided by the Ministry of Defence. These include tankers, munitions and dry stores ships, troop and logistics supply ships and helicopter support ships. Within the merchant navy it is a rule that any ship carrying more than 100 men was required to also carry a doctor.

The article was offering the opportunity of joining this service. With the added opportunity of travel to various locations around the world, and the security of permanent work, this seemed very appealing. I made my application but it was mislaid and I was enrolled too late to join the initial task force to the Falklands. A subsequent application was successful and I was eventually posted to serve on the tanker, RFA Olwen, which I joined in Gibraltar in 1982.

Numerous deployments followed. During this period I was to experience the first signs of an increasing dispirited fatigue characteristic of MS that was to become more severe later.

My final deployment was on the Olwen. Nearing the end of my term I grew aware of certain changes in my level of fitness. My walking was no longer as steady; I had also become aware of episodes of profound fatigue in more recent months, when I seemed not to have the energy to even pack a suitcase in preparation for leaving the ship.

The feelings of increasing weakness and lassitude that I had previously experienced on the Resource became not only more severe, but more prolonged. These deep and pervasive feelings became not only physically, but also emotionally and intellectually draining, affecting not only my mood but also my processes of judgement and rational thought. This overwhelming fatigue seemed to sap both the spirit and the soul, leaving an empty loneliness that, by whatever means, could not be filled.

I was by this time, aware that during my time on the ship it had become necessary to abandon many of the requirements of the restricted diet that I had been previously following. Unfortunately, on a ship, it was no longer possible to choose the menu in the way that I had been able to while ashore. I therefore found myself occasionally eating those foods that I had previously attempted to avoid.

In this way, I was once again able to demonstrate the adverse effects of such a nonselective diet, when my symptoms clearly began to get worse as I strayed from the desired path of suitable foods.

Thus, as my symptoms became progressively worse, I seemed to know that this was to be my final trip with the RFA, which was also to culminate in a somewhat anxious episode when, during our return to the UK early in 1986, the ship's engines failed during our transit of the Southwest Approaches several hundred miles from the tip of Cornwall.

The ship was subsequently left adrift for three days while the ship's engineers worked frantically trying to establish the necessary repairs. It was at such a time that it may be realised how dependent we were on the various ship's systems: with no power there was no water to wash or to drink, the toilets did not flush, there was only emergency lighting to see by; and food could not be cooked.

For three days we lived on sandwiches, drinking emergency bottled water supplies, and flushing toilets with buckets of water lifted from over the side of the ship. The greatest concern however was the risk of collision with other ships. It was cause for celebration with the power restored, when all the various ship's systems came back on line. With normal services fully restored we quickly made our way back to the UK to dock in Portsmouth.

On reaching port, we were once more able to reconnect to all the routine shore services including luxuries such as telephones and television. I remember reading news of a female patient in America, apparently diagnosed with MS, who seemed to recover from her symptoms after having all her mercury amalgam fillings removed and replaced with silicate fillings. This was obviously of interest to me as I had, for some time, begun to consider the diagnosis of MS in myself.

I was later to undertake this same procedure in the hope that my symptoms too would

be equally resolved. The process however, although considered advisable, failed to make any apparent difference to the further progress of my symptoms.

With this increasing sense of doom and coincident symptoms associated with my cigarette-smoking habit I resolved to, at least, bring this habit to an end. As ships doctor I was able to order a quantity of Nicorette, nicotine chewing gum. I then planned to use up my last packet of duty-frees, at 27p for twenty, and, at 8-30 pm, on the 27th February 1986, in company with the Senior Radio Officer in the officers mess, I smoked my last cigarette.

Having seen many others who had made such similar claims the SRO was not convinced that my resolve would be successful, but after 23 years as a non-smoker, I think I have won the battle.

When the inevitable craving came to greet me several hours later I was prepared with my nicotine gum. Chewing this hopefully, I remained in some doubt that it would be effective. I was however, surprised that the demand, that intense craving to place yet another cigarette in my mouth, disappeared like magic. On each subsequent occasion when this urgent demand re-occurred, I would simply chew on the gum for a few minutes and once more, I was free of the craving that had maintained this damaging habit for so long.

I continued the use of the Nicorette long after I had left the ship when, after using the gum for about four months I felt confident enough to change the nicotine gum for plain chewing gum. I continued with this for a few weeks more, then abandoned the gum, and the habit, forever.

I now know that had I continued smoking, this habit would have contributed greatly to the further decline of both the MS and my remaining physical abilities.

Soon after this, my term of attachment to this ship was completed and I left the Olwen, and the RFA for the last time. I felt particularly demoralised when leaving the ship as, by this time, I felt so weakened that, making some excuse of a trivial injury, I was forced to seek help just to carry my suitcase down the gangway to finally leave the ship.

On reaching home I soon made an appointment with my GP to seek a neurological opinion regarding my worsening symptoms. This eventually resulted in an appointment with my local, but not very well informed, neurologist, who immediately, and falsely, assured me that I did not have MS.

I insisted on further investigation and after a CAT scan, a visual evoked response test (VER), and a lumbar puncture, it was finally confirmed that MS was, in fact, the diagnosis.

I fruitlessly inquired about diet and nutrient therapy, of which I had read much in my basic research, but this was entirely denied and briskly condemned as placebo effect. I left the hospital intent on pursuing my own line of research and inquiry.

I thus established a routine of attending the hospital medical library at Singleton where I was able to use the full range of research journals and books available there.

At that time there was no facility for computer searches of journals etc. so the only

means of tracking down appropriate articles was to look up any interesting sections of the monthly compendium of scientific references, the Index Medicus.

I was to continue this process ultimately for years until I had established a clear and effective means of minimising my symptoms.

During this period I had also decided that, on the basis of some of the research that I had revealed, I would consider the use of certain minerals in the treatment of MS. I surmised that both zinc and copper might be of relevance in this condition when I found that both these minerals contributed to the production of prostaglandins, important cell mediators in the expression or resolution of inflammation in disease.

I also joined the MS society and asked their advice. I was sent a bundle of information sheets including details of an advised low-fat diet. I subsequently joined the local branch of the MS Society, which met twice-weekly, on a Monday and a Thursday.

I noticed here that the Centre provided tea and lunch for those wanting it, but I was surprised that the meals often consisted of many of the foods that the MS Society had already advised against.

During this period of early searching, when I attempted to find as many sources of advice and information as were available, I was unfortunate in suddenly developing a bout of acute pneumonia. Immediately my MS symptoms become much worse and I was promptly admitted to hospital. During my stay, with an appropriate course of antibiotics, I had the opportunity of discussing some of my research with the neurologist who had made the initial diagnosis of MS.

I was quite shocked when he seemed totally unaware of much of the research that I had discovered, and even denied the association between various different auto-immune conditions which had been declared as common. This conviction that neurologists are not always the most expert at dealing with MS has been reaffirmed to me on many occasions since.

With my recovery and subsequent discharge from hospital I was free once more to seek out further help from other sources. I was dismayed by the apparent lack of concern over the most suitable diet, and absence of more positive support at the local MS Society Centre, I therefore decided to leave and joined the newly opened ARMS (Action and Research into MS) Treatment Centre in Llansamlet, Swansea.

This had been opened and equipped with funds raised by the local ARMS charity group, the members of which had raised over £35,000 in donations.

The Centre had a six-man hyperbaric chamber capable of being pressurised to an equivalent depth of water of 33 feet. In practice, most patients using this treatment, a method that had been in use since about 1940, were treated at pressures lower than this.

Traditional intermediate pressures used are usually, expressed in equivalent depths of water, at 8 feet, 16 feet or 24 feet.

I started using this method of treatment early in 1987. Following the introductory 21, almost daily treatments, I slowly became aware that I was beginning to feel some benefits. I felt more vigorous, stronger, and more mentally alert than I had been.

Up until this time I had been suffering initially severe levels of depression, weakness, disturbed sleep, an increasing, stumbling disability and mental lassitude. On many days it had taken huge effort to motivate myself to the actions that would finally reveal the methods that would resolve so many of my symptoms.

One morning, while watching the morning television on ITV I was drawn to a presentation of a new book by a professor of biochemistry from Reading University. This was Professor Derek Bryce-Smith, an expert in the study of many common minerals and their effects on both health and disease.

The book was entitled 'The Zinc Solution', jointly written by Derek Bryce Smith and Liz Hodgkinson, described how zinc deficiency was a common occurrence in many conditions, including auto-immune disease, atopic problems and other conditions, such as anorexia nervosa. I was fascinated by these revelations as, together with MS, these were the conditions I had been researching and testing in association with the possibility of deficiency of this very mineral.

Within the book Professor Bryce-Smith also described a simple test that he had devised, the zinc taste test. This was based on the premise that zinc is essential in maintaining the senses of both taste and smell. Thus, in a state of zinc deficiency it would be expected that these functions would be diminished.

This simple test involved tasting a solution of zinc sulphate, at a concentration of 1 g/ litre. The duration of the test was confined to just ten seconds because during this time the zinc would be rapidly absorbed onto the taste buds of the tongue, thus enhancing their function and taste perception.

Four different grades of response were defined denoting four different levels of deficiency or normality.

I was so intrigued by these details that I bought the book and subsequently wrote to Professor Bryce-Smith, describing my interests and observations regarding MS. I was flattered when he replied to my letter offering to visit Swansea and test any willing members of the local HBO Treatment Centre.

This meeting was duly arranged when the professor gave a short talk about his work with MS and zinc deficiency. We then tested about thirty MS patients who had attended. The professor also described how his research had also shown a consistent deficiency of both copper and vanadium.

He explained that these minerals were important in many vital functions, including immune activity, adrenal function, preventing oxidative stress, and maintaining both mood and energy. The results of the zinc taste testing showed that every single patient with MS was shown to be at least moderately deficient in this vital element.

As a comparison we tested some of the partners or carers of these patients, when most of these showed a relatively normal response. It was of interest however, that some of these also showed deficiency at various levels, showing how common zinc deficiency actually is.

The most dramatic response was when testing the nurse in charge of the Centre, who

tested so strongly positive that she later declared that she was still aware of the taste three days later!

We then planned a simple research project providing supplements of zinc citrate, copper, and vanadium to a number of volunteers to see what response was obtained.

This study however proved to be less than ideal as many of the volunteers, keen and enthusiastic at the beginning, ultimately failed to maintain their compliance with the recommended treatment and within weeks or, at most, several months, largely gave up the treatment. Those symptoms that improved in those that continued the supplements long enough reported increased energy, less depression or fatigue, improved appetite, and improved sleep.

With this supporting evidence available however, I remained convinced of the method and have continued these supplements ever since. With additional supplements, also determined by my continuing research, I was subsequently able to maintain my MS in an almost complete state of stability with just a slow rate of progression for about 15 years.

As my research continued I discovered, one by one, new connections and links in a long chain of facts that together formed a rational method of combined diet and nutrient therapy.

This I decided to test by offering it to others who might be willing to consider my advice in dealing with their problems, as I had, to a great extent, already dealt with my own.

Thus, in February, 1991, I set up the company, Dietary Research Ltd, as a service to others, offering advice in the treatment, not only of MS, but numerous other problems, such as arthritis, post-viral fatigue syndrome, irritable bowel syndrome, and other atopic or auto-immune diseases.

I contacted the Evening Post newspaper, which agreed to send Ms Jill Forward, an independent, free-lance journalist to write a story about my work and intentions. Ms Forward subsequently came to my house, where we discussed my research and intended purpose in finding a means of resolving MS symptoms. She then wrote a very positive article which, when presented in the Evening Post newspaper raised a large number of inquiries from the local community.

With these first inquiries I started my work in earnest, discussing the problems presented to me and offering advice as I considered necessary. I found the work fascinating because, as I had found in general practice, determining the fundamental nature of a problem and treating it effectively by simple means, the ideal in medical practice.

I had always found it most informative to discuss individual problems extensively with each patient, which is why I disliked the intensive time-related appointments of general practice. I found greatest satisfaction, and gained important information, from inquisitive discussion, often at length. These often prolonged discussions would frequently reveal details and facts that would directly or indirectly provide an immediate answer to the treatment needs of that patient. I was also learning that disease was often related to simple nutritional deficiencies creating problems that so often were traditionally treated with drugs.

These drugs, often addictive, sometimes toxic, and occasionally dangerous, would then create even greater problems of side-effects, which were also then treated by even more drugs. The result is an ever more complicated spiral of poly-pharmacy which benefits only the drug companies while leaving the patient in a state of drug-induced dependency.

I considered it infinitely preferable to use simple means, such as diet, vitamins or minerals, which may be of equal or even greater benefit than the drugs they replace. Two such examples are the use of vitamin E, effective in reducing thrombosis risk by a much greater degree than the low-dose aspirin traditionally used for this purpose. The other is the simple mineral selenium, which has been shown by numerous studies to reduce the risk of developing cancer by at least 50%.

In addition, I was often able to gain an additional benefit by learning of the methods that others had independently found to be also of benefit. It was often therefore possible to learn as much from the patient as I was able to offer them in advice.

My biggest expense at this time was continuing to reach those who might possibly want my services. This initial impact of the newspaper article was soon dispelled and I rapidly found it necessary to place regular advertisements in newspapers and magazines.

Such advertising was very expensive: £40-00per week for a small newspaper advertisement, and about £400-00 for a similar advertisement in a national magazine. With the additional cost of a part-time assistant I soon found that I was regularly losing about £2000-00 per year in excess of the income gained. This overall expense was conveniently provided by my service pension from the RFA.

By 1994 an additional personal problem also became of greater significance. Since about 1988 I had experienced an increasing degree of angina, chest pain associated with a slowly diminishing circulation to the heart. This increasing occurrence of chest pain led me to seek advice from my own GP, who recommended admission to Cardiff hospital for a coronary angiogram.

Before this could be done I was put on a vasodilator drip with an intravenous cannula inserted in my left hand. This continuous infusion was intended to reduce the chest pain, which continued intermittently. After a few days however, I began to feel increasingly unwell. Blood samples were taken for bacterial screening, which showed a severe form of septicaemia demanding a powerful antibiotic treatment.

After a number of days of worsening symptoms the angiogram was deferred and further tests carried out. These showed a continuing infection with no resolution of the septicaemia. After trying a second antibiotic, when the infection again appeared to persist it was deduced that the likely fixed source of the infection was the cannula itself.

This was duly removed and my temperature, and the infection, resolved within twentyfour hours. I continued the antibiotic for a few more days to ensure complete eradication of the infection, when the angiogram was at last booked and carried out.

This showed only moderate narrowing of some of the branch arteries of the coronary circulation and I was offered two drugs, one a calcium antagonist, and the other a beta-blocker. I soon became aware of the dramatic side-effects of the beta-blocker when my

sleep became grossly disturbed, with bizarre dreams for the maximum of two hours sleep I would attain, plus daytime hallucinations that made me wonder if I was actually awake or not!

The beta-blocker was thus changed for one that did not cause these strange sideeffects and I was finally discharged home.

After some days I became aware that the drugs, although temporarily effective in reducing the pain, had no prolonged effect in preventing its recurrence. I therefore surmised that, as I was already taking a moderate dose of vitamin E, a potent vasodilator, and that the nature of the angina could be due to vasospasm of the arteries of the heart, I might gain a significant benefit by doubling my dose of this simple vitamin. I promptly increased the dose from 400iu to 800iu, when almost instantly, within just a couple of days, the pain had gone entirely.

I abandoned both the drugs, that had proved so ineffective, and I have continued with this high dose of vitamin E with no further recurrence of the pain ever since.

My logic, and the results I obtained, were later reaffirmed by a study at Addenbrooke Hospital in Cambridge, conducted in 1996, when a double blind, placebo controlled trial of a single daily dose of vitamin E, 400iu, in patients already having suffered a heart attack, showed a 79% reduction in further risk by taking this simple vitamin.

I continued my work, now gradually limiting the range of problems I chose to deal with. Eventually, I was dealing almost entirely with just MS, plus a few related conditions, such as colitis or rheumatoid arthritis.

Slowly, as my work increased, my reputation grew and, by 1997, as I had begun to make increasing use of the internet, I had become sufficiently well known to be able to stop advertising entirely and just rely on word-of-mouth recommendations to gather new inquiries.

It was this connection with the internet that was to later reveal the final link in the treatment regime that was to complete the stability of my MS.

This was the discovery, in late 2000, of low-dose naltrexone (LDN), a method initially applied in significant numbers by Dr Bernard Bihari, a New York physician. At that time Dr Bihari was treating about 70 patients with a variety of complaints, by this treatment method.

On first reading mention of this apparently simple method, first noted in the web forum of an internet advisor referred to as 'Goodshape', (actually an ex American Airforce doctor), I was naturally suspicious of its claims.

I therefore spent more than a year both investigating and testing the method by first obtaining a supply of the drug in 50 mg tablet form. I also obtained from the manufacturer, Dupont, a list of research references describing the various ways in which a liquid preparation could be prepared.

Choosing the most suitable method, which gave a stable suspension, with an appropriate shelf-life of about 60 days (when stored at 4 deg C or below) I finally started testing this on myself over a number of months.

After some initial difficulty by the chemist in preparing the mixture I was able to establish a regular supply, which I used over a period of several months. After confirming its response and freedom from side-effects I later made the decision to order 5000 capsules from Bigelow Pharmacy in New York. These were initially all at a dose of 4.5 mg, and with lactose filler, as advised by Dr Bihari.

I publicised details of the method in New Pathways, the bimonthly magazine of the MS Resource Centre. This article was published in issue 15, Sept-Oct, 2002, which, on publication, heralded a torrent of new inquiries, which initially, I found both encouraging and flattering. Obviously, I was not the only one who had heard of LDN.

Within weeks it was obvious that I would need to order a further supply. I therefore started placing repeat orders so that I could maintain an ongoing supply for those already on the treatment. The numbers treated slowly increased and so the size of the LDN orders also necessarily increased in proportion. It soon became obvious that the initial dose of 4.5 mg was not suitable for everyone so I later also requested an additional supply of 3 mg.

A further problem also became obvious when a significant number of patients started to complain of muscle or joint pain within weeks of starting the treatment. This, I surmised, was due to the use of lactose filler and so I arranged for this to be replaced by calcium carbonate. This appeared to resolve the problem so I continued with this filler for several years with no complaints.

I also changed my supplier to Irmat Pharmacy when, on investigation, it became obvious that their prices were significantly lower than my previous supplier.

Continuing and increasing both the use of LDN and the range of problems that it might be used for I slowly increased the range of doses to provide six different sizes, including 1,2, 3, 3.7, 4.5, and finally, 6 mg.

The very low doses were used in the few cases that remained intolerant to the usual range from 3 to 4.5 mg. Only rare exceptions, about 0.5% of all those treated, were able to gain benefit from the extreme 6 mg dose.

Following some discussion on the internet suggesting that calcium carbonate filler was subject to clumping, thus reducing the rate of absorption of the drug, I later changed the filler to Avicel (methyl cellulose), an inert filler.

This principle of dissolution rate was also tested prior to the USA LDN conference in 2005 by Victor Fallah, the senior pharmacist at Irmat Pharmacy. He found no difference in comparative tests between all three different fillers, lactose, calcium carbonate and Avicel.

My current list of about 500 patients includes mostly those with MS, with a few suffering other auto-immune conditions, such as rheumatoid arthritis, ulcerative colitis, Crohn's disease, or psoriasis.

An increasing range of cancer patients have often shown a remarkable rate of recovery, in some cases with proven cancers actually disappearing completely. One of the most successful problems treated seems to be follicular non-Hodgkin's lymphoma. Currently,

with five cases being treated, all remain stable, with no further relapses even after up to six years of LDN treatment.

It is my primary intention to bring this simple, and obviously safe, method to the attention of the medical profession. I pursue an active campaign of informing GPs of patients on this treatment, emphasising both the safety and effectiveness of the method, with the deliberate purpose of encouraging and inducing them to provide this treatment, at low cost, on the NHS.

It is hoped that the anticipated publicity planned to occur during LDN awareness week in October will advance these aims.

I am already greatly encouraged by the progressive increase in the number of NHS GPs and private doctors already using this method and I was recently delighted to attend the very first UK LDN conference in Glasgow on 25th April this year, generously presented and sponsored by Dr Tom Gilhooley, of the Wellness Centre, Glasgow.

The talks and discussions presented by the various very notable speakers clearly demonstrate the intense and increasing amount of work being conducted in the vital field of research.

The first speaker at the conference was Linda Elsegood, one of my first patients requesting to use LDN. Linda skilfully, and very capably, demonstrated the distinct effectiveness of this unique method. An inspiring and impressive presentation by Joseph Wouk also amply demonstrated the potential for recovery of this dreadful disease. Joseph has also written a book, 'Google LDN', that can be read online or purchased as a download from the internet.

An additional talk by Dr Phil Boyle, of Galway, Eire, also emphasised the extreme safety of this method, proved when he used the drug in company with a regimen of natural hormone therapy to effectively treat infertility in many women.

In 50 cases, in order to prevent such as late spontaneous abortion or stillbirth, the treatment was continued throughout the pregnancy, when not only was the method clearly shown to be safe, with no abnormalities of any kind demonstrated, but the babies born of the LDN mothers were actually found to be fitter, stronger, and even better behaved, than the average child.

This clearly confirms the safety of LDN when used throughout pregnancy in the treatment of other conditions, such as MS or rheumatoid arthritis.

Videos of all the talks and other links may be found on the conference website, <u>www.glasgowldn2009.com</u>.

# 17

#### Brenda M, Northern Ireland 22 May 1990 - Multiple Sclerosis July 2006 - LDN

I come from a town in Northern Ireland. I started taking LDN about 3 years ago after hearing about its benefits, and I heard it straight from those who found it beneficial.

I had never heard about it before and was very interested to find out more. As soon as I got back from the MS conference where I had heard about it. I looked it up on the internet and researched it. I was told that there were no side effects once you got started on it and I was very intrigued.

I got Dr Lawrence's phone number and gave him a ring. All I had to do was go to my own doctor and get him to write a letter to Dr Lawrence telling him that it was okay for me to start the treatment.

I started it and within a few days of being on the treatment I felt a big difference. I had to self-catheterise morning and night and I had bad double vision at the time. Within one year I had no more need to use the catheter and my double vision had gone from 5 steps prism in my glasses to 1/2 in one eye.

It has helped me move on with my life a lot and it has helped me sleep a lot better. It still hasn't taken away the MS but it has helped me a lot. I am so glad that I take LDN, thanks to Dr Lawrence and a lot of his guidance.

I am grateful for LDN.

#### UPDATE March 2010

I am still taking LDN and now I am down to quarter step of prism in my glasses. The optician was going to take it out of my glasses completely but she thought she would leave a bit in to let my eyes adjust to it. I am now able to lead a normal life and do whatever anyone else can do, and even do some dancing.

# 18

### Brenda P, USA 1989 - Chronic Progressive Multiple Sclerosis (CPMS) 11 July 2003 – LDN

It is December 2005, and LDN has given me a better quality of life than I ever thought possible, so I'm telling my story in two sections - before I started LDN & after I started LDN – and when you read my story you'll see why.

I was one of the lucky people to have symptom improvement with LDN. Not everyone will see symptom improvement but hopefully you'll see a halt in progression with LDN.

My MS story BEFORE LDN:

I've had progressive MS since 1989. It is suspected that I had MS as early as age 9 years. I had the symptoms but they were thought to be growing pains.

I'm skipping the years MS should have been a considered diagnosis for me ... ages 9 through 25. I had the symptoms for 16 years and progressed to paralysis before I got a diagnosis.

Dec. 1989, age 26. I was in horrible pain in my muscles & some of the pain felt like it was inside my bones. I had enduring and debilitating fatigue, double & blurry vision, excruciating migraines, petit-mal seizures (periods of confusion), repeated and disturbing forgetfulness. Both feet felt like they had stone bruises. The doctors were not finding anything wrong.

An absence of diagnosis meant no knowledge of what was happening to my body meant an absence of treatment options. All this left me feeling isolated, hopeless and helpless. I'm good at coping, but coping was becoming increasingly difficult and physically draining. I wanted to fix this problem and get on with my life.

I decided one December day to soak in a warm tub of water to relieve my pain. I had 3 days off work so I thought I'd really get this pain to go away during my days off. I soaked that night in a warm tub of water and went to bed.

I awoke paralysed on my entire left side. That landed me in the hospital, and then my MS diagnosis came. WHAT A RELIEF!! There was a name for what I had and I wasn't going crazy after all. My type of MS attack is extremely rare. Explanation below.

Reproduced from a book that explained my form of MS attack: '... Cerebral Attack (Falling in a 3 Percent incidence rate of ever occurring): This occurrence comes with a very rare MS attack known as the Cerebral Attack. The symptoms come on like those of a stroke and include memory loss, seizures known as 'absence seizures, which are short confusional seizures', also known as 'petit-mal' seizures. One-sided visual field loss, paralysis of the face, arm and leg on one side, Lassitude fatigue, loss of speech expression or comprehension (aphasia) ... '

I managed to regain the use of my left side again but was left with significant weakness on the left side. The doctors told me to file for disability immediately, that I would not be able to continue to work, that my MS would only get worse as time passed. I was diagnosed Severe MS.

I refused to file for disability and returned to work in January 1990. In February 1990 I had an Optic Neuritis attack of the left eye. Had to be away from work. I recovered with a major visual loss in the left eye, 20/180. I returned to work.

I had another attack on my right side in March 1990 involving my right arm, head and neck. I couldn't hold my head up on my own. I had to lay it against something...went through IV steroids for many months and I got to where I could hold my head up on my own again. I can still feel the weakness and fatigue in my neck muscles even today.

I had to quit my job April 1990 and moved home with my parents. 1993 or 94 I went through years of intravenous steroids, ACTH every 4 months, I had had paralysis of my torso and couldn't hold myself up so needed a mobility scooter with a lumbar support seat that tilted backwards slightly.

Spasticity has steadily increased over the years. I was born spastic in all 4 extremities and spasticity has only increased as years passed. Fatigue has been horrendous. My muscles from the so-called MS Hug (I call it the MS Torture Chamber) were so knotted & drawn that when felt by the human hand it felt like bone, not muscle.

My vision slightly improved in my left eye to 20/160 on steroids. I've had migraines so bad that I've had to be knocked out in the ER. I've had to use a cane, a wheelchair and then a scooter. I refused Betaseron when it became available. By the time Betaseron came around I needed symptom relief more than I did anything else. The side effects of Beta didn't sound too good either. I tried Provigil and it was a flop for me. I did consider taking Copaxone about a year ago but changed my mind due to its cost.

About 8 years ago I started taking numerous supplements. My ophthalmologist is also an alternative medicine doctor. He gave me trigger point injections into my stomach, ribs, back & neck muscles & my scalp & temples using Procaine & Sodium Bicarbonate. A temporary fix of pain but not fatigue. I've done cool water and slightly warm water pool therapy off & on during the past 8 years. Warm water need not be over 87 degrees in winter in an indoor pool facility. My mom massages me.

Oh, MS has left me 100% deaf in my right ear. It has actually done eardrum damage. It has left me moderately deaf in my left ear. I have mild to moderate lymphedema (lymph channel blockage resulting in swelling) everywhere I've had paralysis and that is in approximately 90% of my body.

In 2003 I had viral pneumonia for the entire month of March and 3 weeks into April. It put my MS symptoms at rock bottom. I was considering Copaxone, IV Steroids and Botox injections into my muscles and the possibility of a morphine pump. I had heard of LDN for at least 3 years prior to my trying it. I had been too sceptical. It sounded too good to be true. I was finally to the point of no return with this knock down I'd just been given.

I knew that none of the ABCR & N drugs would make me feel better. It's well known that these drugs do nothing for symptom relief and that's what I desperately needed. I was experiencing a fatigue & pain that had me couch and bedridden. I needed Superman!!

July 2003 I decided I was going to try LDN before the Botox injections or steroids. I hoped LDN would be my Superman. My alternative medicine doc said he suspected my MS, which was moderate before 1989, was triggered by my severe bout of cat scratch fever, causing the existing undiagnosed MS to become chronic progressive. I remembered my symptoms did get much worse and I also rapidly developed new symptoms after my cat scratch fever incident.

I started taking low doses of Naltrexone (LDN) in July 2003. To my surprise, several symptoms eased overnight after my first dose of 4.5mg LDN with lactose filler. The first symptom to be noticeably reduced was the horrendous MS hug. I also had reduction in frequency of trips to the toilet at night and I noticed my fatigue had eased slightly.

Here's my MS story AFTER LDN:

Fourteen continuous years of progressive MS has been halted dead in its tracks – because I decided to take a chance on LDN.

It is December 2005, Christmas is here, and I have been taking LDN for 2 and a half years now (since July 11 2003).

I have continued on the same dosage of LDN for the whole period - 4.5mg with lactose filler. I obtain my LDN from Cantrell Drug Co in Little Rock, Arkansas ... they use pure naltrexone powder, which I believe is very important.

I haven't needed my mobility scooter in 2 years but LDN did not do this by itself, I had to do my part too (see my NOTE\* below).

I never took the CRAB drugs or Novantrone (also known as chemo) and I believe these decisions have played a huge role in my success on LDN. By the time I was diagnosed at age 26, I was diagnosed chronic progressive. I'm in my 40s now and a May baby.

What has LDN done for me? Well, soon after starting LDN my MS hug pain reduced by a good 60% and my bladder control improved. I noticed less fatigue and would say it reduced by about 25%.

After 6 months my vision slightly improved, my migraines halted, and LDN corrected my many years of suffering insomnia. I've also noticed the tremors in my hands improved slightly.

Here's that NOTE\* I mentioned earlier: It's very important for readers of my story to understand LDN won't do it all for them.

I had to do my part too to stay ambulatory (mobile) once I got out of that scooter - like exercise my behind off in the pool. I was doing pool therapy before LDN but after I started LDN I took full advantage of the reduced fatigue and reduced pain that LDN gave me, and I went GUNG\_HO on the pool exercising...6 days a week in the pool for no less than two hours each session for 1 year.

I've reduced that time lately because the YMCA is a 50 mile drive one way and fuel prices have risen so high - but I still do pool therapy as often as I can.

LDN is not a cure. It could not help my slurred speech nor my hearing loss or the muscle damage from past paralysis, BUT, based on everything I've read and everyone I've spoken to face-to-face or in forums – LDN appears to be the best available treatment for MS at this time.

Having said that, LDN doesn't alleviate symptoms for everyone who tries it. It may be because they give up too soon. It may be because they don't adhere to the recommended regimen. It may be because their pharmacy doesn't use the pure powder or the right filler. It may be because they've been incorrectly diagnosed. It may be because of their genetic makeup. Regardless, I do believe it helps stop progression in many, not all.

We don't yet know the answers to all the questions, and that's why LDN supporters and users promote the need for a clinical trial.

In terms of my diet - I do a Low-Carb Diet to keep my energy level up. I don't have high blood pressure (never have had), or high cholesterol. I don't drink alcohol nor have I ever smoked or done illegal drugs in my 40 odd years of life.

If you decide to try LDN I hope, like me, you're one of the lucky ones. But please remember luck is only part of the equation. You have to do your bit - like improving your diet - like getting the Naltrexone made correctly by a good compounding pharmacy, by experimenting until you can find the dose that best fits your body and particular illness, by using the right fillers, by making sure your Naltrexone is fast release - and by taking advantage of any improvement LDN gives you and increasing your exercise to strengthen your muscles, keeping them as mobile as possible.

LDN might do something for you straight away or it may take a few weeks or 6 to 9 months for LDN to start halting your disease progression. At first, adjusting to the dosage may be trial and error and I know that's difficult to cope with when you're not well. All I can say is, don't give up on LDN too soon. Try your best to give LDN at least 9 months to halt your disease progression.

Update August 2007:

All I can add is that I've had no progression since starting LDN 4 years ago. I still follow a Low-Carb Diet and still do pool therapy to complement my treatment.

Update July 2008:

No progression since starting LDN 5 years ago. I still follow a Low-Carb Diet and still do pool therapy to complement my treatment.

Update January 2010:

I'm still in remission but still have permanent damage MS caused before I started LDN. I'm extending the length of my home at present, replacing ceilings, putting in new hardwood flooring, etc. I could not even have contemplated that before LDN.

My pre and post LDN journey is recorded on my site here: http://www.ldn.proboards3.com/index.cgi

# 19

Bridget, New Mexico 2005 - Ankylosing Spondylitis 2006 - Fibromyalgia, Endometriosis, Raynaud's, Osteoporosis 1 May 2007 – LDN

I developed Ankylosing Spondylitis at age 10. I was diagnosed by the time I hit adulthood, then developed Fibromyalgia soon after.

I started LDN two years later on May 1, 2007, and I had a baby (while still taking LDN) the following year. I'm now in my mid twenties, am healthily breastfeeding my daughter, and wouldn't stop LDN if someone put a gun to my head.

My AS is in the 'Moderate to Severe' category, with almost every joint in my body affected, including jaw, fingers and toes, but not much fusion. The year before I started taking LDN, I was using a cane about 40% of the time, using a wheelchair occasionally, using the handicapped parking spot 100% of the time, and absolutely unable to even think about going to the mall. I had to drop out of my college classes because I could no longer write or draw. My doctor told me the Fibromyalgia is a secondary diagnosis . . . and that I probably developed it BECAUSE of the AS.

I had tried Remicade (broke a big flare but fizzled out and wasn't helping anymore), Prednisone, Methotrexate, multiple NSAIDs, and opiates (had a long-term relationship with Vicodin and Tramadol, with a nasty break-up) and several other things. When my doctor said the next step was Enbrel, I decided to try LDN instead, mostly because I didn't want to inject myself, and Remicade had already failed. A friend of the family had been telling us about LDN for a long time because it had helped her father with Parkinson's.

After one week on 3mg, my family noticed that I was moving more smoothly. After two weeks, I was absolutely ECSTATIC because my pain was cut down drastically, and I was running around in the rain chasing the sheep. Running, chasing, and rain had all been impossible before.

The second month I went to 4.5mg, and my improvement plateau-ed after about a month at that dosage. I'd say that my daily pain number before LDN was 7-9, and after LDN it's 2-4. When I overdo it, and send myself into a flare, the flare lasts a fraction of the time it did before (for example, 6 hours on the cane instead of 2 weeks on crutches).

I'm still nowhere near NORMAL, but now, 95% of the time, no one would know I have AS. I can go to Walmart now, without using the wheelchair, and I don't have to use my parking pass very often, and I even get to DANCE with my husband occasionally.

I worked at my job for about 11 months before anyone even knew I had AS. When I came in one day flaring, on the cane, everyone asked if I'd been in a car accident. Before, I'd have been on the cane for two days after going grocery shopping, or any time it rained. I can stand in line at the bank or the post office now without crying. So this is a HUGE improvement.

And another thing worthy of mention... I took LDN all the way through pregnancy, and my daughter is amazingly healthy, smart, etc (really, I'm not just a proud mom, she really IS healthy and IS smart IoI). It's even possible that LDN helped her, because I had lost 3 pregnancies before starting LDN, and this pregnancy went well and never threatened to miscarry. Now she's 10 months old and I'm breastfeeding her while still taking LDN.

My 16-year-old nephew put his 'Incurable' metastasised Medullo Blastoma Brain Cancer into full remission with LDN at 4.5mg. At least, his parents, his oncologist and I credit LDN with the 'miracle' turnaround. We don't have proof that it wasn't a direct intervention from God. The cancer had metastasised to his bloodstream and lymph system, and in October of 2007 they said he'd be dead by February 2008. He started

LDN in early November 2007, and on January 17th 2008 was in full remission. He remained in remission until he died of an accident in May 2009.

My husband is also taking 4.5mg LDN for a mystery illness (includes seizures, tremors, high blood pressure, dizziness, vomiting, anxiety, and other symptoms) and he says he started feeling better within 3 days and now he feels 60% better than before LDN. He'd been sick for a year and started LDN in June 2009. He's in his late twenties.

So, here are three different LDN stories in one email! I think I may be the first AS patient to ever try LDN, and I know that my success with it is directly responsible for several of my AS friends trying it. I should really be the poster child. My life is SO much better. I could go on about LDN for weeks.

## 20

### Bruce A, UK 2004 - Primary Progressive Multiple Sclerosis (PPMS) July 2009 - LDN

I'm nearing 70 and was diagnosed with Primary Progressive MS in 2004. In retrospect, I'm sure I suffered with the surreptitious advances of MS symptoms for pretty well all my life. In the early years I was able to hide my athletic inabilities and embarrassing toilet frequency, and concentrated instead on making the most of the 'cards that life had dealt me'.

However, in my 50's and early 60's my immobility became increasingly obvious. I was at first diagnosed with back problems. I underwent all sorts of physiotherapy and traction treatments until, seemingly as a last resort, I was finally diagnosed with MS in 2004.

Since my US-based neurologist could only prescribe quarterly massive doses of steroids, and my UK based doctors had no effective medication to offer for Primary Progressive MS, I became resigned to a continued slow progression into a wheelchair!! Luckily in 2009 I discovered Dr Bob Lawrence, who, as an MS sufferer himself, personally uses LDN and is willing to privately prescribe LDN to other MS sufferers.

I consulted with Dr Lawrence in mid 2009 and following his advice, have since then slowly ramped-up my LDN dose to 4.5mg per day. I have suffered no side effects and generally feel good in myself because I'm able to do something positive to combat the progression of my MS. In the months since starting LDN, I've noticed that my night-time leg spasms and incontinence are less bothersome and, most importantly, my mobility problems have not gotten any worse.

It should be noted that Dr Bob Lawrence has never claimed that LDN is a cure for MS but, based on his own experience and feedback from his many patients, he strongly believes that LDN is effective in slowing or even halting the progression of symptoms, and hence, MS.

I hope my story helps in the fight to raise LDN Awareness.

# 21

### Bruce R, USA 1982 – Relapsing Remitting Multiple Sclerosis (RRMS) March 2008 - LDN

I've had MS for 27 years, and I was a hemodialysis technician for 22 of those years.

I had to go on disability when my right hand became paralysed. I later regained function in my right hand, but with altered feeling.

My first MS medicine was Avonex. I used it for about 5 months. The shot was worse than the disease. I would give myself a shot and then have flu-like symptoms until about a day before my next shot was due. After Avonex, I went on Copaxone for about 6 years.

I then did some research and found LDN. My neurologist would not prescribe LDN, nor would my internist.

After calling about 5 different doctors, I found one who said 4.5mg wouldn't hurt. I've been taking LDN since March 2008.

## 22

### Cam P, USA March 2007 – Relapsing Remitting Multiple Sclerosis (RRMS) June 11 2009 - LDN

I was first diagnosed with MS in March 2007, and started on Rebif in September 2007. My last Rebif was on June 10th 2009, and my first 4.5mg LDN capsule was taken on June 11th 2009.

I would like to share my wonderful experience so far, since being on LDN. I live in Canada and am a male in my late forties. I have had RRMS for almost 3 years now. I was on Rebif up until 9 months ago when I started LDN. I finally found a doctor that is prescribing it to other MS patients. She prescribed 4.5mg for me and sent me on my way.

I stopped the Rebif injections. It was my own decision based on LDN promoting the immune system and Rebif suppressing it. I did not want that internal battle going on within my body.

My RRMS symptoms the day I began taking LDN were;

cold numbness in my feet made it painful to wear socks and shoes,

- cold numbness in my hands made it painful to wear gloves or mitts;
- a sensation of bands around both knees;
- sinus infection;
- no energy;
- full of aches and pains, and;
- mental awareness and thinking skills were diminishing.

In general my health was around 50% of what it was prior to the start of MS.

Within 3 days of taking 4.5mg LDN I noticed improvements in my hands and feet, and the bands around my knees went.

My sinus infection was gone in 3 days, with no medication other than LDN.

My general health and mental awareness strongly improved.

After 1 week on LDN I felt like a new man. I went from feeling like an 80-year-old man getting close to needing a wheelchair to feeling like a 30-year-old man full of energy and excitement. I became alive again. I got out and about, and was able to do 'normal' things. My wife now says to everyone, "I can't keep up to him. It's wonderful.".

It's March 2010, and it's been 9 months since I started on LDN.

My hands and feet are now almost free of what was an unrelenting numbness.

I have had no side effects from using LDN: I feel like I am 30 years old again. I know that I will be on LDN until there is a cure. LDN has changed my life forever. I hope that everyone else has the same results. LDN is a wonder drug for me.

I wish everyone the same success I've had on LDN.

I will never take Rebif ever again as I know it was slowly killing me from the inside out.

I have helped 2 other people get on LDN and have been contacted by many others. The problem is convincing the rest that this is not snake oil or something weird. Thursday of last week, a friend of mine started LDN: By Sunday her shakes had stopped, her energy level had increased, and there were other improvements. She said she'll keep me updated. I now know 3 people personally who are on LDN, and everyone is reporting similar benefits.

# 23

## **Carol L, USA** 2004 – Secondary Progressive Multiple Sclerosis (SPMS) 2005 – LDN

In 1988 I experienced numbress in my right hand and was told it was carpel tunnel. I wore a brace for about a month to no avail. One weekend my whole right side went numb but it only lasted the weekend. Slowly, my vision began to be affected, then my

bladder with incontinence, then I started to stumble and fall which became progressively worse. I was finally diagnosed with RRMS in 2004 after finding a good physician.

I had to wait for three months to see the local neurologist and since I was progressing rapidly at the time, I researched and found Calcium EAP from Germany. It was an intravenous therapy so I had a port placed in my left chest.

Unfortunately the surgeon placed the line too close to the heart where the vibration caused a clot that grew for three years until the port was taken out. As a result, I'm now on blood thinner for the rest of my life. I went 9 months without any MS medication, then found LDN. I progressed to Secondary Progressive MS during those 9 months.

The first thing I noticed after my first dose of LDN was that I was breathing better and easier (I have COPD). After a few nights I noticed that the spasticity pain left my legs, allowing me to sleep. I had a few vivid dreams but nothing disturbing. Next, I was able to stop using my cane when walking. I also have foot drop from the MS and have just won an insurance appeal to get coverage for the Bioness Foot Drop System.

With LDN and The Foot Drop System I should be getting back to normal in 2010 because since I have been on LDN, the MS has not progressed and has somewhat reversed. I have more energy as well as an overall good feeling.

# 24

### Carole, USA May 2008 – Relapsing Remitting Multiple Sclerosis (RRMS) Nov 2008 – LDN

This is a story about my success with LDN.

In May 2008, at just over 60 years of age, I was diagnosed with RRMS.

In late 2007, I needed to have back surgery, but through the MRI's ordered by my spine specialist, he told me I needed to have ACDF (anterior cervical diskectomy with fusion) neck surgery right away because my spinal column was compressed to a dangerous degree.

He also noticed some lesions on my brain and spine and told me to see a neurologist. I saw a neurologist within a month and took more MRI's and an Evoked Potential test, plus a ton of blood tests.

The next visit he confirmed the diagnosis of MS and he wanted to start me on steroids right away to settle things down. He had his MS nurse discuss the so-called CRAB drugs with me and I went home with the literature to make my decision.

On my next visit, the neurologist asked me if I had decided which of the CRAB drugs to take. CRAB is an acronym for MS drugs... Copaxone, Rebif, Avonex and Betaseron. I told him I still had not decided what I wanted to do and that I did not want to rush in to a decision, since I did not get this MS overnight.

I spent an untold number of hours on the computer trying to learn all I could about multiple sclerosis. That was when I came across the lowdosenalxtrexone.org web site. After reading their wealth of information, I now had the answer to what I wanted to do. Now I had to find a doctor to prescribe it for me, and a pharmacy to compound it.

I first asked my neurologist if he would write me a prescription for LDN, but he refused. He told me LDN was not an FDA approved drug for MS. Well, it is an FDA approved drug, but it's approved at much higher doses, primarily in the management of alcohol and opioid dependence. Just like Sinemet is FDA approved for Parkinson's Disease, but was then found to help RLS patients like myself.

My next appointment with my Primary Care doctor was coming up, so I took her some literature and explained to her why I wanted to try the LDN. She glanced over it briefly (with much interest) and said she didn't think she'd have a problem with it, but she'd get back to me after checking it out. My next appointment with her came up about a month later. She told me she did not have a problem with writing me a prescription for LDN (which she did), as she saw nothing in it that could hurt me. I was more than happy to sign a waiver for her.

Next I had to find a compounding pharmacy. Lucky for me I ran in to my former boss at the grocery store, and in our conversation she mentioned she had to have something compounded and told me where to go. The pharmacy was only a few miles from my home! I think they mentioned that I was their first customer to request LDN. I began my LDN at 3.5 mg in Nov. 2008, then increased it to 4.5 mg 2-3 month's later. The cost was \$40.00 for a month's supply. My cost was only my co-pay of \$15.00 for a once a night capsule, AND NO INJECTIONS!!!

Now it was time for my next appointment with my neurologist, and I had to tell him I'd started taking LDN. He was silent for a few moments and I thought he was going to tell me to find another doc, but instead, he asked me if I wanted my PCP doctor to treat me (his MS nurse was also surprised he didn't tell me to find another doctor!). I said to him that I would love for both he and my PCP doctor to work with me as a team... to let me be his guinea pig. It would help both of us. He agreed.

Almost immediately I began seeing many of my symptoms either improve or disappear completely. The feeling of 'cement' and that tight, heavy feeling in my stomach and thighs, and the spasticity in my legs was nearly gone in one leg, and all gone in the other. My energy level increased tremendously, and the pain and numbness in my left jaw and neck disappeared.

I am still taking LDN. The constant tremors in my left shoulder and arm now only occur once in a while and very mildly, to say the least. My bladder control has improved considerably. What used to be hourly trips to the bathroom became only 2-3 times the whole night.

I fall asleep as soon as my head hits the pillow. I have not had a cold, the flu, nor any bronchitis in the last two years I did have those very vivid dreams/nightmares I read about some having when they first start LDN, but for the most part they pretty much disappeared. I also had what sounded to me like crickets chirping in my ears for many years... I hardly ever hear them anymore.

I am now a strong advocate for LDN. I tell everyone I can about LDN, including my

doctors, anaesthesiologist, pharmacist, nurses, friends... anyone that will listen. The purpose of sharing my story is so others like me will know they have another choice... another avenue in the treatment of MS, and other autoimmune diseases and it's an inexpensive one that doesn't involve shots.

To those who decide to try LDN, I pray you will have as much success as I have had, and more. At least until the cure is found... there is another choice.

Blessings to you all.....

# 25

### **Cheryl M, Australia** 2001 – Relapsing Remitting Multiple Sclerosis (RRMS) March 2010 - LDN

I'm married, in my early fifties, and have 3 daughters who are all married now. I come from a family of 5 children but I'm the only one in the family with MS.

I was the sickest child in my family. I always seamed to be getting something. I had Rhematic Fever when I was 4 years old. When I experienced a lot pain as I grew older it was always put down to that, or growing pains. In spite of that, I did very well at sport in school but not very well at schoolwork.

As my girls were growing up there were times when I couldn't get out of bed. I experienced a lot of pain and fatigue during those years, and winter was always the worst time.

In 1992, long before I was diagnosed, I was flown to a Hospital twice. I was told nothing was wrong and was sent home both times. Between 1992 and late 2001 when I was finally diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS), I continued to experience MS symptoms, so it was a very long journey with lots of ups and downs.

Earlier this year, in February 2010, I participated in a program called 'Taking Control Of MS' at a Health Retreat in Australia, and it's the best thing I have ever done for myself.

As a result, I've modified my diet. I am now a Vegan who eats seafood but no dairy or deep fried food at all.

While I was at the Retreat I was told about LDN, and how well it has been working for people who have MS. I wanted to give it a try, so I started taking LDN in March. I've been on LDN for 10 weeks now and I'm feeling the best I have ever felt in my life.

LDN, in combination with my new improved diet, has changed my life for the better. I have very little pain, no fatigue, and my bladder has settled down so that I'm able to go to the toilet without using a catheter. I only need to use it in the morning, which is one

big buzz for me. The only problem I've experienced with LDN since starting is a few dreams, but no nightmares, so that's okay and I can live with that.

I am a Peer Support Volunteer with the MS Society and I'm very positive about my MS. I meditate every day, walk for a 1/2 hour daily, get my 15 minute dose of sunshine 3 days a week. I also take 1 capsule of 5000mg Vit D daily and 1 tablespoon of flaxseed oil daily. I only use olive oil or sunflower oil when preparing meals, and I use a cooking spray with canola.

# 26

### Chris M, USA October 2002 – Hepatitis C April 2009 - LDN

In October 2002, I was devastated to find out that I tested positive for the Hepatitis C virus. I had been feeling tired but had attributed it to working full time, caring for my cats, along with my work in local cat rescue here in New Orleans. I also had a bad skin infection that would not go away despite taking a course of antibiotics. The skin infection was later diagnosed as MRSA (staph) on top of the initial ringworm that I had gotten from a newly rescued cat, that I credit with leading me to my eventual HCV diagnosis.

My initial tests showed elevated liver enzymes and a high viral load test. An abdominal ultrasound showed 'fatty liver', and a follow-up biopsy thankfully showed only minimal liver damage. Still, the virus and the Staph infection left me exhausted... some days I was unable to get out of the bed, except to care for my cats. I had severe abdominal upset; IBD and bouts of diarrhea that made it impossible to leave the house. I was afraid and worried about what would happen to my cats. I was newly divorced and my cats were like children to me.

I soon learned as much as I could about the Hepatitis C virus. I was not impressed with the 30-40% success statistics of the combo treatment on my genotype, or my strain of Hep C; so I chose not to do the current therapy of Interferon with Ribavirin... despite being pushed to do so by my doctors. I also read about and met many people who had many bad experiences during the gruelling 48-week regimen of weekly shots and daily pills.

Over time I changed my diet and began taking a variety of supplements. I soon felt well enough to exercise again and was able to walk several miles at a time. My viral load and liver enzymes really did not change that much but my other test results got better. I was able to work part-time but I still got very tired.

Hurricane Katrina and the ensuing levee breaches had a big impact on my health (and everything else as well). My car broke down and I couldn't take my cats, so I stayed behind with them. We survived by climbing up into a high closet to get out of the floodwaters caused by the nearby levee breaches. I had to swim out to my roof in the end to be rescued - and miraculously, the 8 cats all survived too! We lived out of state for 6 months before returning to a new apartment in the Mid-City area of New Orleans in early 2006.

The ordeal took a toll on my health and I soon developed severe chemical sensitivities, then Fibromyalgia, Sjogren's syndrome, and terrible IBD symptoms. I had an attack of shingles and seemed to be in constant pain. It also became increasingly difficult to even leave the apartment, because I'd grown sensitive to many of the everyday things encountered in daily life.

Even going to the grocery store became a chore and I had to hold my breath going down the detergent or bug spray aisles. It was during this time that I finally qualified for disability.

Then in 2007 I started seeing an integrative doctor who told me about Dr. Burton Berkson and his work with ALA (alpha-lipoic-acid) in liver disease. I began to use the supplements that Dr. Berkson uses on his own patients and noted a slight decrease in my liver enzymes.

My own doctor also told me to cut down or completely avoid wheat, which she said many people had sensitivities to. I cut out wheat, and I was amazed at how much better I felt. I was later tested for food allergy and intolerance and found to be sensitive to wheat, cow's milk and yeast. Eliminating those foods alone improved my symptoms a great deal as well.

For my Hepatitis C, I was able to go to Las Cruces, New Mexico to see Dr. Berkson in early 2009. He prescribed 3mg of Low Dose Naltrexone, or LDN as it is commonly known, to be taken at night-time. Aside from initial sleep disturbance, I had no discomfort or other side effects when I began using it.

My first lab work done after being on LDN for 3 months was amazing! My liver enzymes had dropped down to normal, and my viral load had dropped from over a million to less than 50,000!

My integrative doctor was very impressed with the results, but my gastroenterologist was less than supportive. I faxed him my liver enzyme test results and requested that his office run a Hepatitis C Viral Load test, and he flatly refused. He said the LDN was not supposed to affect one's viral load, and he would not order the test. I have since faxed him my viral load test results and have never heard back from him.

Follow-up lab work done in September showed an even greater drop in the viral load test to18,729, and my liver enzymes were still in the normal range as well.

It is now March 2010, and my most recent labs (January 2010) also had very good results - normal liver enzymes and a still-low viral load at 38,000. My integrative doctor is very willing to order these tests and has since prescribed LDN to many of her patients.

I feel good most of the time and am able to exercise daily as well as take care of an online bookselling business. I'm also able to return to helping with the ongoing cat rescue throughout my community. My Fibromyalgia has improved, and I'm less bothered by chemical sensitivities.

The stomach upset and IBD have completely disappeared, and my Sjogren's levels have decreased, as have the symptoms. I joined an online support group called Hepatitis Children and Cam Alternatives, and many members with various forms of liver

disease are also using LDN with remarkable results. We are maintaining a Database with 'before' and 'after' LDN lab work in an attempt to interest researchers in conducting a clinical trial for Hepatitis.

I'm also documenting my use of LDN and my own health journey in my blog: (http://nolahepper.blogspot.com/)

I recommend LDN for Hepatitis and also for the multitude of diseases thousands of people around the world are successfully treating with LDN.

My next lab work is due in May 2010 and I'll update again then.

Update May 2010

Labs done in early May 2010 are also excellent - normal liver enzymes, and a very low viral load at 11,300!

# 27

### Christian C, UK 16 Mar 1995 - Multiple Sclerosis 29 June 2009 - LDN

I don't have Multiple Sclerosis (MS), nor take low dose naltrexone (LDN), I am just a witness to how LDN can change one person with Multiple Sclerosis in two weeks.

MS:

My mother was diagnosed with Multiple Sclerosis in 1995 with relapsing-remitting MS and over the first 10 years had many relapses until the MS was re-assessed as secondary progressive. I think it is fair to describe how MS has affected her before talking about the results with LDN.

She was a very successful businesswoman, and due to the MS, had to cut her career short and retire due to ill health.

MS is different for everyone. What primary symptoms does she experience today? Fatigue, tiredness, incontinence, self-evacuation, memory loss, inability to walk, fidgety leg (uncontrolled muscle spasms), but the end result is loss of dignity. Remember these are her main symptoms. She is affected by a whole host of other MS symptoms, but as her son, these are the most visible to me. Imagine the need to urinate, but by the time you get to the bathroom you have wet yourself.

One thing that is very hard to describe to non-MS sufferers is fatigue, the usual response is 'I get tired too'. MS fatigue is very difficult to describe, and perhaps the closest analogy is having severe flu where you are so weak you can't get out of bed. She is a keen gardener, but on most days she does not have the strength to prune one rose.

This is what living with MS is like for her, and from my point of view, seeing my mother being slowly ravaged by this horrible illness is impossible to describe.

#### How we learned of LDN:

A fellow MS sufferer first talked about LDN about 12 months ago and the effects it had on him. Being cautious, we researched LDN, talked to our local doctor, and she asked her NHS MS consultant his views and if there was a trial, i.e., she played by the book trying to go through existing routes to try LDN. This proved fruitless.

With the help of the LDN Research Trust we found a very sympathetic consultant in London who is experienced working with MS sufferers. After examining her symptoms and reviewing her medical history he prescribed LDN. The dose started at 3mg for two weeks then moved to 4.5mg. This is being written at the end of week two, where she is still on 3mg.

### Results after starting on LDN:

Initially she was understandably very nervous about starting LDN, as anyone is with a new medical regime, but her response to the LDN was almost instantaneous, and the main symptom that has been relieved is fatigue.

Now, remember the flu analogy above and when you recover it is such a relief and how you feel when you are back to firing on all cylinders.

Other symptoms are more manageable, because her fatigue has been greatly reduced:

- Sleep has improved, with her fidgety leg bothering her less.
- Walking has improved (she does not stumble from being exhausted).
- Walking has improved, so she can make it to the toilet.
- Her memory has improved.

Like the results Doctor Oliver Sacks experienced in 1969 with the drug L-Dopa (unsuccessful treatment of encephalitis lethargic), we accept the current results of LDN may not last and may wear off over time. We hope not, as the changes over two weeks have been outstanding. Not every day is a magical day, she still suffers from fatigue and the symptoms of MS are always there.

#### What I am doing:

I provide support by being there when needed to help both my parents live as normal a life as possible. As a side note, my holiday this year is a banger car rally around Europe of 2400 miles, to be undertaken in September 2009. The contestants are encouraged to raise funds for their chosen charity. As LDN has had such an effect and the LDN Research Trust has been so helpful and forthcoming, I will raise funds for them. It may not raise a large amount of money, but I know it will be greatly appreciated.

#### How LDN works:

LDN (3mg to 4.5mg) works by blocking the endorphin receptors for only a few hours and the body apparently compensates by creating more endorphins. Once the low dose naltrexone has been metabolised, the body is left with a 'normal' amount of endorphins, which consequently normalizes the immune function. This theory of LDN's mechanism contradicts the widely-held belief that autoimmune diseases are caused by an overactive immune system.

Conclusion:

I can understand the views and hesitation of the consultant. The main problem is the BMA has to use evidential medicine. This is to stop fad medicine and the Shipman's of this world. So for MS treatment, that means drugs to suppress the immune system to stop it attacking the myelin sheath.

LDN is the reverse of this, a drug that encourages the immune system. This is the very same immune system that is attacking the myelin and causing the MS.

What is needed is a full double blind trial of LDN. If the results back up the current experiences felt by people taking LDN, this will give the BMA another weapon in their armoury for the treatment of MS.

Who am I?

I'm a businessman in my mid thirties. I work in central London for a large international charity. I work in the IT department where I am responsible for a wide area network of over 300 sites with 5000 users. In my spare time I enjoy gardening, home improvement, movies and a good book.

# **28**

### Christine H, UK 2001 - Multiple Sclerosis October 2008 - LDN

I'm pleased to say I've been taking LDN for ten months, and am even starting to forget about the unpleasant symptoms I used to manage on a daily basis. Before LDN, never knowing what the day would be like was a real problem.

I'd always try to plan things in advance because just going to work on most days was the only thing I was able to do. By the time I got home, I'd be worn out. I often wondered back then just how much longer I could keep going to the office, but the thought of sitting at home day after day made me push on.

The disability caused by the MS in earlier years is what slows me down, and unfortunately, the LDN cannot cure that.

But I have my car and mobility scooter and I can get out and about and make commitments to do things now, which I would not have been able to do as easily before - especially on those days I used to wake up knowing it was going to be a bad day.

Another thing which has been helped by the LDN is my asthma. I've been on asthma medication since the age of 4, but around Christmas time, 2-3 months after starting LDN, I was able to stop taking my prescribed medication and have not looked back since.

I'm really glad LDN is part of my day now, because the benefit it gives to me is huge - not only for my MS but also my asthma - and it all started with a cutting from a newspaper that I was given to read.

When I read it, it sounded like something worth investigating further, so I went on the web to find out more. Whilst doing that I was very lucky to find Dr Bob Lawrence and contacted him by email. He sent back a very detailed list of all I needed to know.

After reading through it all I went to my local GP armed with all the paperwork. After discussing LDN with me, he was willing to let me try it.

That all happened last year around September-October. I didn't experience any of the early unpleasant symptoms I heard could happen, and my days are much more level. I wish I'd been told of LDN back when my MS started 8 years ago because the condition might not have taken a lot of my mobility away.

I for one am really grateful to Dr Lawrence for all his dedication in researching LDN and dietary requirements so people like myself can have a better standard of living with Multiple Sclerosis.

# **29**

## Christine K, UK 1974 - Multiple Sclerosis July 2009 – LDN

Serendipity... chance and incidental happenings can play a huge role in the remedies you seek to cope with Multiple Sclerosis (MS).

I was travelling home by bus one day when the passenger next to me, recognised me: We had shared a school-run for our daughters thirty years before. A coffee morning quickly followed, and she told me how some friends of hers with MS had benefited from low dosage naltrexone (LDN). I eventually procured a prescription and have been taking LDN for six months.

I was first diagnosed with MS thirty-six years ago. Then after initial tests I was in hospital for a course of ACTH and physiotherapy. At a subsequent review, my neurologist said; "We have done our bit. Now you are on your own.". These were words, so dire, that they were branded on my heart.

What could I do? Then at a literary luncheon I met a faith-healer who was discussing his latest book. Having no other ideas on how to help myself I made contact with him and his ministrations kept me going. I felt more or less fully recovered and returned to work.

The second attack seven years later was early in 1981. Back then the medical procedures were much more low key. ACTH injections were given by my GP while I was on my way to work. This was not a happy situation but I was rescued by a good Samaritan in the office.

My colleague had a flat-mate, who had written a review for a local newspaper of 'Multiple Sclerosis' by Judy Graham. She gave me the book and it changed my life. I began to understand my problem, but most importantly, the book gave me hope and

showed me how I could help myself. I started a programme of vitamins and mineral supplements, which I use to this day. This book was a godsend and delivered to me quite by chance.

The next happy accident was in 1992. I had become increasingly prone to migraines and depression that lasted for six or seven months. The start of a depression was precise, like a light switch being flipped. I would know from one minute to the next that a depressive period had arrived. The migraines were also increasingly frequent, lasting three or four days, three or four times a month.

In August 1992 my husband and I were touring Germany by car, bound for the Wagner Festival in Bayreuth. On the first day we drove from London to near Cologne, with a temperature of 30C and no air conditioning in the car. By the evening I felt a migraine starting and the prospect of a long autobahn journey during extreme temperature with a thudding head was daunting. At breakfast I asked the hotel manager, if he could recommend something for a sick stomach, which is where I always thought the migraine started. My GP had tried various prescriptions for the migraines and depressions over the previous ten years but to no avail.

The hotel manager gave me a couple of tablets of magnesium. Magic!! Within ten minutes the migraine had lightened and in half an hour it had disappeared. I have taken the same brand of magnesium every day since then and have not bad a single headache or depression for the last eighteen years.

My relief and joy, and that of my family at this simple discovery is hard to express in words. It truly changed my life and has meant that my retirement has been happy and fulfilling, with entertaining at home, travel abroad and doing so many things that I had given up. The problems had been caused, not by MS, but by hormone deficiencies associated with ageing. But this experience also shows that magic bullets do exist, and that is a great source of hope.

The next accidental happening contributing to my welfare was in 2006. My son's girlfriend picked up a flyer at a private health clinic, which she thought might interest me. It dealt with the vital part polysaccharides play in enabling cells to communicate with each other: boosting cell efficiency and leading to optimal health. The science sounded interesting and I signed up to the system, which I continue to use. My energy levels increased and life seemed really good, which makes the sudden down turn on New Years Eve 2007 all the harder to take.

At 6pm on that fateful evening the dreaded symptoms in my legs reappeared. This time I was given a five-day course of steroids, which cleared the aches and stiffness while the course lasted, but returned as soon as the medication was stopped. I did not have a good recovery, and am now registered as disabled and walk with two sticks. The multitude of vitamins, minerals and polysaccharides did not prevent a new attack, even though I seemed so well.

Some twenty years ago, a newspaper article on the effect of diet on disease had caught my eye. Although fully accepted now, this view was fairly new then. Feeling at a low ebb because the medical profession offered no hope, I made contact with and was introduced to, a naturopath who uses vibration therapies to improve health. Imbalances in the body are assessed by electro-magnetic equipment and appropriate remedies prescribed. I underwent treatment and this again gave me a sense of well-being. Then I met the friend who told me about LDN.

A medical prescription is necessary to obtain LDN and I found that I had write to my consultant specifically requesting that he prescribe it, before my GP would continue the provision. I started taking one 3mg capsule at night for four weeks before increasing the dosage to 4.5mg.

The results after six months are encouraging: My condition has stabilized, with fewer muscle spasms and more energy. I think total remission is still a long way off, but I look forward to slow and steady improvement in the months ahead.

# **30**

### Christine L, Ireland September 2004 - Multiple Sclerosis October 2005 - LDN

I was diagnosed with relapsing-remitting MS in September 2004 after experiencing two relapses within the course of 12 months. I experienced double vision and shaking and had to be put on steroids to get my bowels working.

My main symptoms were:

1. exhaustion and weakness

2. lack of concentration - I couldn't read anything longer than an article or very simple novel (5 years prior to my diagnosis I had qualified with a law degree so my ability to read had deteriorated quite rapidly during those 5 years)

3. when people were talking to me directly my brain very often couldn't absorb what they were saying and my eyes would start to roll in my head

- 4. Any sort of concentration at all would make my head and eyes hurt
- 5. I had recurring urinary tract infections (2 or 3 each year)
- 6. My eyesight was becoming increasingly blurred in my right eye
- 7. I was dropping things and bumping into things all the time

I started a course of LDN in October 2005 and felt immediate benefits. The only sideeffect I felt from the LDN was vivid dreams for a couple of weeks or so and then these passed.

The improvement in my health has been so immense it is very difficult to remember all of the improvements but I shall try to list as many as possible.

No wait, it is probably easier just to mention the only remaining symptoms I have of MS and that is basically these 2:

(1) I still suffer from tiredness and so probably will not work again but my energy level has increased enormously to the extent that I can get out and about every day now, whereas before I was lying either in bed or on the sofa all day, and;
(2) I still suffer from mood swings.

Essentially those are the only 2 symptoms remaining.

I used to list the improvements in my health for my consultant neurologist to show how I was improving - so perhaps it is best if I just copy these out for you and update you with my latest improvements.

MS SYMPTOMS 24 May 2006

### Improvement

- eyesight in right eye virtually normal
- tingling virtually gone was tingling all over a lot

• improved concentration - within last 3 weeks was able to read a 'heavy' book as opposed to a novel

• appetite has returned - had lost appetite from Sept 2005 to Jan/Feb 2006

• agitation has improved - I can lie and doze during the day now (both steroids and LDN seemed to improve this symptom)

### No change

- no improvement in fatigue or lack of energy
- have a lot of food intolerances my diet has become very restricted
- worsening Symptoms
- pain in right arm from elbow down when lifting things, eg, cups of tea, teapots etc this is more or less permanent

• when increasing dosage of LDN from 3mg to 4.5mg, I was in pain all over my body and had to reduce dosage back down to 3mg again

### Update 4 August 2008

Eventually I was able to tolerate 4.5mg and now I am on 6mg per day and have been for over a year.

• eyesight normal, except when under severe stress

• no urinary tract infections at all in 3 years - used to be on antibiotics 2-3 times a year before LDN

• tingling gone, except when under severe stress

• I can read with no problems whatsoever now, apart from tiredness, but concentration is excellent

- my appetite is back, with a vengeance, putting on weight rapidly
- I'm not agitated at all, although I can become impatient when very tired
- I still have food intolerances but these too are improving and I can eat many more foods now
- I'm physically and mentally stronger and more optimistic about life.

I can get out and about most days when before I was only able to get out maybe once or twice a week.

Update 10 July 2009:

Even during the past 12 months I can see more improvement both physically and in my mental well-being.

When I was first diagnosed with MS I could barely concentrate, however, I can now work a little from home. During the past few weeks I have type-set a book and

prepared it for publishing, and that took about 4-5 hours work each day and required great concentration to proof-read etc.

Last week I travelled to Preston by car from Ireland to promote the book and was able to cope with quite intense physical and mental strain. I was able to talk to people for 4 hours during the book signing and not only did I not find it particularly difficult, I actually enjoyed it (which is miraculous). Before starting LDN I didn't enjoy anything because of constant tiredness and weakness.

My brother and his four young children came to live with my mother and I for a number of months. I was able to prepare our small house and help look after them - cook meals and collect them from school etc. This would have been absolutely impossible before starting LDN.

My quality of life has improved to such an extent I can say that I enjoy life again (not always of course because I get very frustrated at not being able to work).

I am so convinced about the efficacy of LDN that I tell practically everyone I meet that I have MS because most people know someone with MS and this gives me the opportunity to spread the good news of LDN. In fact I have become something of an LDN evangelist. I have helped persuade 5 people to start LDN and they are all finding great improvement in their health.

I am so grateful for all the work Linda and Dr Bob Lawrence in Wales do to raise awareness of LDN. I can say that it has changed my life beyond recognition both in large and small ways, and if I had my way everyone with MS would automatically be put on LDN.

# 31

### **Christine R, UK** 1977- Multiple Sclerosis September 2006 - LDN

My sister in law first introduced me to LDN almost 3 years ago.

Where my sister-in-law worked, there was a young man who also had M.S.

One day she noticed how much better he was walking and asked him what he was taking. He then told her he had been taking a new drug called LDN for a few weeks. She asked for the details and who to contact to find out more information.

I made an appointment to see a doctor who'd been recommended and shortly after, started taking LDN at 1.5mg, with intent to slowly build up to the optimum dose of 4.5mg.

Prior to taking LDN I had no balance, my left hand would not straighten, my arms were weak, I used a Zimmer frame, was bent over all the time, and had constant fatigue.

After a few weeks of taking LDN, I could open my left hand and the strength in my arms

had much improved. I was able to sew and do my own hair again. These are little things, I know, but they mean so much. My balance had significantly improved I could stand straight, not bent over all the time. The constant fatigue had also improved.

All progression of my MS has ceased since taking LDN, and I have only had positive benefits from taking it.

The doctor I have been seeing for the last 3 years is to retire very soon, and as awareness in the UK for the use of LDN in the treatment of MS is very poor, I now fear for the future of my treatment.

# 32

**Claire S, UK** 1993 - Multiple Sclerosis 2005 to present, but with breaks due to cost - LDN

I have been taking LDN for 4 years, since 2005, and can confirm that there have definitely been improvements with regard progression of my multiple sclerosis.

After being diagnosed with MS in 1993 in my early teens, my condition began to progress slowly with occasional and partial remissions. My ability to walk began to degrade by the time I was around 15yrs old. I was still walking, but the distance I could walk was greatly reduced.

I was started on beta-interferon before I was 20, which may have slowed the condition but had extreme side effects, so much so that in the beginning of 2000 I decided that I would rather take my chances with the MS being untreated, despite how the condition was progressing.

By the age of 20, and after having suffered several falls, I was having to use a manual wheelchair, even in the house. By 23 yrs I was limited to only being able to stand up, and the only movement I could manage was shuffling a foot.

In 2005 I started LDN at 3mg capsules. I noticed the first beneficial effect within 20 minutes. My legs started to feel lighter and easier to move. The muscles felt more relaxed, rather than the usual feeling of rigor mortis setting in. I found it easier to get to sleep and woke up the next morning feeling refreshed rather than still tired. My energy began to steadily increase to a reasonable level.

Due to financial difficulty in reaching the prescribing doctor (in Reading) and the cost of the prescription, I had to stop taking LDN in late 2006. I soon noticed a decrease in my energy, my emotional state became depressed, and my legs felt like they were made of rock. I tried to obtain LDN from my GP, but they were unwilling to prescribe it, even privately, because they had not heard of it for this use or of its beneficial effects, etc.

So I had to find the money to return to Reading for the LDN prescription. I recommenced taking LDN at 3mg, but again I had to stop due to financial difficulties.

I also had difficulty reaching the doctor. Again, my energy and strength decreased. My eyesight also deteriorated. I experienced optic neuritis and nystagmus, and this impacted my emotional state and I became depressed.

I thought I would have a last go at trying my GP (different from the first time as I'd moved elsewhere). To my joy, she agreed to prescribe the LDN privately at no cost for the prescription. I only have to pay the medication charge to the pharmacy.

My GP is now even trying to seek the LDN on the NHS. This has reduced the cost of treatment from approx £360 per month to £315 per month. My energy is returning, and I can stand up straight again now, which was very difficult due to every leg muscle being taut and tense.

The improvements I've noticed so far:

- More energy and endurance
- Better dexterity
- Sleeping better (more refreshing)
- Skeletal muscles are looser with less cramping
- Eyesight beginning to improve (less flashing light or sun spots)
- Easier to stand (more leg strength)
- Slightly improved balance
- Clearer thinking (less brain fog)
- More cheerful and less argumentative (more relaxed)

The side effects I've noticed:

• Drowsiness, lasting maybe an hour after taking LDN (not to the point of sleep just very relaxed)

• Dry throat - I take the liquid version (drinking something stops it)

• Stomach - I get some digestive system twinges (but they're short lived, normal reactions of smooth muscle)

My progress, and the LDN benefits seem to get better each day with new things noted.

The benefits of LDN for MS need to be known to people.

## 33

### Clare F, France 1994 – Multiple Sclerosis March 2005 - LDN

I was diagnosed with a slow developing form of Multiple Sclerosis in 1994. Early on my family Doctor told me to change my diet & so I cut out animal fat and protein, and started taking evening primrose oil. I have done Yoga since I was 19 & it has been excellent at keeping me supple & mobile. Twice a week is best but that's not easy anymore.

I was averaging one attack per year from which I seemed to recover quite well. No handicap was noticeable till 1999. Having studied Physiology at university I refused to

take immunosuppressant drugs: I just couldn't believe I didn't need my immune system. The various purported side effects such as post injection flu symptoms also put me off. Had I taken those drugs I would not have been able to do my full time job, which was very competitive but rewarding.

In 1997 I transferred to India and worked in Bangalore for 20 months, but the chilli combined with the heat caused my worst attack ever. On my trip home I'll never forget standing in the immigration queue, which is long and slow, getting weaker by the minute. Once I got past the officials my legs would not move. I was literally petrified, rooted to the spot! It took a while to get help, but eventually they brought a wheel chair, with string for a footrest!

After that attack I developed a drop foot, which today is my principal handicap. Because of the MS I moved to a non-competitive but still very interesting job in March 2005, the same time I started LDN.

Keeping abreast of the latest developments is hard in France, which has a very reactionary mentality. It was through a Doctor friend of my parents (whose daughter has MS) that I first heard of LDN, and they wrote my first prescription.

LDN improved all my 'problems' with MS: I gained better balance, better bladder control, more energy, and had fewer spasms. My only side effect is that it makes me stiff all over which is a nuisance. Through a good pharmacy in Paris I found the name of another doctor prescribing LDN in France.

In 2005 I also met my future husband. We have a gorgeous little boy, in perfect health, who'll be two this year. I took LDN throughout my pregnancy. It seemed a bit risky at the time, given that I could find no info on the Internet regarding safety for my foetus.

Being over 40, having a child is something I know I would not have had the courage to do without LDN (and a great husband!). To avoid fatigue for me, my son was born by C-section and bottle-fed from day one. We also employed a special nanny for the first three weeks to do the nights and get him into a good rhythm. It was well worth the expense.

I'm using my wheelchair a lot - more than is good for me - to chase after the rascal, get major shopping done, or go to a museum. Otherwise I use a stick to maintain balance or to hook things out of my reach, or stuff spare pillows onto the top shelf! Since being on the LDN the MRI has picked up one attack, my Neurologist agrees that the LDN is doing me good & suggests that I keep taking it - though understandably (?) he will not prescribe.

Over time I have become quite strict about my diet & if I don't watch out I'll have the whole family on the best bet diet soon! Recently I did a blood test to check for allergies with mixed results - all milk products, including goat and sheep - have to go, and so do soy and black tea! However, I was not reactive to gluten. Nevertheless, I know gluten increases leaky gut problems.

Oh boy! All this makes for so many recommendations for me to navigate. Two weeks in to this milk free diet I am less stiff & more energetic. I wake up refreshed rather than craving a bit more sleep. I try to get plenty of rest, vitamins, minerals & probiotics. I still do Yoga occasionally and have every intention of doing more in the future. I swim once

a week, sometimes twice, though with our little boy turning two, I suspect this coming year will be the most tiring physically.

A really wonderful therapy is reflexology: It keeps my feet alive and in contact with the ground. A really good practitioner can even detoxify my liver. Through various helpful exchanges the next steps will be an apparatus to correct my drop foot called a 'Pneumaflex', and a Doppler to see whether or not I too have Chronic Cerebrospinal Venous Insufficiency' (CCVSI) – I'll take things from there.

All in all I feel very hopeful for a healthy and dynamic 2010 year.

## 34

### Colin T, UK 17th April 2002 - Chronic Progressive Multiple Sclerosis 2005 - LDN

I spent a long time trying to decide how to respond to your LDN awareness campaign.

I have been taking LDN for about four years now. A member at the therapy centre that I attend told me about it. Some years before, I started the Cari Loder treatment, which I am sure you're familiar with (b12, I-phenylalanine and lophepramine).

I had for months been plagued by what I can only describe as a combination of flu-like symptoms and hay fever which would come on over the morning and get progressively worse over the day. Having got to the desperate, try anything stage, I showed an article about the treatment to my doctor. He could have easily have put me off, but was in fact very encouraging about my trying it. The result was absolutely amazing and very quick.

Several years later the symptoms started again. It was at this point that I started the LDN and within a very short time the symptoms disappeared and have not come back. In short I have always felt very well during the time that I have taken LDN. Unfortunately, other symptoms of my Chronic Progressive MS have continued to get worse, particularly my hands and arms over the last month.

I am afraid this isn't very helpful to you. I am going to carry on taking LDN, but for me it hasn't stopped the progression of my disease.

# 35

### Connie A, USA

#### June 2000 - Diabetes, Nov 2002 - Hashimoto's Disease, June 2000 - Hypertension November 2008 - LDN

I first developed a chronic fatigue of undetermined origin when I was twelve years old but it was not diagnosed as CFS until 2006, by EBV titres test. A cortisol saliva test in January 2007 revealed adrenal fatigue, and Anemia caused by iron deficiency was diagnosed in June of 1971. That same fall I tested deficient in Vitamin D, then later tested deficient in Ferritin, around July 2004.

As a twelve-year-old with chronic fatigue I was still able to function but I could no longer run around the neighborhood with active friends. I walked when my friends ran. I couldn't stand for longer than a few minutes without feeling faint. I was always looking for a seat to sit down and rest.

I was first diagnosed with iron-deficiency anemia in my late teens, and that was confirmed by other doctors in my adult years. In my twenties I married and had my son, my only child, thirteen months later. When my husband died in a car accident, I became a widow. My son was three months old.

When my son was growing up, I had difficulty keeping up with him and often had to crash on the couch or my bed when I would have liked to be playing with him and taking him places. If I did anything active, even something as mild as going out for groceries or clothes shopping, I immediately had to lie down afterwards and it sometimes took hours for me to recover.

I had insomnia from childhood, and when I did sleep through the night, my sleep was unrefreshing. I always woke up feeling worse than when I had gone to bed the night before. I remarried before turning 30, but after sixteen years of marriage I learned of my husband's long-term unfaithfulness. In the late 90s we separated and divorced soon after.

Those years were the most stressful of my life, and other stressors like moving across the country, living alone in a new city, going back to school to graduate from college, and working full time to support myself while going to school full time, compounded the stress. I knew I was depressed and tried to block out my personal woes by concentrating on excelling at school, staying up till all hours writing and revising and perfecting my school papers. I was making little money, not eating right, and suffering from nightmares, heart palpitations, and panic attacks. It was probably inevitable that I would get physically sick as well.

In the early 2000s I graduated from college summa cum laude, still on the younger side of fifty years old. Not long after, I was diagnosed with diabetes and hypertension, amd a couple of years later with Hashimoto's thyroiditis. In the following couple of years I was diagnosed with Post Traumatic Stress Disorder and Chronic Fatigue Syndrome (CFS) caused by chronic, relapsing Epstein Barr Virus (EBV), and finally, Adrenal Fatigue. I also had very low ferritin, B-12 deficiency, and my vitamin D levels were undetectable.

For several years I could only work part-time, had no energy for socializing, and had doctor's appointments an average of one every two weeks due to the Primary Care Physician sending me to specialist after specialist, and having to have all kinds of tests run at the area hospitals. And yet, even with thyroid hormone medication and trials of various meds that ultimately caused me worse side effects than not using them, nothing seemed to help me feel better.

Of course, I went to counselling too, and tried about five different anti-depressants but their side effects were intolerable. I have always believed in natural healing over pharmaceutical treatment anyway.

My PCP finally decided I was non-compliant with meds and told me I should try a clinic in my city where there was a doctor who specialized in CFS and they tolerated alternate healing treatments better than the clinic I was currently at. So I switched over and started seeing a homeopath, a new PCP, and a nutritionist. But even with healthy diets and vitamin-mineral supplementation, intravenous infusions of nutrients, and an exercise program, nothing seemed to help. In addition to all my official diagnoses, I also had severe bone and muscle pain that even if I was tired enough to sleep, kept me waking up constantly throughout the night as my own body weight seemed to crush my skeleton with pain whenever I turned over in bed.

I spent my days reading health publications, especially the alternative healing ones, as I had long ago given up on the traditional medical establishment. I went on the Internet looking for new supplements to try, and studying up on autoimmune disease, which I was sure was being overlooked as a cause of my fatigue and pain. I spent a fortune trying everything that promised relief.

Finally, in July of 2008, I read about LDN on the Internet and how it helped people with MS and other auto-immune diseases. I joined the LDN forum at Yahoo groups and spent hours reading every single post before I decided I very much wanted to try LDN for myself. Through the forum I sent for a list of LDN prescribers in Massachusetts. There were only three.

The first one I called wasn't covered by my insurance and an appointment would be out of my financial reach. The second one was on the opposite side of the state about 250 miles away, and the third one was a doctor at the clinic where I was now seeing my homeopath. I emailed him and learned he was on the list incorrectly. He was against prescribing LDN and was surprised to learn he was on a list. I also tried my own PCP, but she had not heard of it and frowned in opposition to the idea.

I then followed advice I read on the LDN forum, to call a compounding pharmacy in my area and ask them if they filled any prescriptions for LDN, and if so, who were some prescribing doctors. My local compounding pharmacist gave me the names of three physicians. The first two denied that they prescribed LDN. The third one, who was the seventh doctor I had tried, was the winner. He was a neurologist who prescribed LDN regularly for his MS patients. I asked the receptionist if he would consider prescribing LDN for a different autoimmune disease, for someone with Hashimoto's Thyroiditis. She got back to me and said yes, he was willing to see me about that.

I started LDN in mid-November, 2008, at 1.5mg and took it at bedtime. I was expecting that LDN might kick-start my thyroid into working again and I would be able to cut down

on my thyroid med, but that never happened. My thyroid antibodies must have destroyed my thyroid gland beyond repair in the years before I discovered LDN.

Since I felt no effect at all on 1.5mg, I went up to 3mg after two weeks. I had learned on the forum that 1.75mg was considered the minimum therapeutic dose and that seemed true for me. On 1.5mg - nothing, on 3mg - something! The very first night I noticed I slept deeper and in longer shifts than I had in thirty years. Instead of getting up five or six times a night to go to the bathroom, I only had to get up once, and I felt I emptied my bladder more thoroughly than I ever had.

In the first week or so I did have a few of those vivid dreams people mentioned on the forum, but I want to make it clear vivid dreams does not mean nightmares. The dreams were not frightening at all, they were just colorful. On the contrary, I stopped having the nightmares I had had since I was a very little girl. Only on very rare occasions do I ever have a nightmare now, since I started LDN, and after the first few days the vivid dreams lapsed. I still get them sometimes, like when I occasionally try lowering my dose, then increasing it again to the higher dose of 4.5mg. It seems to be only when raising a dose that the vivid dreams happen, and only for two or three days at most.

I did notice one minor side effect upon starting the 3mg dose: I seemed to feel a flush around twenty minutes after taking the dose. I felt a heat in my body and face that only lasted a few seconds and then went away. It was milder than a hot flush a woman might get during menopause. It was not uncomfortable, just noticeable. It happened every night, just once, always about twenty minutes after taking the LDN. But it wasn't something that bothered me, and it only continued for a few weeks, then stopped.

I had hoped to get the great energy some people talked about, but I can only say I got enough energy that I noticed a difference, and was able to stick with an exercise program I had often had to postpone, prior to LDN (when I had relapsing 'crashes' of intolerable fatigue). After LDN, those crashes stopped, and I maintained a more regular, steady energy that, while it wasn't as good as I had hoped for, was dependable, enabling me to maintain a regular exercise program these last fifteen months. Previously, I would crash and sometimes need two or three months of recovery before I could take up the exercise again.

When I went up to 4.5mg after about eight weeks on 3mg, the warm flushes returned for about one week and then were gone for good. I haven't had them since.

Before I forget, let me tell you about my CT scans on my thyroid. When I was diagnosed with Hashimoto's and goitre in 2002, my PCP ordered a CT scan on my thyroid. It showed multi-nodular goitre, chain nodules. The doctors were worried about thyroid cancer but I refused a needle biopsy. So, they ordered two more scans, one a few months after the first one, and another five years after the second one. All three CT scans showed the nodules and there was no change over a five-year period.

The third scan was done just before I started LDN in 2008. In May of 2009 I needed a neck and face CT scan because I was having swelling in my cheek parotid gland. I asked the technician to tell me the condition of my nodules. He had the previous CT scans in his records. This scan showed the nodules were entirely gone and there was no abnormality in the thyroid gland! The only thing I had been doing differently between the third and the final CT scans was that I was taking LDN. It got rid of my nodules.

One thing I learned on the LDN forum is that LDN is not a stand-alone treatment. I have incorporated a gluten-free diet and feel better for that. There are also a lot of helpful hints that might be considered off topic on the forum, but I like learning whatever can help me. One gentleman on the forum, from the Netherlands, posted information about taking vitamin C to bowel tolerance to rid one's self of EBV. I took his advice and within one day of reaching my vitamin C saturation level, all my muscle pain left me. And it never came back.

I also started taking higher levels of vitamin D than the 2,000iu that my homeopath suggested. I now take 10,000iu in the winter and 5,000iu in the summer months, topping up what I can't get out of the sun. After two weeks of 5,000iu of vitamin D, my bone pain left me. It's been nine months since I last had bone or muscle pain, but I'm still so thrilled, hardly a day goes by that I don't pause and reflect, "Wow! I don't have any pain!" I can turn over in bed at night with ease and comfort. I smile and thank God the pain is gone.

The parotid gland swelling went away after a few months of iodine supplementation, a nutrient I looked into, also on the advice of the gentlemen from the Netherlands.

Before LDN I used to have several (sometimes up to six) loose bowel movements a day - my 'fight or flight' system was overactive. The least bit of startle, or the least bit of exercise, like going up the stairs to my apartment, used to activate my bowels and that sometimes led to accidents where I had to shower and change my clothes, which could be embarrassing if I was out or around other people. LDN regulated my system very soon after starting a 3 mg dose, so that I now average three normal movements a day.

So, overall, LDN has helped a lot. It helped my thyroid disease, calmed my bowel and bladder activity, and it gives me enough energy to keep me functioning on an even keel without those hateful 'crashes'.

# **36**

### Cristina G, UK April 2003 - Multiple Sclerosis March 2005 - LDN

I am working full-time in the software industry and I have RRMS.

My first relapse was Dec 1993, but I was not diagnosed until 10 years later.

My second relapse was in March 2003, and in April 2003 I was diagnosed with MS.

I then had relapses in Dec 2003, and again in Jan 2005. I started taking LDN in Mar 2005, and I have not had any relapses since then. I get tested for vitamin D every 6 months and adjust my vitamin D supplements according to the test result.

I take various vitamins, supplements, and 4.5mg LDN daily at bedtime. I do some exercises 5 times a week. I do not generally eat wheat and I eat very little pork (I have

been tested and am sensitive to wheat, pork and cow's milk). I try to minimise my intake of saturated fats and maximise intake of fresh fruit and vegetables. I do not currently have any disability and the only symptom remaining from my earlier relapses is a mild bladder problem - mild urgency and some hesitancy.

### 37

### Crystal N, USA Nov 2004 - Secondary Progressive Multiple Sclerosis (SPMS) and Transverse Myelitis Sept 2005 - LDN

I am a 40+ year old mother of 3 kids. On November of 2004 I was diagnosed with Secondary Progressive Multiple Sclerosis and Transverse Myelitis.

At the time I had been working for a brochure company driving a van to hotels and other places putting in brochures in the racks to keep them full.

My first symptom was feeling extremely tired all the time. When I got home from work I would have to lie down and take a nap, which was unusual for me. Later, I read that tiredness is one of the first signs of MS. I then started having a lot of back and neck pain and then went numb from my feet up to my chest and could barely walk.

I visited our family doctor, and after explaining to him what was wrong he only asked for an x-ray and checked my lower back and of course he found nothing. So he quickly dismissed my symptoms to stress and too much physical activity. After months of this constant numbness and pain, I decided to go to a Chiropractor because I thought it was a pinched nerve. So I went and he did some x-rays and an MRI. The next day that doctor asked me to come in right away.

That 10 minute drive to his office was the longest drive filled with fear and anxiety I'd ever felt. When I arrived for my results he told me he could not examine my back or carry out any procedures on my back because there was a mass in my spinal cord from the lumber region to my shoulder blades but he could not tell me if it was a tumor or just a mass. He said he had made an appointment with a Neurologist for the next day.

The hours before the appointment with the Neurologist were the longest that myself and my family had to endure - at home, wondering what was in store for me and us.

The next morning at the Neurologist I explained the symptoms I was having. He did some more tests in his office, and asked for another MRI with and without contrast (important to diagnose MS), and admitted me to the hospital to do a Lumbar Puncture. He ordered three days of Steroids through IV in the hospital and another week at home.

A week later my Neurologist explained that after reviewing the symptoms I had complained about and reviewing my medical records he determined that I had Transverse Myelitis. Also, he knew I had Multiple Sclerosis before he got the results of

the Lumbar puncture and that MS had been present at other points in my life. He just needed the Lumbar puncture results for confirmation.

When he told me I felt like I was in a bad dream. It felt like I hit a brick wall. My mind was numb and I didn't want to believe what I was hearing. I was so devastated and all I thought about was that I would end up being a cripple the rest of my life and would have to depend on others to take care of me. I was scared to death!!!

My husband and I sat my kids down and explained that I was sick. We tried to explain it in a way that they could understand for their age. They seemed to understand and didn't say much but I know they were worried. We also told them that I wouldn't be able to do a lot of stuff I was able to do before and they said they understood.

My Neurologist started my treatment right away, which is essential in treating MS. He prescribed Betaseron injections, a medication for MS which is suppose to help slow down the progression of MS but what the doctors don't tell you is that it's only supposed to help Relapsing Remitting MS (the 1st stage).

I was on Betaseron for the first 8 months after my diagnoses, but it wasn't helping me at all and just made me feel worse. I ended up getting a bad infection, called Cellulitis, in my right upper thigh from the injections. I was bedridden with Cellulitis for 3 months during the summer of 2005. I ended up having to have surgery to drain all the fluid. It was the most painful thing I have ever felt in my whole life. My husband had to help me up to the bathroom because I couldn't walk by myself and I cried all the way there and all the way back because of the pain.

In the next 8 months I went from using a walker to a wheelchair to a Hoveround power chair.

When I was bedridden with the infection I did a lot of research online and found out about another medication that some MS people were using, and it was helping them a lot.

I started e-mailing them and got all the information I could. The medication is called LDN (Low Dose Naltrexone) and it can be compounded into a capsule you take every night between 9pm and 3am. I went to my Neurologist and asked him about it, but he had never heard of it because it had not been approved yet for MS.

I printed a bunch of information about it and gave it to him and he said he would read through it and get back to me on it. A couple OF days later he called me and said it looked good and we could give it a try if I still wanted to. I said "yes", and he called it in. I started taking it on September 3rd, 2005. My understanding is that it can take up to a few months to get the full effect from LDN, but I started feeling effects from it the very first night.

LDN took away my MS Hug, and helped me walk without a walker, wheelchair, or Hoveround power chair. It also helped with some of my back pain, muscle spasms, most of the numbness or tingling in my legs, and my swallowing problems. Another benefit was that I was no longer fatigued most of the time. LDN gave me back the ability to do a lot of thing's I never thought I'd be able to do again.

It is difficult for people that don't have MS or Transverse Myelitis to understand what you are going through. This is a Neurological disorder and some of the symptoms cannot be

seen on the surface. So others who do not understand what MS is may think there is nothing wrong with you.

After I was diagnosed with MS and TM I thought back to all my symptoms over the years and I can now link them to symptoms of these diseases. I was always misdiagnosed with something else or the Dr's would tell me it was all in my head. Believe me, I wish it had all been in my head.

After I was diagnosed with Secondary Progressive Multiple Sclerosis (SPMS) and TM, we went looking online to find information about MS and TM, but couldn't find any website that was comprehensive, so I decided instead of sitting around and pitying myself I'd start my own website. I gathered all of the websites I found about MS and TM and other information and posted it to make it easier for other people to find this information.

I started Crystal's MS, TM and LDN Website in 2005 and with that a monthly newsletter. I created an LDN Users Support Group for people that need support and information about LDN - for all autoimmune diseases and cancers, and I started Crystal's LDN Gift Shop.

May there be a miracle in YOUR life today and may you have the EYES to see it.

### Update April 2010

I have had a lot going on. I thought things were settling down and now I have to have surgery to have my Gallbladder out due to gallstones. I go tomorrow morning, 14 April, for a surgery consult to find out when they are going to do the surgery. I'll keep you posted...

Yes, I am still on 4.5mg LDN. This year on Sept 3rd will be 5 years on LDN. Yes, it is still benefiting me for my SPMS and TM.

All I can say is Thank God for LDN and Until There Is A Cure - There Is LDN!!!

May there be a miracle in YOUR life today and may you have the EYES to see it.

## 38

### Daisy Z, UK 1992 - Multiple Sclerosis February 2005 - LDN

I first read about LDN at the end of summer 2004.

My body doesn't work well in the heat and I found myself looking on the internet for alternatives to the CRAB drugs my neurologist had been offering me for the past couple of years.

Although I fell within the NICE guidelines for being offered disease-modifying drugs I felt that the 'marginally better than placebo' benefits shown in the different drug companies' trial data didn't outweigh my symptoms at the time and didn't encourage me enough to start any of the NHS sanctioned treatments available.

I had been reading about the Swank and ARMS diets, theories on avoiding gluten and increasing poly-unsaturated fat intake so, after finding out about LDN on the internet I wanted to find out more. The more I found the better it sounded if only because it didn't require regularly injecting myself! I also preferred the idea of coaxing the body to treat itself better, rather than, as far as I could see, flooding the body with an inefficient set of pharmaceuticals - which utterly ignored what's not working in the first place.

The following month I started back at college as a mature student and picked up 'freshers flu' which would have been fine, almost a right of student passage except it appeared to trigger an MS attack where I didn't know which way was up and I couldn't stand or walk unaided. It seemed very unfair: My fellow students got this effect at the uni bar but were still able to stand up the next day! This subsided but has left its mark and flares up whenever I get overtired. For me, the disease modifying interferons seemed even more a wrong approach.

After visiting doctors on Linda Elsegood's list, I finally got a prescription for LDN. The medication was delivered from Florida shortly afterwards and I started treatment in February 2005. I couldn't have gotten this far without all the phone calls Linda must have been making to doctors around the country to lay the groundwork for UK LDN availability.

The first month was fantastic, my mood lightened, I felt I had less 'brain fog' and everything seemed possible. I enjoyed the vivid dreaming. I hadn't been remembering dreams, vivid or otherwise, for years! I felt I had almost boundless energy and could walk the half mile to and from college twice a day.

I use a stick now, do regular Pilates exercises to a DVD in my front room and use an exercise bike at home, because I still lose my balance whenever I turn my head and that isn't a good feeling when cycling amongst traffic!

LDN hasn't stopped the disease dead in its tracks for me but I wonder where I'd be if I didn't have it. It seems a small price to pay for what could be doing me a lot of good. This is the hard bit about MS for me, not knowing for sure what might have happened anyway. When I take a day's break from LDN my bladder control worsens and I get fatigued more quickly but I have found when I take LDN continuously it loses effectiveness my muscles begin to ache and occasionally, spasm.

After listening to Dr Zagon's interview with Mary Bradley I'd really like there to be trial data on dosing that I could rely on rather than falling back onto trial and error with my own body.

I believe LDN has the potential to be a great treatment. I'm pretty sure It's made a difference over the past four and half years for me (as close to 100% certain as you can be with MS) but I wish there were further trials - not just on its efficacy or on whether to use it, but how best to use it.

## **39**

### Daniel B, USA November 2006 – Crohn's Disease January 2008 – LDN, Ginger, Turmeric, and Krill oil

I have a hard time doing a brief story, since I did so much research and experimentation with treating the disease, but I will try to stick to the truncated version. If this is not acceptable, let me know. I am not sure what you are looking for.

My first episode that started my Crohn's roller coaster ride was in 2004, while eating dinner at a restaurant in Minnesota. My wife and myself were having a nice meal with some friends, and following the meal I felt ill. I thought I may have had food poisoning, but no one else was sick, and we all had much of the same food.

I did not sleep well that night, as I had a knot in my stomach that would not quit. I ate nothing the next day, as I still was not well. By that night, I started to recover. I wrote it off as an isolated incident of possible food poisoning, and I went about life as normal.

The next episode happened while on vacation. We stopped at a restaurant and I had a Cheeseburger with Onions and a Malt. We were heading home and I had the same uncomfortable feeling in my stomach while driving. It was the same as the last time. I had several more of these episodes and quite often while on vacation.

Soon, I was having problems most of the time. I could not hardly eat without being sick. After much prodding from, my wife, I went to see the doctor. I have little faith in doctors, as our family has not had the best experiences with them. But, I had to do something, as I could not diagnose my problem, much as I tried.

The doctor gave me the universal treatment for all Gastrointestinal problems, an acid blocker. It made me more sick than I was before. I went back and told him it was making me sicker. No problem, try this other brand of acid blocker. Now we had some progress! This one did not make me sicker, but it did not help either.

Now I have developed another problem - a burning stomach. Doctor gives me a test for H-Pylori, and it comes back negative. I also am losing weight from not being able to eat much. So far my suspicion of the doctor not being able to help me is panning out quite as expected. Finally, my wife is getting a little irritated with the lack of progress. I am down about 30 lbs of weight, am vomiting from time to time, and look like I should start picking out a casket for my burial. She comes with me to the doctor, and I am not going to be able stop her.

The doctor finally decides I need some additional tests. A barium swallow was scheduled with some expert, and that produced nothing but another medical bill. Next testing was a endoscopy and a colonoscopy.

These were performed and no one saw anything that indicated anything was wrong, other than my stomach was inflamed. They also took a biopsy of my stomach. So now we all knew that my stomach was inflamed, but they did not know why. The biopsy was

tested for H-pylori, and none was found. Now I am getting a little ticked-off, as I certainly had something wrong with me, and it should not be that hard to diagnose it.

I researched bacteria that could cause stomach inflammation and found out that about the only candidate was H-pylori. Since I was familiar with some effective alternative treatments, I decided to treat for H-pylori myself. I treated myself and eliminated the burning stomach problem in one week. I have never had that problem since. Apparently H-pylori tests are not too accurate. It is a good thing I do not believe anything they are telling me.

While I feel much better now, as I am not in as much pain anymore, I am still not out of the woods. My food still feels like it does not move, once I eat it. I am still vomiting quite regularly. I am actually getting good at vomiting. Hardly any mess at all. I am now down to about 170 lbs. I started out at 215 lbs.

Another trip to the doctor, wife in tow. Finally he thinks it would be good to see a specialist. Better late than never. I guess it would be better to see one while I was still alive. This is when things turned around dramatically.

It is now November of 2006 and I am over 40 lbs lighter than I started. I have been ill since 2004. I had an appointment with an excellent Gastroenterologist in Minnesota. He performed the same scopes that had already been done, and later ordered a CT scan. Shortly after that he diagnosed me with Crohn's and scheduled me for surgery since I had a stricture (narrowing) that was choking off my small bowel. I was looking forward to the surgery.

The surgery was performed by a highly skilled surgeon by everyone's account, and I woke up in pain, but feeling better right off the bat.

Now I have my follow up visit and we are discussing treatment options. The Gastroenterologist tells me he has had good results treating Crohn's with Imuran. I have already looked up common Crohn's medications and I know this is an immune suppressant. I tell him that I will certainly consider Imuran as a treatment option, but I do not do anything without some research first.

I decide that I will treat the problem with anti-inflammatory supplements while I try to find out what makes this disease tick. I like to treat the cause of the disease, if possible. In order to do that, I will have to find out the cause of Crohn's.

My research led me to the conclusion that Crohn's is caused by a dysfunctional immune response. It is not caused by the body attacking itself, but by the body trying to kill pathogens that it is not able to kill.

I even have a good idea which pathogens are likely responsible. I discover on a Crohn's forum the orphan treatment of using Low Dose Naltrexone. I read all I can about this treatment, and ask people who have used it, how it works for them. Most people that use it really like it. There are a few who do not respond to it, but the odds are good that it will work for any given person.

In the mean time I have been treating with higher doses of Ginger, Turmeric and Krill oil. This has reduced my symptoms, but it is not 100% effective. What it was 100% effective on was my life long battle with depression. Apparently, my depression was directly linked to the chronic inflammation due to the Crohn's. Now that I had reduced

the inflammation, I have no more depression. 30 years of depression accidentally cured by my ad hoc Crohn's treatment.

I called my Gastroenterologist's office and talked to the nurse. I told her I found a medication I was willing to use, and that it was LDN. She said she would forward that information to the doctor and that they would call back. When she called me back, she told me that he was not willing to prescribe LDN.

I thanked her for asking, and was about to hang up when she asked me what I was planning to do? I told her I was going to find a doctor to prescribe LDN. She said that I was unlikely to find a doctor to prescribe LDN. I did not argue with her, as I already knew of at least two doctors that I could get a prescription from.

I am under the assumption that the person who has to take the medication, and deal with the consequences, good or bad, should have the last say in what they take. I do not think doctors are too wild about that concept, but at 47 years of age, I am certainly capable of making my own decisions. I am old enough to do it, and stubborn enough to get my way.

I proceeded to make an appointment with a doctor in Chicago who treated many people with LDN. I was also treating with an alternative treatment, prior to using LDN that, hopefully would clear out much of the bad bacteria in my intestinal tract. This method put an end to my symptoms before I started LDN.

Since that time I have been symptom free most all of the time. I did have food poisoning a few weeks ago that sent me in a brief tailspin. I resolved that and am good as I was before. I have been on LDN for over two years now, and I could not be more pleased with how it keeps me stabilized. I still watch what I eat, and avoid carbs and sugar, as they feed bacteria and yeast that can make this disease worse in a hurry. I still take small amounts of Ginger, Turmeric and Krill Oil, but just for their health benefits. I do not need them for Crohn's, but it does not hurt taking them either.

I still use my alternative treatment on occasion, but LDN is doing most of the work now. I am able to function just as anyone else, and not too many Crohn's patients can say that. I also resolved my depression problem in my battle with Crohn's, so I can honestly say "I am glad I got Crohn's". If it was not for my diagnosis, and treatment, I likely still would have my depression.

I am of the opinion that LDN should be the first line treatment drug for most Crohn's patients for the following reasons.

It is effective more often than not.

It is affordable to most anyone.

It has no serious side effects.

It has many benefits such as protection from other autoimmune diseases that can accompany Crohn's, such as Arthritis.

It protects you from Cancer, instead of increasing the odds of Cancer as some other medications do.

Its method of action is unlikely to stop working since it is effective only a few hours.

I challenge any doctor to find a medication for Crohn's with that many benefits.

## **40**

### Darlene N, USA 1989 - Systemic Lupus Erythematosus (SLE) April 2009 - LDN

I have had systemic lupus for 30 years and was diagnosed with it in 1989. I wish I had known about LDN earlier as I think about all those years I was sick with the debilitating fatigue of lupus. I could not make plans to go anywhere or do anything without having to cancel at the last moment because of a flare-up.

My Lupus flare-ups caused extreme fatigue and weakness and I would wake up that way in the morning. If I was a little stressed over anything, it would come on during the day, and there was nothing that would stop it or help it. I would just have to wait it out 24-36 hrs, until it decided to go away. I would feel so bad I could barely get out of bed to get to the bathroom. And going anywhere? Forget it!

I struggled with trying to go places for years. When my children were little and I wanted to be super mom, I forced myself to go to school functions, etc, but I can remember coming home and going to bed feeling ill (that was before I was diagnosed).

After diagnosis I was put on prednisone, but it didn't help much. Even on days when I wasn't flaring I would tire easily and have to use an electric cart at the grocery store and elsewhere. I remember going to the store and coming home sick in the middle of shopping.

A lot of lupus people say the fluorescent lights at the store can make us sick, but I don't know if it was that or something else. Most times I would try to grocery shop I would come home ready to go to bed and my husband would have to put away the groceries, etc. Anyway, I did survive that way for years but finally gave up pushing myself and had to submit to rest when the flares would hit and, of course, trying all kinds of medicines from the rheumatologist. I took Plaquenil for about 5 or 6 years (didn't help much), and then it started making me weaker so the doctor took me off it.

Prednisone didn't really help much. I tried Cellcept and it didn't help either. I was still getting lupus flares at least every other week or so, some lasting 2 days instead of 3. Think of trying to live a normal life then having this interruption constantly - feeling like you have a high fever or flu, and having to cancel plans made and instead, stay at home in bed.

I had got to the point where the rheumatologist could not really give me anything to help me. She said she'd tried everything and told me I would have to put up with the flares as

she didn't know of anything for the fatigue. (I was just lucky to not have it in my organs as some do). Then I received an e-mail from a friend of mine who knew I had lupus. It was all about LDN. I went directly to the website and read about it, and checked where I could find a doctor to prescribe it. I printed all the information and gave it to my rheumatologist, but she said she didn't know anything about it and wouldn't give it to me. I told her I was going to go to the doctor in St. Louis who would give it to me. I also showed the info to my primary care doctor and she said she didn't know a thing about it either, and so wouldn't prescribe it.

Well, I saw the doctor in St. Louis and started on 1.5mg LDN in April 2009. I increased the dose to 4.5mg in about a month. I began feeling good immediately! It's almost a year now, and since starting on LDN I haven't had any flares of weakness. It worked like a miracle for me!

And, I can't believe that I'm actually feeling like a normal person. I can make plans for things and do things a normal person can do, without getting sick, and without having to cancel.

I exercise every day now. I walk on the treadmill for 30 minutes and do some weights. I am just amazed at every day when I wake up feeling great and continue feeling this way! I want to tell everyone I know with Lupus or MS about LDN, and wish my friends who are really sick would start on it; but most are afraid of anything their doctor doesn't tell them about.

I guess I've always been brave in trying new things (I took an experimental drug from the Burzynski clinic in Houston) for 6 yrs, and I was in an FDA trial with it for 3 yrs. I was doing well then also, but not as well as the LDN is that's helping right now.

I only hope & pray that this continues and I can continue to take LDN. I haven't had many side effects at all and continue to eat mostly whatever I want. I haven't seen any negative effects like some have written about. But, I do try to eat as healthy as I can to help the LDN help me, and I take a daily vitamin and Fish Oil. I'm also a thyroid cancer survivor, so I know how important it is to eat right.

I feel blessed that I found out about this medicine, and that it works so well for me. I thank God every day.

My rheumatologist can't believe how well I'm feeling and that I haven't had any flares. She is checking this out on the web but says that she doesn't see anything for lupus and wonders if I have MS also for it to work so well. Well, I have been checked for MS and I don't have it. So I think she just didn't see that Lupus was listed as a disease it helps (or maybe didn't want to see it).

Anyway, it's working for me and I would recommend for anyone to try it. It's such a low dose it can't hurt to try, which is what I did, and I'm glad now. I sure wish the neurologists here were aware of it, and the rheumatologists; but maybe someday they will with our help. I'm in my early sixties and I can really enjoy my grandkids now, thanks to LDN.

### David C, USA 15 March 2007 - Stomach Cancer, Tumors 28 March 2007 - LDN

My father went to the doctor because he had been experiencing some symptoms.

My father was diagnosed with a stomach cancer on 15 March 2007.

His CT scan showed the tumors.

My father's doctor prescribed chemotherapy, Taxotere x 59mg once a week, and stents were put in his kidneys as well.

My sister and I worked with an LDN friendly doctor to get him on LDN. She made sure the chemo and any other meds would not interfere with LDN, and he took his first LDN dose on 28 March 2007.

The Oncologists advised my father and sister he had only 6 MONTHS to LIVE, IF THAT.

His chemotherapy treatment continued but was considered only palliative - a treatment intended to delay/defer death.

My father underwent the weekly Taxotere chemotherapy for 6 months in total, between March 2007 and September 2007.

After 6 months on LDN and Taxotere he had another CT scan, and it showed his tumors had shrunk in HALF.

The oncologists said they'd never seen THAT happen in their careers.

They stopped the chemotherapy treatment immediately.

From September 2007 onwards my father took only 4.5mg LDN, complemented by a healthy diet and vitamins my sister thought would help: Ubiquinol 100mg; a multivitamin with extra B vitamins; Combination supplement with Calcium 1000mg, Magnesium 500mg, Vitamin D 100mg; Cranberry; EFA fish oil triple strength; Iron; Vitamin C 500mg. After being put on prescription Calcitrol 25, my sister switched from the Combination Calcium, Magnesium, Vitamin D (1000/500/100mg) supplement to a single Vitamin D 1,000 supplement.

In December 2007, 3 months after stopping Taxotere, the Oncologists declared my father was in remission and stable because his tumours had ceased to grow.

A further 3 months after that, in March 2008, a subsequent CT scan showed my father's tumors had again shrunk in HALF.

Continuing CT scans have evidenced further measurable reduction in tumor size.

It's now May 2010, over 3 years since my father was diagnosed with incurable cancer, and he's still walking, talking, driving, playing poker, enjoying what he can, and carrying on as usual.

My father continues to take 4.5mg LDN every night.

His tumors are now almost undetectable, almost gone, and he is not only alive but feeling well 2.5 years beyond the '6-month end-of-life prognosis' delivered by his Oncologists.

His only medication is 4.5mg LDN. He is also on prescribed calcium supplementation, Calcitrol 25. He follows a basic, healthy diet, and my sister also gives him the following vitamin supplements daily: Ubiquinol 100mg; a Multi-vitamin with extra B vitamins; Vitamin D 1,000; Cranberry; EFA fish oil triple strength; Iron; Vitamin C 500mg.

### **42**

### David M, USA May 2009 – Multiple Sclerosis 14 Sept 2009 – LDN

My relationship with MS began well before I knew it had arrived in my life. Before that, I'd been blessed with good health for 57 years.

Looking back now, after nearly a two-year odyssey through the health care maze, there were clear signs before my definitive diagnosis in 2009 - but they were easily ignored as any advance in symptoms played no large part. There was even an MRI in 2004, which showed UBO's (unidentified bright objects), as the neurologist called them, but with a history of excessive alcohol use, (long ago curtailed), they were no cause for concern as my function, mobility, and cognition were all above average.

But then... the decline. A decline so notable it could not be ignored - mostly immobility and it slowly became worse. After yet another MRI, the superb physicians at Penn State-Hershey made the official call in May, 2009. It was MS. There was no way to diagnose the precise form of the illness, but from the manner in which my symptoms have progressed, there is absolutely no doubt in my mind, or in my own knosis (critical thinking), that my form of MS is the progressive type.

After the usual emotional adjustments, helped immensely by coincidental personal and spiritual evolution on a grand scale, I rather quickly decided my approach would be an alternative one, that is; one that didn't involve the usually prescribed drugs with side effects so serious that in at least one case, had resulted in fatality. No, none of that for me.

Instead, major diet changes, supplements, and a modified life-style would be my routine. Besides, even in my new paradigm, I was not overtly disabled, as I could still work, drive, and function day to day. Yet decline was extant, hovering as a shadow over this daily routine. Its existence was undeniable, and I dreaded the day I would confront

the MS specialist at PSH who would deliver the final pronouncement that I was inching toward a wheelchair. I was, however, firmly resolved to rejecting the so-called CRAB drugs, no matter what.

That day, September 10, 2009, became a red-letter-day, even as I almost cancelled the appointment. For, while the details of the give and take discussion are unimportant, the end result was that this wonderful doctor, clearly half my age, opted for the 'Hail Mary', and prescribed low dose naltrexone (LDN) at 4.5mg. After locating the local compounding apothecary, I began my LDN on September 14, 2009.

Since that time, and until now as I update this in January, 2010... while the results have not been dramatic, in the less than one month on the medication, improvement has been nonetheless discernable.

Gone is almost all spasticity, brain fog, and that overwhelming fatigue at the end of a normal work day, which would often force me to bed by 6pm. Also mobility, while still a challenge, is not as laborious and has improved somewhat. Moreover, there is a feeling of wellness, hardly describable, which has replaced the feeling of discomfort, equally indefinable in words.

And all without any side effects to speak of, save some vivid dreams in early stages of use, which were actually quite pleasing. This all fits, as I have seen testimonials from all over the world as to not only how LDN works generally, but how long-term MS users have seen progression stopped, as evinced in regular MRIs.

So, as a proponent of LDN, I am now a true believer, and another living proof of the effectiveness of LDN.

### David N, UK 1995 - Multiple Sclerosis 2006 - LDN

I first started having MS symptoms in 1995 when I was working in London.

My walking became awkward, and I tripped over in the roadway. At first I did nothing about it, but when it continued, I decided to get it checked out. I went into the National hospital for tests and was diagnosed with MS.

I was able to continue working until 2003 when I was forced to give up.

I knew about LDN for a long time before I decided to take it. The sheer thought of taking tablets that I'd never heard of, or the possibility of unknown side effects was not something that filled me with glee.

Then again, what did I have to lose? Absolutely nothing. So, in 2006 I plucked up the courage to take LDN, and within a few days I noticed I had more energy.

When I experienced Trigeminal Neuralgia, a horrible mouth pain that required pain medication, I had to stop LDN for a while. My MS became worse up until the day I went back on the LDN.

LDN is not some sort of miracle cure. My MS didn't disappear. I still get my off days, but with LDN, the good days vastly outweigh the bad.

Since starting on LDN in 2006 my energy has been fantastic and my quality of life is so much better, and who knows, one day....

I take one 3mg capsule each night before bed, and for the moment that dose is fine for me. I get the LDN as compounded capsules from Dickson's Pharmacy in Scotland and would recommend them to anyone.

I had nothing to lose, everything to gain, and I now have a life.

To anyone undecided about LDN, I say 'give it a try'.

Don't expect miracles. See what happens. If you don't try to help yourself, then no one will help you. Be positive and go for it. Good luck!

## 44

Davinia W, UK DATE - Multiple Sclerosis July 2008 - LDN

I found out about LDN on my own.

I was searching online seeking some sort of treatment for my MS, because I don't think MS sufferers get any help at all.

I found Linda Elsegood's story during my search, and I was amazed. I was also determined to start this drug, and I had nothing to lose.

Since taking it, I have more energy, and don't seem to be as forgetful as before.

I think LDN should be available to everyone on the NHS. I buy my own, yet my friend gets hers from the NHS because her Neuro agrees to it, whilst mine refuses to let me try it. Like many others I had to get it myself privately and I will stick by it now. It really is time to have this choice.

### **45**

### Deanna V, USA October 2003 – Relapsing Remitting Multiple Sclerosis (RRMS) July 2005 - LDN

My first symptoms were leg weakness, tingling, buzzing, urinary urgency, and L'hermitte's sign.

I was in my nursing clinical when symptoms began. After my MS diagnosis, I quit nursing school.

From the onset of symptoms in July 2003 until August 2005, the only medicine I took for MS was Copaxone, with occasional IV Solumedrol treatments. During this period, I suffered with severe fatigue as well as the onset of new symptoms: Mild numbness began over about 50% of my body. It occurred in my limbs and in various areas all over.

Scans indicated my MS was mostly in my spinal cord, so a lot of my symptoms occurred over both sides of my body... both legs, both arms, both hips. I also had bladder urgency, and the fatigue was crippling.

I went looking for alternative treatment. I did some web searches and came across LDN. I remember one woman named Joyce told me about it and how to get it. I took all the info to my Neurologist, and I basically told him, "I am going to try this". He smirked, as if thinking it was a bunch of bunk, and prescribed it for me.

That was in the Summer of 2005. From the moment I took it, I felt a difference. The fatigue diminished the very first day, and it continued to get better every day after that. Even the numbress eased. I then went back to work a few months later and have been working ever since.

It is now almost 4 years since starting on LDN, and I still work full time.

I guess what I'm really trying to say is... Here I am, 6 years after my MS diagnosis, and I am still up and running. I walk 3.5 miles a day, do aerobics for 30 minutes straight, and I lift weights.

I don't even look like I have MS. Is it the LDN??? All I can think of is... what if? What if I never took LDN? What would I be like today?

Oh, and I also have a sister with MS who refuses to consider LDN. She uses a cane and a wheelchair.

## **46**

### Deidre A, Hong Kong

Sadly, Dee passed away Thursday 22<sup>nd</sup> April 2010

**October 2005 - Cervical Cancer (Adenosquamous Carcinomas)** 

I am a LDN user of 2.5 years.

I was diagnosed with cervical cancer of the type Adenosquamous Carcinomas, the rarest form, which has features of both squamous cell carcinomas and adenocarcinomas. I underwent Wertheim's total hysterectomy and right salpingo-oophorectomy (removal of right fallopian tube and ovary).

After surgery, reassessment found 'Poorly differentiated Adenosquamous Cell Carcinoma, at least 4 cm in maximum extent with prominent lymphatic permeation, 3 positive Lymph nodes - Comment pT2N1Mx (\*TNM System Cancer Assessment).'

I began concomitant External Beam Radiotherapy (RT) with Cisplatin chemotherapy treatment. This involved 29 RT treatments over a period of 5 weeks, 5 cycles of Cisplatin (one each week for 5 weeks). I completed the treatment on 9 January 2006. During treatment I experienced the following side effects: fatigue, severe cystitis, severe pain on bowel movements.

Conventional radiation and chemotherapy treatments following surgery, from October 2005 through 2006, but didn't halt the growth or spread of the cancer.

In January 2007 a follow-up PET scan (2) identified nodules in my lungs suspected as metastatic cervical cancer, and confirmed as metastases with at least 13 nodules, the largest nodule (3) being 1.3 cm. Reclassified cancer to Metastatic Stage IVB (based on TNM System Cancer Assessment).

By Feb 5th 2007, my cancer had progressed to Metastatic Stage IVB, with multiple lung mets. My cancerous nodules were doubling in size every 33 days. All conventional therapies had been exhausted.

As a prognosis, I was given 10 months to live and told to get my affairs in order. I was offered palliative chemotherapy, but I declined.

Then I found out about Dr Bernard Bihari and LDN.

I got my first LDN prescription for 4.5mg on Feb 12th 2007. I began taking it between 10pm and 11pm each night.

In the first year, new tumors were detected, but nodule growth of old tumors had slowed dramatically, with the doubling rate reduced from 33 days to 212 days.

In June 2008 I underwent Radio Frequency Ablation (RFA) to destroy the largest nodule in my left lobe, hoping to reset the 'clock' on the largest tumor growth, expecting that the LDN would continue to hold down the growth of the other existing nodules, and extend my high quality of life.

The treatment with RFA to one of the larger tumors in my Left upper lobe was successful. A subsequent scan revealed multiple metastatic nodules but some were now showing calcifications.

My last treatment was surgery in Feb/Mar 2009 to correct pelvic radiation damage caused by the External Beam Radiotherapy (RT) in Dec 2005/Jan 2006. After that surgery I spent 4-5 months healing and didn't go in for any more scans.

Doctors have continued to classify me as terminal, but I'm still feeling well after 2.5 years on LDN, and I'm still here - 28 months later, and 18 months past the most optimistic 10 months I was given.

Apart from early on, LDN has had no side effects for me, and anyone seeing me would never believe I have cancer since I feel and appear healthy.

### Update April 2010

I haven't been doing so well after all the operations, beginning with the fistula repair back in January 2008, and corrective surgery since then (see earlier entries). In all this time, I've only stopped taking LDN when I needed strong pain medication due to very painful medical procedures. I would go off LDN for a few days so the pain meds would work, then back on after I eased off the pain meds.

The most recent development was in January. I developed severe nerve pain in my right leg. A Pelvic exploratory via CT guided catheter determined an enlarged lymph node was pressing on the nerve in my leg. The lymph node was aspirated by needle and 10ml of liquid was removed, which is a substantial amount for a lymph node. The doctor was sure it was cancerous but lab tests came back as negative (thanks I'm sure to LDN).

An added complication was that my ureter tube almost closed, causing severe back pain and almost collapsing my right kidney. Doctors went in and inserted a stent into the ureter to resolve the kidney problem.

So things have been difficult, but I'm still taking LDN nightly. I'm hoping to hang in there as the body replaces its tissues and maybe sometime in the future, a workable treatment for fistula repair will be found. In the interim I'm considering my options.

This is an article <u>http://www.jfponline.com/Pages.asp?AID=4165</u> on possible experimental procedures for fistulas such as mine, so I might next try pig tissue patch porcine small intestine submucosa (I guess a form of transplant) which is applied to the fistula and hopefully allows new tissue to grow over the patch to seal the fistula. I haven't gone this route yet as my doctor needs to research the procedure and find sources for the patch material.

The only procedures my doctor will do are those that can be done without resorting to surgery because my tissue will not heal from another surgical procedure.

I don't think direct tissue transplants would work for me because most doctors don't want to do anything (because I'm stage 4). My current doctor, however; will try anything and so far has been trying experimental things with so far only temporary success as he expects the 3 catheter balloon fistula seals to soon work free.

So I'm on a low residue diet and 'Ensure', a complete liquid nutrition by Abbott Labs, to try and limit the discharges. I've also had trouble swallowing solid foods and my taste buds are very finicky.

I hope I find a treatment eventually that will get me on some path towards normalcy.

I had my last CT scan of the Thorax on 22 August 2009. The Oncologist said the radiologist's report was 'heartening' because for the first time the report mentions '... some of the nodules show intralesional amorphous calcifications ...' and '... intralesional calcifications are present ... '.

The Oncologist said that intralesional calcifications are an indication that a tumor is dying from the inside (indicated by the calcifications) and according to the report there are numerous such calcifications throughout the lung. So even though there was some growth in nodules and number (consistent with what LDN has done which is reduce growth to about 1 mm per month), the numerous calcifications indicate a positive outcome if the tumors are not healthy, and the report adds 'no significant interval change is seen'.

My rationale is that if a tumor isn't able to grow at the rapid rate it requires, then many of the rapidly growing cells must die off before the new cancer cells take root. LDN is holding down the growth rate so the cancer doesn't grow at the rate required to overwhelm my lungs. The oncologist was happy after that result as he sees it as having the cancer under control.

SO... all my current difficulties are directly related to the radiation treatment damage done in 2005/2006, and if I were to give any advice to someone in a similar situation to me, it would be to do the surgery and don't do the radiation (since it didn't work anyway), and go on LDN.

I'm still surviving 2 years longer than my original oncologist predicted I would "if I didn't do his 2nd line chemo regimen".

So from an LDN point of view, it's been doing what it's supposed to do.

### Sadly, Dee passed away Thursday 22<sup>nd</sup> April 2010

### Update April 24 2010

Some very sad news.

Dee (Idn4cancer.com) passed away Thursday 22<sup>nd</sup> April, 2010.

Dee did not die from cancer, but from a suspected heart attack.

Due to 3 irreparable fistulas in her bladder and intestines, Dee had lost a lot of weight in her last 3 months, her body unable to metabolise the nutrients she so desperately needed.

Coupled with that, Dee had been experiencing severe pain throughout the last few weeks of her life; in her legs, chest, and back, and when in hospital, doctors also detected an irregular heart beat for which she was taking medication.

Dee continued to believe in LDN, and continued to take it up until her last night; but unfortunately Dee's body continued to suffer the after-effects of radiation treatment undertaken between Dec 2005 and Jan 2006, which had taken a heavy, irrecoverable toll on her body.

From the moment we met Dee we were impressed by her courage, her patience, her kindness, and a generosity of spirit that shone its light on everyone. When faced with a life-threatening illness, Dee chose not to be introspective but instead to share her story and her challenge with the world... all in the hope her journey would help others... all of whom she didn't know, and would never meet.

We held Dee in the highest esteem, admired her fortitude, and most especially... her altruism in sharing her journey in the hope it would help others, continuing to do so even when suffering and in great pain.

All of us who've read, benefited, or will benefit from her shared journey, and all those who will suffer less thanks to Dee, are forever in her debt.

We'll miss Dee, and we're so very sad she suffered much in her final months... but also know such a beautiful spirit, now released from pain, will be free to soar across the heavens... and her brilliant light and warmth will instead be reflected on all of us from above.

Dee was incredibly special to all of us.

We'll miss you Dee.

# **47**

### Denis T, USA 1988 - Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) 24 October 2009 - LDN

Before LDN, I had continuing symptoms of Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and I was taking 10mg Prednisone daily to minimize their impact on my daily life.

Overall, apart from CIDP, I was healthy.

In preparation for starting LDN I titred down my Prednisone dose over a 2-month period from 10mg to 2mg. I started taking 1.5mg LDN on 24 October 2009 but as I had no side effects, was able to ramp up fairly quickly to 4.5mg over a 2-week period.

Since commencing LDN, I've achieved a FULL recovery... but who knows as it seems I am the first doing this and so, am still unsure about longer-term benefits.

### **48**

### **Denise G, USA** 1999 – Multiple Sclerosis

I was on the phone with a man who was newly diagnosed. I was letting him know the internet can be our friend and it can also make us overwhelmed with all the information. Some of which can be scary. I was searching for the link in which he could sign up for the quarterly research support for Multiple Sclerosis.

There it was, not the quarterly research report link, but on <u>www.thisisms.com</u>, a page refuting the National Multiple Sclerosis Society response to LDN. What was this? What is LDN?

I left the page open and finished my phone call. Some time later, I went back to that page and read the whole thing. Then I ran a web search for LDN. I found more information and all of it was intriguing.

Now, I have stumbled on things that others have swore by in the past, none of which left me wanting to talk to my neurologist. This, however, was a very different story.

At that time I was waiting for Tysabri to be re-released so I could start it and get out of the awful downward spiral I seemed to be stuck in. While I was eager for Tysabri to be released again, I was also scared. What if I were one of the unlucky and had horrible side effects, or worse, PML. But what I was living with was awful, nothing was making me feel better. I could barely get through each day! But here was LDN, and it was an oral medication!

I printed everything I could find. Waiting for the neuro, I was anxious. What if he wouldn't talk to me about it? The time had come, this was it. "I know I'm supposed to start Tysabri, but I came across something..." I gave him the printouts and asked what he thought of me trying this since the risks seemed to be none at all...

He looked at a few pages and said "Well, I have several patients taking LDN with success". Wait, what? He already has patients on this? Did he say success? He did let me know of 1 patient that didn't seem to be able to handle it but felt it was an allergy issue unrelated to LDN. Well, he wrote me the script and let me know that now I had to find a Compounding Pharmacy, but that he thought there was one in the Central Jersey area.

I found a pharmacy, no problem. Only a half hour drive away. I couldn't wait to try this. I picked up my prescription and couldn't wait for the evening. I started LDN and I was cautiously optimistic. I never expected to feel as good as I did as quickly as I did. Within a week I was feeling a little better. What was even better news was that the feeling of being stuck in a downward spiral was no longer part of my day.

Within 2 weeks, I actually felt like I had energy. Energy, what was that?! And I was enjoying it! I did need to take some of my sleeping pills a few of the days. I did experience some trouble getting tired enough to sleep. But thankfully I had Sonata, which is short-acting and enough to get me to sleep and sleeping through the night.

In the next few months, I increasingly felt better. I was getting back out hiking. I was back out in my kayak. My recall, though not back to normal, was improved.

My neurologist had scheduled me for another MRI about a year later, to see how I was doing on LDN. When I went back for the results, I heard something I had never heard from him... "Well it is working"!!!!!! :) I had no new lesions!!!! I was feeling better, and I had no new lesions. Sadly, I feel I waited too long to find LDN.

I do have some permanent scar damage. I still suffer cognitive impairment and although my fatigue has improved and has never been as bad as it was prior to LDN, it is still there. I still live on that roller coaster ride called MS, but again, nothing as bad as prior to LDN. I never felt better as quickly on either Avonex or Rebif.

# **49**

Di M, Australia 1989 - Myalgic Encephalomyelitis (ME) Nov 2009 - LDN

The man stood in front of the doctor smiling. The doctor was speechless. She had been treating him for a long time for severe psoriasis. Treatment had been less than successful, but now he was symptom free. Clear skinned and well. His partner had persuaded him to try LDN and this was the result. I thank him because his doctor is also my doctor and she was seeing the results of the use of LDN in front of her.

I have had severe M.E. for over 30 Years. I am one of the 25 percent-ers (the 25% of sufferers who are mostly house-bound and often bed-bound with only about 3 hours of 'up' time daily). I have severe relapses, often, completely helpless and bed-bound for months at a time. My story is reminiscent of most - a story of misdiagnosis, mistreatment, disbelief, trivialisation, etc.

However, this is a good news story. My doctor told me about LDN - hesitantly it must be said - but she said I was desperate and that maybe this would help. Coincidentally, as a Christian, I had made a special prayer for help. My daughter and her husband live in Switzerland. I live on the opposite side of the world in Australia. The first baby is arriving soon and I dearly want to travel to Switzerland sometime to see them. This may be an impossible dream, but it made me more willing to try another treatment, where usually I am very wary of things that might cost heaps of money, and lead to great disappointment when they don't work.

I went home and began my own research on LDN. I spent most of my 'up' time doing this until I was persuaded it was worth a try. Firstly though, I had to detox and withdraw from 35 years of codeine use. LDN and codeine are not compatible due to the opiate content. I think it is a measure of my determination that I went through this process, because it was horrendous. It took about 6 weeks and the withdrawal symptoms were very nasty. Still, I stuck to it, as I very much wanted to try LDN at this stage.

I am so glad I did. The LDN has been a blessing. It has not cured me by any means but the easing of symptoms has made my life easier to cope with. I don't think I will get to

Switzerland, but I am very pleased with the results. I increased the dosage in 1.5mg increments until I was taking 4.5mg nightly at about 11.00pm. I have been on this dosage for three months now and I will try to list clearly some of the improvements I have written in my diary.

1. My sleep is better. Usually subject to days of insomnia at a time, I have had only two nights without sleep since beginning the LDN. I go to sleep more easily and wake more easily, without the struggle I used to have just to open my eyes and swim up from some deep dark place to some sort of wakefulness.

2. I have a general sense of well-being. Life is not a drag to be gotten through but a gift to enjoy. This is a huge shift in how I feel.

3. The fatigue has lessened. It is still a big symptom but I no longer feel I am dragging bags of cement around on each limb every time I move. It's wonderful to have the 'dragged down' feeling lifted. I still cannot use my muscles much but I really think I recover more easily if I do overuse them.

4. My family and others say things like 'you just look better' or 'the pallor has gone'. They also comment that my eyes look more 'alive' and I seem more 'with it' (as opposed to 'without it' probably).

5. I usually describe my mind as if my thoughts are cars driving every which way and in a deep fog. Now the cars are still wandering around but the fog is no more than a sometime-mist. I still have trouble finding words, following a conversation, using the right word, etc but it doesn't seem as bad as it used to be. I can read a novel again!!!! THAT is wonderful. I can write this story in bits, but I can do it!

6. 'Wee' get ups during the night are a thing of the past. My struggle with cystitis and thrush seems nearly over (unless I use antibiotics), and my need for hormone replacement therapy has extended from a week at a time to 3 or 4 weeks. No more hot flushes and sweats.

7. I am managing pain with only paracetamol or ipobrufen though I have to use tegretol for trigeminal neuralgia flare-ups. I must admit the thought of using a panadeine forte sometimes for head pain does tempt me, but I cope without it.

8. Restless legs no longer bother me, and the baker's cysts behind my knees haven't troubled me since taking the LDN.

9. I take medication for reactive depression and severe anxiety. Despite the medication, I still had problems with anxiety at night, however; I have just realised that this has not been happening for weeks now. And LDN is the only newish addition to my medication regimen.

10. I took antibiotics every day for 5 years to try to control infections. I have needed two lots in the last 3 months and am pleased that I have gone a month now without needing them. Will keep watching to see how this pans out.

I have one query with the LDN. I have had a lot of trouble with allergies; sinus trouble, itchy skin, and sneezing. Now I have always had these troubles but they seemed to increase at the same time I started LDN. However, both the chemist and the doctor have told me that many people are noticing an exacerbation of symptoms with the

strange weather we are having, so I suspect it is that and not the LDN that is the culprit. I did reduce the nightly dosage to 3mg to see of this helped but I slid back in all the areas I have mentioned. My husband 'suggested' I go back to the 4.5mg and the next day I felt so much better. So that is the dose for me it seems.

I wish to acknowledge Jodi Bassett's website formerly called 'a hummingbird's guide to M.E.' (unfortunately, I've forgotten the new website name). This is an excellent resource and it was the comparison there between M.E. and MS that convinced me finally to try LDN. I had read how much it helps MS sufferers and decided that as ME resembles MS in so many ways, maybe I could benefit in the same way.

Doctors at the surgery I attend are documenting anecdotal evidence of our experiences and I know are using it more and more if they think it will help people. I am grateful that they prescribe for us and that there is a compounding chemist in a nearby town who accepts faxed scripts and will post medication to housebound clients. After fighting all the way to get any help, I really appreciate this.

This is a continuing story of course. I can only tell my little bit of it in the hope that others may find some relief if it suits them. And if I ever do get to Switzerland, you can be sure I'll let the world know!

## **50**

### Dianne W, Australia Oct 1986 – Relapsing Remitting MS (RRMS) 2003 - Secondary Progressive Multiple Sclerosis (SPMS) January 2008 - LDN

I was diagnosed with MS in 1986. I chose not to take any of the 'usual' MS drugs and started on the Swank diet in 2005. I became SPMS in 2003 when walking deteriorated (weakness with limp and spasticity) plus sensory symptoms buzzing, tingling, jumping skin etc.

By 2007 I began having bladder problems (nocturia) and urge incontinence.

I started LDN in January 2008 at 3mg, then later increased dose to 4.5mg. I did have some problems with increased symptoms and lowered my dosage back down to 3mg. However, after dealing with stress, illness etc. went back up to 4.5mg, which I have now been on for over 12 months.

My main improvement has been with bladder function - now normal again, and sensory symptoms are now almost non-existent.

Walking is still affected and weakness in right arm is also evident at times but I believe this has been caused by 'old damage', which may be permanent.

Occasionally, I get return of some symptoms but these can be attributed to stress, over tiredness, or illness and usually resolve after a short time of rest etc.

I very much believe in LDN and will never stop taking it.

It is very frustrating that trials to prove its efficacy are not being done.

I am sure this is because the drug companies 'don't want to know' and it would affect their profits significantly.

I am trying to spread the word as much as I can here in Australia and more people are aware but many are still not and LDN needs to be recognised as a viable treatment for MS.

### **UPDATE January 2010**

I've been taking 4.5mg LDN for two years now with no further progression of my SPMS. I still have some problems with my right Leg when walking. I limp and need to use a scooter for long distances, however; many symptoms (sensory) and bladder function have markedly improved and I plan to take LDN indefinitely.

I will continue to spread the word about LDN as far and as wide as is possible so that others with immune system problems are made aware of this wonderful treatment.

I now only have to see my neurologist annually although he will not admit that my current good state of health may be attributed to LDN. He will not prescribe LDN and does not recommend it to his patients. He continues to maintain that this is because LDN has not undergone the usual trials required.

## **51**

### Didem K, Turkey 2003 – Multiple Sclerosis Dec 2008 - LDN

My name is Didem K. I'm between thirty and forty years old, but my health story began in the early 90s when I was still young, attending university, and very active.

During weekdays I would spend my time having long walks in the city, from noon till midnight. My friends used to tell me I was very strong because when they felt tired and wanted to rest, I would say it was the beginning for me. At weekends I used to have trekking camps in the mountains. Running down the cliffs and passing through canyon walls climbing, was my joy. Mountains have always been the place I felt at home.

I remember waking up one day with double vision and going to the optician. She examined my eyes and asked if I was reading too many books. Yes, that was right, I was a very dedicated reader. So she made me get my first glasses. But the glasses didn't help. The double vision became triple, then within a week, mysteriously passed. So, I went on living my active life for another five years knowing nothing about MS.

Then in 1998 I noticed a white spot in my right eye. I thought I hadn't properly washed

my eyes in the morning, that maybe it was a piece of crust disturbing my vision. But after some trials to get rid of it, I came to realise it was something in my eye. Within one short week it had spread, and my vision was lost. It was like trying to look through a white curtain in front of me. It lasted for around 2 weeks. I went to an optician again. His examination could find nothing wrong with my eyes, so I still didn't have a proper diagnosis.

Five years later, in 2003, I experienced extreme dizziness while I was at the office. The trip home was extremely difficult and over the next week I could only manage to eat, then sleep. As I wasn't improving, I went to a private hospital for an examination. I had to see a number of doctors before being diagnosed, thanks to a neurologist ordering an MRI. The MRI showed multiple plaques, and his diagnosis was MS.

I was prescribed a five-day IV steroid treatment. After that, I was prescribed Betaseron, which I stayed on for three years. Those three years were very difficult for me because I suffered with the effects of MS on one hand, and side-effects of Betaseron on the other hand.

My body had zero flexibility, so walking for long hours was now history. Running and trekking was also impossible... I didn't even have enough balance to manage walking. Due to extreme fatigue, I started using elevators instead of stairs, and for the first time in my life I comprehended the meaning of 'exhaustion'. When I look back to those three horror years, I now see I was slowly but surely giving up, day by day.

It was around that time that I came across 'low dose naltrexone' (LDN) on the internet. I questioned the drug's effectiveness for years, but almost daily, I would read another new success story. Because the people who used it were telling happy, life-changing stories about it, I believed I might benefit from this little capsule. I asked my doctor about it, but he wouldn't recommend a non-FDA approved drug.

But for me, Betaseron had side-effects, such as depression, knee aches, anxiety, hair loss, etc. I went to a generalist doctor. After some tests she asked me if I were using any medicine. I said, "Yes". She decided to write to my neuro about my side-effect complaints, and the test results, which were clear. She reasoned the most probable reason for my symptoms was the medicine I was using. That was the day I decided to quit Betaseron (one of the CRAB medications), and lead my life in a much more positive way, with the help of LDN.

As I was going to the States, I got an appointment with Dr. Martin Eurlich in New York, and I was very lucky to get my prescription from Irmat Pharmacy the same day and that night, my relatives and I went to the hotel feeling happy, with renewed hope.

At exactly 2100 (9.00pm), I opened the medication packet and took my first LDN capsule. I was excited because I'd been anticipating it for a long time! I went to bed, then woke around 3.00am. I didn't mind... I was feeling happy for the first time in a very long time. The only side effect I experienced with LDN was vivid dreams that continued during the first two weeks.

The morning after my very first dose was really interesting... The back pain I'd been suffering for 8 years was gone! I was elated. I felt like a bird, like I could fly! All of my pain began to gradually fade. As time progressed, I was able to control my bladder and climb up and down stairs more easily. Others also noticed changes. Every time we went out my mother told me she noticed my walking had improved.

Almost every day seems to bring small but consistent improvements. I feel stronger... almost near the old strength I had before my last attack.

I've been using LDN for a year now and will continue using it. I highly recommend it to everyone who has MS. Myself and thousands of other users are real, living examples of our personal experiences with LDN, and what it's done for us, so I hope you too will consider it.

I hope all are able to heal as I have.

# **52**

### Donette G, USA Jan 2009 - Ankylosing Spondylitis Jun-Sept 2009, Jan 2010 - LDN

I am a female in the 30-40 year age bracket with very active Ankylosing Spondylitis.

Though I'd suffered symptoms of active unremitting Ankylosing Spondylitis since October 2006, it was difficult to get a diagnosis. Then in January 2009, I was finally diagnosed with Ankylosing Spondylitis, with a second concurring specialist opinion in March 2009.

I first tried 4.5mg LDN for two months, then one month at a 6.0mg dose between June and September 2009.

Soon after starting LDN therapy, I got back the ability to raise up my arms. Overall I would say that LDN lessened the severity of my disease by 50-60%. I still had fusing going on, but LDN gave me a large measure of quality of life back by reducing pain, stiffness and overall fatigue.

I used the non-steroidal anti-inflammatory drug (NSAID) 'celebrex' with the LDN, and the LDN seemed to further help the celebrex reduce inflammation. Without LDN, celebrex and many other NSAIDs I've tried, had zero effect in combating my Ankylosing Spondylitis.

I enjoyed zero illnesses during the three months on LDN. At different times my children would have colds, stomach bugs etc, and each time I would not succumb due to my improved immune system. I also experienced an overall improvement in intestinal health while on LDN.

Prior to LDN I started to suffer with long bouts of alternating diarrhoea and constipation, which I suspected was the Irritable Bowel Disease so often associated with Ankylosing Spondylitis, but LDN renewed my digestive health.

While on LDN you can't take opioid-based painkillers, and I also heard you couldn't take anti-depressants. For me, that was the only downside to using that LDN I struggled with... occasionally I wanted/needed those other meds.

During the period October to December 2009, I tried other alternative treatments to attempt to control the fusing. I went off LDN during this period, but always intended going back on again after trialling the alternative treatment.

So I recently started LDN again (earlier this month, January 2010), and I'm already enjoying not getting sick with any colds etc that my family brings home and trades around.

## **53**

### EF, UK 2002 – Primary Progressive Multiple Sclerosis (PPMS) 2007 - LDN

I am a 48year old man who has been diagnosed with PPMS since 2002 - although I suspect I had it several years before that because the symptoms and signs were around before that.

I have been taking LDN for around 12months after being told about it from a friend of a friend. It has helped my fatigue, bladder and hopefully, is stopping the progression of M.S.

I wish I'd known about it before.

Another positive effect of LDN that I didn't expect is that it has helped my erectile dysfunction, which is bonus.

The negative side of taking LDN is the cost. Although the drug itself is cheap I have to get a private prescription for it. This costs me a lot to see the private consultant and then I pay for a month's supply of pills on top. Due to my tremor I cannot administer the liquid form of LDN, which would halve the cost.

I am about to be medically retired from work and money will be tight in the future.

I resent paying such a high price for the prescription but feel that it is making a difference to my life.

#### UPDATE 12 April 2010

Yes, I am still taking LDN and I feel it is still helping; although I still get the occasional bad day with my MS. I am already gluten and dairy free with my diet and I think the trigger to my bad days may be eating soy. I have researched on specific diets for MS and many have found soy to be detrimental to their health.

I have only just stopped eating soy so it may be too early to say if that is the cause of my bad days yet.

With regards to getting LDN - my own doctor is quite keen on it, but he needs the approval of my consultant before he will prescribe it and she is still unconvinced of the benefits of LDN for MS.

So, this means I am still paying for a private prescription to get LDN.

I still benefit sexually with LDN, my erectile problems are no more (which makes my partner very happy). This is another argument I am using to get approval from my consultant with the benefits for taking LDN.

### **54**

Eileen P, Ireland 1996 – Multiple Sclerosis July 2004 - LDN

My first symptoms appeared in Autumn 1990, six months after my son died, but I wasn't diagnosed with MS until 1996.I've been taking LDN for 5yrs now. Prior to starting LDN, I used a walking stick from time to time because my legs and arms were so very heavy. I had no motivation as fatigue would take over.

The heavy-ness in my legs went after starting LDN, but for a while, I felt like I was slightly worse and wondered if I should stop. Around the same time, I was attending an Occupational Therapist for Shiatsu. They told me I had more tone in my limbs, and that helped me to decide to continue with LDN.

It's now 5yrs later. I work part-time. My energy levels are high, and I am flying it without any aids.

I have no hesitation in recommending LDN to anyone with Multiple Sclerosis. I know it is cheap and profitable, but I cannot understand the reason why any neurologist who cares about his patients does not prescribe it.

## 55

Elise K, South Africa 2004 - Multiple Sclerosis 13 August 2008 - LDN My name is Elise and I am still under 40 years old, married and don't have any human children. I am a dance teacher (ballet, tap, jazz, ballroom, Latin, hip-hop).

My first symptoms started in about 1995 or 1996. We lived in Gauteng and I had a dance studio. When I pointed my toes my one toe didn't point down properly and my husband noticed that I was walking into him when we went out for a walk or to the shops and I also started forgetting things (he noticed not me).

I had my first big attack in 2001 when my feet went numb. It happened at our farewell party (we were moving to Canada). I thought I had a pinched-nerve. I just let it go. We didn't like it in Canada and came home and moved to Wilderness. Then in 2004 my right leg stopped working. A few months later I was diagnosed. The neurologist wanted me to come for more tests and then start drugs as soon as possible but I resisted, as I wanted to treat things as naturally as possible.

I heard about LDN from the mscured chat group on yahoo because they spoke about it quite often, and my doctor at the time was even prepared to give me a script, but I was not able to get stock in South Africa and I didn't realize how important LDN is to stop progression. I thought that I could control things with diet and supplements. If I knew then what I know now, I would have made a plan to get stock by whatever means possible.

We moved back to Gauteng the following year.

At the beginning of 2008 I started getting worse again. Not a relapse as such, but I was battling to walk and had to buy a stick to help. I was desperate and went to a neurologist who then told me that I must go on Rebif and that it would keep me stable (liar liar).

The day the nursing sister was due to come to give me the injection I broke down and said to my husband that I didn't want to go on Rebif and that I needed to get stock of LDN. But we decided I'd give Rebif a try, and all went okay until I got to the full dose. The side effect I had was paralysis lasting about 6-8 hours. It started about 2 hours after I had the injection. It was then that I became very determined to go on LDN.

The Rebif also made me very depressed and suicidal, so I spent 2 full days on the internet trying to find somewhere that I could get LDN. I finally managed to find a doctor who'd prescribe it, and I got the stock within a few days. I stopped the injections at the same time: I remember it was a Sunday, and I'd only been on Rebif for 6 weeks.

I started LDN the following Wednesday, 13 August 2008. The first morning I woke up, my depression was gone and has never come back. My energy increased a little and my walking improved a little but I still walk with a stick. I do however, have a lot to be grateful for. I have a wonderfully supportive husband that is the perfect balance between helping when I really need it and leaving me to struggle when I need to be independent. I have loving supportive parents and parents-in-law and have a nice house and lovely animals. I can still drive and shop and even though it's not always easy, I'm grateful that I can do it. I'm also grateful that my brain works and I can still type. My life is truly blessed and yours is too.

I have been doing a LOT of soul searching in the last few years and particularly in the past 1-2 months and have come up with the following that MUST be done in order to heal. You need to let go of the past completely (wrongs you have done and wrongs that have been done to you), you need to live in the moment, you need to love, honour and

respect yourself, you need to get out of your head and into your body no matter how frustrated you get with your arms, legs, bladder etc and you need to be grateful for what you have. Life is perfect for you just the way it is. I think that one of the personality traits of people with MS is the need to control everything and something we need to learn to let go of control, and just go with the flow.

I will leave you all with one thought... There is nothing to fear but fear itself.

## **56**

#### Elise P, Panama September 2002 - Multiple Sclerosis June 2004 - LDN

I am presently living in Panama. We moved here in 2005, following a sunshine hunch that was not yet substantiated by research at the time!

I have two boys, and they were 14 and 6 at that time. I have a family history of MS.

My experience is eerily similar to what my maternal grandmother experienced. No one remembers any relapses, just a steady relentless decline. I only knew her in a wheelchair. Her right side was affected, but with me, it's my left side.

I was diagnosed with the infamous 'white spots' in September 2002. I had a bout with optic neuritis in December of 1997 but MS wasn't even mentioned as a possibility at that time, unfortunately. I have been primarily researching and managing my own care and LDN was one of the first exciting things that I came across. I am trying to confirm the actual date that I started but the prescribing doctor is in the US and this is a holiday weekend, so I couldn't get a response. I think it was Spring 2003 or 2004, so I'll go with the later date for now. I'll let you know the exact date when I get confirmation. I started on a 3.5mg dose, then moved up to 4.5mg.

I started following the Best Bet diet in February 2009. I fought having to give up eating things I loved as long as possible! I chose the Best Bet diet as it was the most different from my normal diet and I figured my normal diet had gotten me where I was. It seems all of the MS diets have low saturated fats in common but differ on dairy, gluten, meats and legumes. I think these could possibly be explained by food intolerances. Not being able to afford fancy testing, I chose the most different.

I don't have a fantastic success story... I hope I'm deteriorating slower but I think that is the same with those on the crabs... in fact, I've read those 'wonderful' accounts of women 'stabbing the monster' to fight this thing and as the book goes on, they discuss incontinence pads and catheters and scooters versus wheelchairs... I read a lot of books standing in Borders... and I read very fast!

I realized that I wasn't reading about people beating this, they just felt like they were doing something. From a placebo standpoint, a painful injection is very powerful, right behind funky colored pills... they both work way better than plain white tablets!

Right now, with LDN, 4AP, and vitamin D, I'm sleeping through the night, mentally alert and rarely napping so that is all good! I just wish I could find the answer to mobility for

me. My foot drop and muscle weakness is still quite a problem. But, I can definitely notice the difference if I stop any of those three! I do take other supplements but there isn't an obvious effect with them. I stopped the LDN for two weeks last year and I was up multiple times every night to use the bathroom and perhaps, as a consequence, much more tired all day. I will stay on LDN... I have learned my lesson!

## **57**

Ellen D, USA 18 May 1994 – Multiple Sclerosis January 2009 - LDN

My story begins Christmas Day 1989 with the birth of my third son.

It was a normal pregnancy as I went jogging into my fifth month. I actually remember running with my tape headset playing, Christopher Cross song, 'Ride Like the Wind', feeling like I could run faster listening to the music.

I felt great nearing 40. My family was healthy and I was working part-time as a Registered Nurse with the plan of taking a few months off before heading back to a job with more responsibilities. I had decided this would be the last day of running until after the baby arrived. Little did I know I would never run again. My son arrived in a very easy birth. No pain! How strange when he was 8.5 pounds. Years later I understood why.

After a couple of weeks, I noticed my legs felt very heavy and I was slow getting around. My body didn't feel right. I went to my doctor and requested an MRI of my brain.

Lo and behold, on July 4th, 1990, it was very hot and humid. My husband and my two older children, 10 years and under, were walking in the village parade and I was pushing the baby in the stroller. I thought of collapsing on the cement. Maybe I was having a stroke!

My doctor had called the night before warning me of possible problems with hot weather after reviewing my initial MRI finding 5 lesions on my brain. My husband ran home to get the car. I could not walk any further. Whatever it was, my plan was to stay in denial. I was a psychiatric nurse at a hospital and talked often about denial with family members on the young adult unit, and now this is what I wanted. Total denial of any physical body problem!

August 1990 was my first appointment with a Neurologist. He told me a possible diagnosis was multiple sclerosis. I asked myself, what is that? Despite twenty years of nursing, I had never taken care of anyone with multiple sclerosis!

The doctor had no information for me. I could probably find something at the library. My husband and I left his office stunned and vowed never to return. I stayed busy at home with family and my body appeared somewhat stable so I didn't investigate until walking became a problem.

1992: My first adventure to solve the problem: An appointment with my M.D. Diagnosis was made with Hair Analysis. His clientele was 90% cancer patients, though he did accept other illnesses. He put me on a specific diet all according to my hair samples. I was fascinated with his unconventional program. He told me right away I would be on organic meat, root vegetables, grains, daily carrot juicing and yes, twice a day coffee enemas. Organic coffee, of course! Coffee enemas were essential for detoxification of the body.

The program also consisted of about 70 daily supplements, enzymes and other modalities that kept me focused. It was good for me and kept me grounded. I did this program for about two years. I had been a vegetarian for long periods of time in my twenties but this diet gave me more strength and balance.

I had returned to my nursing job with a new title as the head nurse of the young adult, unit with around 30 beds. My life was busy. I had a promotion at work and was determined to stick with it knowing all about stress. That job lasted nine months and I stepped down to part-time.

I had taken six-month leaves several times through my nursing years after my diagnosis, so I could regroup and stay healthy. I was lucky to have my job as long as I did.

My career came to a screeching halt in 2001 when my unit dissolved and I was asked to work at the city jail. I did not need more stress. I retired from my nursing career as I was getting weaker and knew it was unhealthy for me.

My husband and I are trained massage therapists. Naturally, it is a joy to give and receive massages. It has been several years now that I cannot participate in exchanging a deep massage. It is not easy to continually let go of your power. I was a follower of transcendental meditation since the 70's, although I wasn't dedicated to a daily practice. It has now been more important for me to stay committed everyday to meditation.

In mid July 1994, I was hospitalised for weakness and had difficulty walking. It was a five-day inpatient hospital stay, with 1 gram daily IV of Solu-Medrol. I then started on daily shots of Copaxone for ten years. I tried all the CRAB drugs at some point, but mostly used Copaxone.

Western medicine had entered my life and I decided to try anything to keep these symptoms at bay. I truly believed I could cure myself. I questioned my doctor many times about the effectiveness of Copaxone as my symptoms continued to get worse. I was upset when my penmanship was almost unreadable. This was not good.

I continued to walk, but now with a cane. Steroids were my only hope, because I always had some relief with my symptoms. I continued once a month with IV Solu-Medrol, but at the same time this was unhealthy for my bones. I had tried plasmapheresis in 1999 with little improvement. I bought a wheelchair, but fought that concept kicking and screaming. Just ask my husband. He has been my partner, always patient and loving through this challenge we share together.

This past year I had accepted defeat, because fatigue had set in and I was so tired of the fight. I love my family, but I was leaning towards depression thinking negative thoughts.

In January of 2009, my dear friend and old boss informed me of a drug called LDN. I thought, 'what the heck', investigate the medication. After research and calls to Dr. Bihari's office in NYC, I decided to start LDN at 4.5mg on January 19, 2009.

I discussed using IV Solu-Medrol with Dr. Bihari's assistant on the phone. I was on 1gm, IV Solu-Medrol, once a month and wanted to get off of this drug. He advised me to start the LDN and slowly titrate down the steroid. This is the plan!

I have decreased my steroid to one half gram every 6 weeks. The only side effect for me on the LDN is insomnia. I have taken Ambien, a sleep sedative and plan on discontinuing it soon, although it's been very helpful for my insomnia.

Feb 8, 2009, I stopped daily injections of Copaxone.

Feb 24, 2009, I stopped nightly Ibuprofen 400 mg. I believed it helped me with inflammation over the years but now take DL Phenylalanine. As of right now, I'm not sure how this works for me.

Since my diagnosis I have had multiple acupuncture treatments and have always found this experience a healing.

I see the chiropractor 3x a week for adjustments. I have done physical therapy this past year and that has been very helpful in understanding body mechanics and the importance of walking correctly. I feel like I'm starting over.

It has been 19 years of learning about disability and how to continually honor the experience. I forgot to tell you that I'm still walking and my cane has become a real need. I am fortunate to drive my car so I'm grateful for things we all take for granted.

My husband has noticed my improved mood and positive energy change immediately since the start of LDN. I am back to my upbeat self. I feel good and I'm noticing little changes, all positive, while on the LDN.

My penmanship has improved 90%. I'm devoted now to optimism and my new regimen. I know my positive attitude will help me with the on-going challenge.

The past two years I have incorporated yoga, (Rodney Yee DVD) into my daily workout and feel that it keeps me centered and aware of my body alignment. I also swim laps in the summer months.

I continue with the supplements: multivitamin, vitamin C, D, E, fish oils, Probiotics, DL Phenylalanine, Calcium with Enzymes. I have also taken Bio-identicals for the past 4 yrs. I can't forget Fosamax with all those years of steroids. I did get a bone scan last month that indicated my bones had improved since 3 years ago. That was good news.

If you are thinking of trying LDN, journaling is a valuable tool to recall past events. All of us make significant decisions for our health and our body/mind needs time to adjust. Journaling has helped me capture those moments of time.

I'm a little frustrated right now with some recent setbacks, probably due to the weather being so cold and so highly changeable. I was going to end steroids in July, but I'm now

considering a longer and gentler path because I've been on them for so long. I'm getting professional advice and trusting my instincts on the best approach and timing.

I have been on LDN for two months and look forward to everyday with the hope of continual improvements with my health. Thank you for this opportunity to share my thoughts with you.

Update - 19 May 2009: I went to see my neurologist today and had my 250mg IV steroid, titrating down, probably finishing in 2 months, July 2009 as planned. Everything else is ok. My doctor actually said good things about LDN and said it looks hopeful as a new treatment!!

I received my news of my MRI taken in April. Everything is unchanged since last MRI. No Active demyelination. Stable. I'll take that and continue with my plan. I went to a MS dinner last week and met an engineer that feels vitamin D does not get into your system unless it's a gel-cap. Tablets don't digest. He also said liquid fish oil is the best. I'm off to the vitamin store to research and will update later.

#### UPDATE 27 January 2010

I titrated my IV Solu-Medrol down very slowly. I had no problems during that period, and I'm pleased to report that I've been free of IV Solu-Medrol since July 20, 2009.

I also stopped taking Fosamax completely on Nov 23 2009, but I suspect cessation of the Fosamax may have caused the headaches that followed. I lowered my dose of LDN from 4.5mg to 3mg to see if that might help, and it did. Since Jan 6, 2010 I've been back on 4.5mg, with no headaches and no problems.

I also stopped taking Dr Sears fish oil. I didn't need it. It was too much. Live and learn.

I have been doing quite well and continue with my Yoga program. I recently added lifting weights to build strength, and since then have noticed improved balance. Oh yeah... I went to China, Vietnam and Thailand for the Christmas holidays, and it was a great experience. I did not take LDN for two weeks while I was travelling, but no problems... Yippee!



#### Emily J, USA August 1991 – Multiple Sclerosis 2004 - Breast Cancer Stage IV May 2005 – Primary Progressive Multiple Sclerosis (PPMS) April 2006 - LDN

I was first diagnosed with Multiple Sclerosis in August 1991.

In 2004 I was diagnosed with Stage 4 Breast Cancer that had metastasised to the lymph nodes. My treatment consisted of a mastectomy, chemotherapy and radiation therapy.

Then in May 2005, after almost 14 years of slow MS progression, my diagnosis was changed to Primary Progressive Multiple Sclerosis (PPMS).

I had to use a cane to walk and was so exhausted I could only shop for around 30 to 45 minutes at a time. This meant I only shopped for a few things at a time. Walking was terribly painful due to osteoarthritis and osteopenia, the first stage of osteoporosis. I could not stand up long enough to cook supper or even to clean my house in an afternoon. Life for me was slowly closing in and I felt as if I could not put my family through this pain.

In 2006 I heard about Low Dose Naltrexone (LDN) as a treatment for my MS. I joined the Yahoo LDN chat group to learn more, and in April 2006 I began taking 3mg every night. It's been almost 2 years now and I can tell you my physician is thrilled with the results.

I started taking 3.0mg Naltrexone in Apr 2006, but in January 2008 after nearly 2 years, I increased my dosage to 4.0mg. I cannot tell you how wonderful it has been to know I'm responding to this drug, especially as I'm well over 50 years old.

After commencing LDN my MS symptoms did not increase. If anything, some of them decreased. It was not an overnight miracle either. As the months, at least 4 or 5, went by I really did not notice any marked decrease in my symptom. It was so subtle I adjusted without noticing - but my family did.

I began to stand for longer periods. I was not using the cane nearly as much. I planted flowers and worked at weeding the garden. My husband brought it to my attention that my housecleaning seemed to be improving. (I hate housework so I schedule it on Saturdays and if I can't do it on Saturday it just does not get done.)

My shopping trips went from minutes to hours. I'd began to shop for longer periods, without carts, at the department store and I'd begun doing more of the types of activities I used to do without thinking before I had MS, but was constantly challenged by after I developed MS.

The improvement was so very gradual I reached a point where I forgot about my MS limitations and pushed myself a bit more into doing things. As I exercised more I got stronger. This could be the key to those folks who may expect LDN to right their symptoms. I pushed because I wanted my abilities back. I would walk farther and not let feeling sorry for myself get the better of me, and LDN (gradually) allowed me to do that.

There have been other benefits as well. Before LDN I was taking 1.25mg thyroid medication (Synthroid), but within 3 months of commencing LDN my doctor noticed my levels were too high. I began reducing the dose and as at February 2008, the dose had reduced 40%, down to .75mg Synthroid daily.

I also gave all the LDN information to my Oncologist who is one of the top men in his field and he too is interested in the effects of LDN.

So far I am cancer free and my MS is at bay. LDN is not a cure. I still have my good days and my bad days but I do feel that my bad days are less since I have been on LDN. I am ambulatory and I no longer need my cane.

Here's a hint for those of you thinking of going to your family doctor: Take all of the information from the LDN website which describes LDN, and ask him/her to read it. The rule of thumb is - 'he who speaks first loses' - so if he reads it in front of you don't say anything until he's finished. If he states he will read it later then tell him you will set up an appointment to go over the information with him. (They get too busy and it ends up in the round file.)

When I took the LDN information to my family doctor he was intrigued, then after a long silence he said, "Let's do this" – and he is amazed at the results. I wish everyone could have the kind of doctors I do. My family doctor is fresh out of Medical school and is willing to listen to patients.

My Oncologist is tops in the field and even he is looking more closely at LDN. Same scenario, I gave him the literature and asked him to review it. He is a very busy man but on my next appointment 4 months later he was so amazed with how I was doing he said he was going to go back and revisit the information for some of his other patients.

I'm still taking 10mg Baclofen three times a day to relax my muscles. I continue to take Arimidex (for estrogen positive cancer as it has to be taken for 5 years, and I take Amantadine to counter extreme drowsiness. Also, my oncologist has me on a cancer regime of eating more fruits and vegetables (minimum 5-6 servings a day).

Thanks to the LDN website and Yahoo group I'm on a lower Synthroid dosage and I have lost almost 40lbs since improving my diet. My symptoms haven't increased - some have decreased, and I hope yours will too.

Update - July 2008: I still take LDN and am still benefiting in the same way from LDN. No changes to report.

Update - July 2009: I am doing well. I have a lot more stress in my life these days but still on two feet.

We lost a house in the Flood in Iowa. We were not in the 'Flood Zone', so no flood insurance. It was totalled. My daughter was living there and she is still homeless, and we are still trying to get a settlement since we are not entitled to Fema help.

We are now in line for a buyout but they are telling us a minimum of 18 months before they begin. Meanwhile we have to mow weekly and shovel the snow when it snows. We live 50 miles away and it is just a pain - let alone we had to clean the place out and check on it weekly because of squatters.

But enough of that... I am seeing a little progression of the MS, but if I take time to rest it seems to abate. I'm working full time and doing well at that. There's nothing else to report. I am still taking all medications and the 4 mg of LDN. Oh, and no cancer has returned. Now 5 years free. Will let you know of anything else new.

# **59**

### Eva H, USA 2001 - Rheumatoid Arthritis, 2005 – Dermatomyositis August 2009 – LDN

About 18 months ago I read in one of the support groups about LDN. They talked about how much the LDN helped with their muscle weakness. I checked into it and the one thing that held me back from doing anything about it was the possibility of insomnia and vivid dreams.

When I got to the point where I could not even look people in the face because I was so bent over, I realized I had to do something about it. I was already travelling in a wheelchair. I finally asked my doctor about LDN, and there was no hesitation in writing a prescription. I did have insomnia and a few vivid dreams after starting, but that went away after a period of time.

I am now using a small three-wheel rollator to get around and the wheelchair is sitting in the living room. I now walk a lot more and I'm able to get off the floor. A year ago I could not do that, two days ago at physical therapy they made me get on the floor and then get up by myself. Everyone cheered when I did it for four times. It was hard but I did it.

For those who're interested in my journey prior to LDN, well, my story with Rheumatoid Arthritis and Dermatomyositis began a very long time ago when I was a child, but I won't go that far back.

Instead, I'll begin in 1999, in my late fifties. I was travelling in the Baltic area and an episode started with a bang. We had been touring with about 180 people (German choirs) and when we arrived in Stockholm, Sweden we had a few days free to walk and visit many interesting places.

On the second night I woke up about 3 a.m. and my right leg felt like someone had hit it with a baseball bat. I went to the bathroom and soaked the leg in warm and cold water. It slowed down the pain, and I returned to bed, but I could hardly walk the next day. Thankfully, sitting in the bus and travelling across Sweden was not a problem. I continued to have pain for more than a week and when we finally arrived back in the USA, I made an appointment with an Orthopaedic doctor who told me I had a

Spontaneous Fracture and put my foot in a cast. Now that was a real surprise. I'd never even heard of something like that.

Two years later (2001) I had the same problem with my left foot, and that is when the doctor sent me to have an ANA x-ray done that showed I had arthritis. The x-ray came back so positive that he sent me right away to a Rheumatologist, who put me on Celebrex and told me that I had to have a blood test done every three months so they could make sure I would not have a problem with my liver.

Now isn't that interesting: a medication that is supposed to help you stay without pain but can damage your liver. Down the road, other medications would cause more health issues.

I took the medication for awhile then discontinued it because I didn't have any pain from the arthritis. Then in the fall of 2004 I noticed little nodules on both of my arms. I went to my allergist and she gave me a cream to put on them but it didn't help at all. At that time I also started to have a dry cough; it didn't bother me much so I just took some cough syrup and went about my merry way.

In November of 2004 I had a very bad bladder infection and the doctor gave me antibiotics for ten days. Four weeks later I had another bladder infection and I ended up taking more antibiotics, plus a medication that was said to clean the lining of my bladder, but I think that was the trigger, the beginning of my road with Rheumatoid Arthritis.

My fingers swelled up like little sausages and typing at work was very hard. We had a lot of work every day and some days my fingers looked like someone had taken a knife to them. They had lots of little sores.

My GP gave me Prednisone to take for ten days. The swelling went down a little, but after a few weeks it was back again. I went to the Rheumatologist, who told me to get back on Celebrex. I could only take 100mg of that medication as higher doses were too much forme.

He started me on Methotrexate. I took this for about three weeks when my cough became extremely bad. By March 2005 my cough was so bad that the girls in the office told me I had a hairball in my lungs and couldn't get it out. Very funny, but it felt like it too.

My GP took x-rays and told me that I had pneumonia. After a week of medication I ended up in the hospital getting Prednisone and antibiotics pumped into me. They took more x-rays, a CT-scan and an EKG. The one thing they were all sure about was that I had this grey spot in the middle of my lung. When I told my GP about the Methotrexate she made me stop it right away. I would later come to find out Methotrexate and lung problems don't mix too well.

I called my Rheumatologist and he just blew it off. It really upset me that he could care less. That was the end of him and I was looking for another Rheumatologist.

I was off work for four weeks and then when I went back to work I could really tell how ill I had been. The pulmonary doctor made me come in several weeks in a row to check me. Then by the middle of June 2005 when I went to see him, he told me that I had to have this five year pneumonia shot. I argued with him, but he insisted, so I had it. Boy, what a mistake, within a week I became sick and by the third week the CT-scan I had showed that I had pneumonia again. AGAIN? So, I stayed home for several days and then went to work again but work became more painful and tiresome by the day. At the end of August 2005 I went back to my GP and she put me on a six week medical leave. (I was to be given more medical leave after that, and was never able to go back to work again. I medically retired in January 2006.)

Within another week (September 2005), I was incredibly weak and losing a lot of weight. The pulmonary doctor had not called me back for three days and I was so miserable, so I asked my daughter if she knew another pulmonary doctor and she sent me to hers.

By mid-September I had a lung biopsy done and then three weeks later I had to have an open lung biopsy to find out that I have pulmonary fibrosis caused by the Rheumatoid Arthritis.

For four days I had a tub in my chest to drain the accumulated fluid. They gave me morphine, which made me sick to my stomach. After I left the hospital I was put on a high dose of Prednisone and also on antibiotics. If I had known then about the antibiotic protocol for my condition, I believe I would be in remission now.

Once I was off the antibiotics my new rheumatologist put me on Cytoxen (a chemotherapy drug) and for one year, once a month, I had chemo. The longer I took the chemo the longer it took to get over it. By November 2006 it was taking two weeks to get back to a more normal life.

My fingers were still swollen, the skin on my hands developed red patches all over and the itching was terrible. The doctor just told me to take my medication and I would get better. That was the Dermatomyositis rearing its ugly head. To this day I believe that the Dermatomyositis was drug induced. I still cannot wear my wedding ring because of the swollen fingers, so it is around my neck on a chain.

By the end of 2006 I had a bad cough and bronchitis and finally refused chemo again.

In January 2007 they sent me to Denver to see a specialist who was not very happy that I had the five-year pneumonia shot. Between him and the Rheumatologist I was put on Cellcept and Enbrel. I was still taking Prednisone but was down to about 5mg a day. I had already heard how much damage that medication could do.

By July 2007 I had several eye haemorrhages and double vision from the combination of Cellcept and Prednisone. I was rushed to the eye doctor, then sent to a specialist to see if I had damage to the retina. Everything was still good. The pharmaceutical company, Roche, stated in an e-mail to me that the combo of the medications could cause several eye problems, including the ones I had - really great when your own doctor doesn't know this.

My Dermatomyositis was not going down with the medication I was taking and my fingers were always hurting. So I cut the medication down for about two weeks and then went back up slowly, but within a few weeks I started to have a bad sinus infection, my feet and hands had sores and I could hardly walk.

I ended up buying a cane so I could at least walk a little; later on I also purchased a wheelchair for longer trips. I had been on a trip with my husband and my feet hurt so

much that he had to put lotion and socks on my feet. I was miserable, but I didn't know back then that it would get worse. The Enbrel and Cellcept made the sinus infection come back constantly, even when stopping the medication off and on. When I went to Europe for two weeks I could hardly walk but I had to go and take care of family business. I did a lot of sitting and also sleeping, the jet lag really hit me hard.

In January 2008 I spend most of the time in bed, not accomplishing much. I had an appointment with my pulmonary doctor and he gave me Biaxin 500mg twice a day. He told me to stop the Enbrel, slowly, but I had to get off. When I came home I researched: 'Rheumatoid Arthritis and antibiotics'. This is when I found 'The Road Back Forum'. I read all the info, bought the book, and went online to find a doctor that used the antibiotic protocol in it.

I found a doctor in Texas, made an appointment, and went to see her within two weeks. I was lucky to find an AP doctor so fast and not too far away. In the meantime I still had to see the Rheumatologist, and when I told her I was on Biaxin she was very upset. For a Rheumatologist this is the worst case scenario. THEIR PATIENT IS GOING ON ANTIBIOTICS AND NOT TAKING THE DMARD's. Guess she felt like she was not going to make money on me again. I finally quit going to her in August 2008 when she told me that only the DMARD's would help me to get well.

At this point the FDA had just black-boxed the four medications such as Enbrel, Remicade, and Humira, and another one for causing a fungal infection. No way was I going back to that stuff. She also told me why I went to Denver was because the chemo had failed me. She told me that 18 months after the fact. Was I ever mad.

The doctor in Texas told me to stay on the Biaxin since that would help with my sinus and she also gave me an anti-fungal antibiotic (Nizoral) to take care of my feet and they healed up fast. After around a year (by August 2009) I seldom had problems with them. I also had to start eating gluten-free foods so my gut would heal or at least not cause more problems. I also take a good probiotic.

In April Dr. K put me on Minocyclin to be alternated with the Biaxin. I had started to feel really good and was able to walk a lot more. My husband told me later that he had thought about quitting his job and taking care of me since I had become so weak. I am so glad he didn't have too. The medication worked well till I found out in June 2008 that I supposedly have a blood clot in my lung, so she had to take me off the Biaxin. She told me that Coumadin and Biaxin don't go well together.

Last year Dr. K also questioned why the Rheumatologist wanted to do a ct-scan every six months. I came to find out that the Cytoxen they gave me for a year can also cause cancer and she told me that they were covering their behinds by testing me. Another nasty thing to find out - what these medications can do to you.

In the meantime my pulmonary doctor questioned the blood clot and had several other tests done and nothing was showing a clot, so he took me off the Coumadin. This medicine had turned my hands almost purple and I am still having problems from that episode.

The Dermatomyositis, diagnosed in 2007, leaves my hands scaly and dry and their redness is very pronounced. It has given me lots of problems. Some days my hands do well and other days I have to put lots of lotion on them. I also have the problem on my scalp and areas on the side of my face and my ears.

In August 2008 it was back to 200mg Minocin Monday-Wednesday-Friday and 500mg Biaxin on Tuesday-Thursday -Saturday. Now I am also taking Thyroid 90mg, Ioderal (iodine), and supplements.

I often think back to when all these problems could have their origins:

I had the usual childhood illnesses, one bout of some kind of illness where I had to stay in the hospital for a long time. Penicillin and other antibiotics were not to be had in postwar Germany. I had scarlet fever when I was about 6 years old. Measles, mumps and chicken pox.

I had the flu in 1951 and the Asian flu in 1956, both times in bed for prolonged times. The flu in 1956 started the problem with the tendon in my arms. As a young adult I had continued sciatic nerve problems, never really going away until I was put on Biaxin, then it faded away. In mid-1960 I twice had a problem with strep throat. It was so bad they had to give me shots to get me well.

Between 1970 and 1996 I had constant sinus, bronchitis, pneumonia and ear infections. Had my ears taken care off when I had a stapedectomy done to both ears, one in 1986 and the other in 1987. During the 1980s I always had dry skin besides the sinus problems. I always thought that the dry skin came from working in a warehouse, but I believe it was already the Dermatomyositis then.

In 1997 I found out that I also had Vasomotor Allergies (from pollution). So I went through a few years of getting antibiotics because I had these allergies that caused me to have a lot of bronchitis. Taking the antibiotics, I think, kept the Rheumatoid Arthritis in check. I had not taken the antibiotics for about a year when it started to creep back into my system with the bladder infection, and in 2004 when the rheumatoid arthritis became full blown. I think I was in a big flare-up for three years until I started the antibiotics.

Back to 2008, and I had to have another x-ray (I'm surprised I don't glow) and they found that I had broken a rib. I asked the doctor why I didn't feel the broken rib and she told me that the Prednisone had leached my bones so much that I now have osteopenia and this could happen again if I fall or bump into something. Great to know what Prednisone can do to you.

Another thing -- my thyroid quit on me, so now I am taking a natural thyroid medication to help with the problems of weak muscles and being tired.

After finally getting online, I joined a rheumatic group, then a Dermatomyositis support group, and 'The Road Back Forum'. These groups are a life saver for many people. The information given out helps. No-one is a doctor, but when they have gone to see their doctor they share what they learn, and that gives a person a chance to maybe ask their doctor if this or that treatment could be good for them too. I've met so many people from many countries that have the same or other autoimmune illnesses. After just a year talking to all these friends, I've learned so much more about autoimmune diseases, that your doctor cannot even explain to you because they have no time.

I am positive that now I am taking Minocin, Biaxin, Thyroid, Loderal and the supplements that I will be in remission by the end of 2009. I know it is a long way, but I had been sick for three years before I started the antibiotic protocol. I also do exercise

three times a week and the people also run the physical therapy group there and are so helpful, I get a free massage once in awhile and it works wonders.

Update January 2009: I'm going three times a week to physical therapy. My legs are still very weak and it takes a lot of energy to go through my therapy session, and after I get home I have to take a nap. The middle of my body is like it's squashed. I cannot stand upright unless I hold onto something.

Update March 2009: I still have a fungus on my hands and the doctor put me on Lamisil and a week later I was put on Thyroid. I am having a hard time taking all the medication and supplements I have to take. Instead of going to the doctor in three months, I have to go back in four weeks. Another blood test, oh well, I should be used to the blood suckers by now. My elbows and knees still hurt when I have them in one position too long, specially at night, and my left upper arm hurts when the weather changes.

Update April 2009: My newest success is that I am walking more upright and don't use my cane as much. I do still get tired easy but that is still being worked on with the Thyroid medication.

My Dermatomyositis goes in cycles: I have some good days, and then there are days where my hands feel like they are on fire and I can hardly touch anything. I tried steroid creams, Manuka honey (which is still the best) and a variety of hand lotions. Some I use in combination, others by themselves. I am wearing gloves to keep from picking on the loose skin and still cannot get off the floor by myself. I talked to the physical therapist and she told me that I need to ride the bike to strengthen my legs and work out on a Pilates ball.

Update August 2009: I started taking Low Dose Naltrexone (LDN).

Update December 2009: It has been four months now and the LDN is really doing its job. Even my husband told me the other day that when I get up in the morning I am almost straight now. In the evening I get a little more to the bend over side but not as bad as I had been. I get more done around the house and am even able to push the vacuum cleaner now.

I have increased my intake of Vit D3. I read in an article that with the LDN it is important to take D3, Alpha Lipoic Acid and B-12. I still take all my other supplements too and feel like a pharmacy sometimes.

Update Feb17, 2010: Well it has been six months since I started LDN, and what a change! I was bent, now I am almost straight. I still use my cane when walking longer stretches. I have so much more energy and no pain during the day – I am only stiff when I get up. I walk almost every day in one of those big stores such as Wal-Mart, Target etc. I walk around the perimeter and then sometimes down some aisles. Walking is getting better and I noticed too that I am lifting my feet when I walk, not shuffling. Improvements are coming along.

Update May 1, 2010: It's now 9 months since starting LDN. I now have a small rollator and I can walk fast and upright. No pain, but in the morning some weakness when I get up. I'm doing more physical therapy now for upper body strengthening. I think the LDN has really helped me, I don't have the problem with mental fog. It is finally going away. I now enjoy going out again, and to other places besides the local stores.

### 60

#### Fabienne B, UK February 2004 – Multiple Sclerosis 11 June 2009 - LDN

I have been taking LDN since 11th June 2009.

I started at 1mg and I immediately started sleeping better.

Increasingly, I also have improved bladder control. I am now taking 2.5mg as I found 3mg too much. It made me too sleepy and I found it harder to get going in the morning.

After just one month I am very happy and hope to benefit further. Overall, my mobility has been up and down. I have experienced better days but not a sustained improvement yet.

I am in contact with Doctor Bob Lawrence who advises me on nutrition as well. Luckily, I was already following an appropriate regime and have only had to increase my fish oil and zinc intake.

This opportunity to take LDN has given me a boost and much hope.

I hope to be able to report more improvements soon.

#### UPDATE March 2010

I continue taking 3.5mg LDN per night. The number one benefit is that I continue sleeping really well. My mobility and strength remains the same, on the up. I have increasing muscle tension (spasticity) in my legs and thighs but this started shortly before starting LDN. My hands have increasing tingling and numbness. So I would say that it has mostly improved my sleep and strength and lowered my lower back inflammation. My bladder control remains better. I should say that I do various things besides LDN: Best Bet Diet, supplements, EFT, meditation and hydro pool therapy.

## 61

### **Farah C, UK** January 2008 – Relapsing Remitting Multiple Sclerosis March 2008 – LDN

My story begins in June 2007. I developed tingling and a sensation of numbness in my right shoulder and breast. I went to my local GP where we discussed what could be the cause. I had been doing vigorous exercise at the time so we put it down to a trapped

nerve. It began to fade over the next couple of months but whilst on holiday in Rhodes in November 2007, I lost sensation down the whole of my right hand side.

Arriving back from holiday, I again visited my GP who referred me to a neurologist. At that stage I chose to go private and went to my local Bupa Spire Hospital based in Norwich. Dr Lee, my neurologist, examined me using various tests and then asked me to go for an MRI scan.

My scan showed two lesions on my spine and a possible one on my brain. He suggested at this point that it was Relapsing Remitting Multiple Sclerosis, but to confirm it 100%, I was given the option of undergoing a lumbar puncture procedure, which I chose to do. On receiving my positive test result, I was officially diagnosed in January 2008.

My brother is a medical student and during this process had researched a lot on Multiple Sclerosis and had found evidence and research from Dr Bihari and Dr Gilhooly.

I was given the option of taking the Disease Modifying Treatments (DMT's) by my neurologist. I had asked him about what he thought of LDN, and he was totally against the idea due to no evidence from clinical trials (I received the same attitude from my GP). I looked at the possibility of DMT's after advice from the doctor and my MS Nurse, but after thorough comparisons between DMT's and LDN, I chose to use LDN.

Before I had my appointment I had asked the GP if I could have a full blood count (DL2L, Vitamin D and B12) but was told it wasn't needed, so I made an appointment with a London clinic privately where I was tested for all vitamin levels and blood counts.

I made an appointment with Dr Tom Gilhooly and saw him in March 2008. After a very helpful and insightful consultation in Glasgow, he happily prescribed LDN. I was told because I had no underlying disabilities from previous relapses, that LDN wouldn't help in that respect, but that it would be more of a preventative measure.

Along with LDN I also take Baseline AM and PM, MorEPA and Inosine amongst other various vitamins. Dr Gilhooly also recommended I take up a dairy-free diet, which I have been doing for the past two years.

It wasn't long after diagnosis that I started taking LDN, so my before and after experiences aren't tremendous. I do know that it has most certainly helped my fatigue levels and I generally, on average, have about 2 mini relapses a year.

I definitely consider LDN a much better option than DMT's. It is far less intrusive and invasive on the body and people should try LDN first. If it doesn't work for them, then by all means they can turn to DMT's.

It would also be nice if GP's and Neurologists gave patients information on both options as its seems very one-sided towards DMT's, and for anyone who isn't into researching etc, LDN will not become apparent to them.

I hope this helps someone else.

126

## **62**

### Francie S, USA Sept 2000 - Multiple Sclerosis Mar to May 2009 – LDN

I was diagnosed with MS in September 2000, when Texas had nearly a week of 100+ temperatures. I had no idea that it was partly the heat that was so debilitating, but it finally landed me in the hospital, where I spent an extra day after the IV prednisone because the temperature was still 112 degrees outside.

My neurologist gave me the choice of which ABC drug to go on, and was pleased when I chose Copaxone as the least destructive to my immune system. I religiously took a Copaxone shot every day for nearly 9 years. I swear that I probably did not miss 10 shots in that entire nine years.

Being over 50 at diagnosis, I felt lucky not to progress rapidly during that time. But, the accumulated disabilities did start to add up. My left leg would occasionally give out totally and even when it was good, there was marked weakness. The fatigue was tangible as only an MS patient would understand, and the heat would put me in bed for days at a time.

Worst of all was the mental fog. In my younger days, I had a photographic memory, but I lost entire years from my memory bank because the short term memories did not get stored into the long term vault.

Then in the spring of 2009, the unthinkable happened -- along with my job, I lost my employer provided health insurance. There was no way that I could afford the \$1,600 per month to continue the Copaxone. Even the \$600 per month insurance payments would have put us in the poor house.

I had no alternative but to do some research on my own and see if there were something else out there that would make a difference in my life.

I am so GRATEFUL that I found LDN, a protocol using Low Dose Naltrexone that helps the immune system, and has put my symptoms in remission.

I can't adequately find the words to express the difference LDN has made in my life. I'm now over 60, and after being on LDN for only a couple of months, I have just returned from a trip to the Colorado Rockies where we took two of our horses and rode for 2 hours a day for over a week. I climbed mountains and breathed the thin, clean air with a renewed joy of life that I feared would never be a part of me again.

My husband is pleased to have his wife of over 40 years back by his side and my mother cried when she saw me on my feet with a grin on my face and a twinkle in my eye, not bent over struggling with each step that I took.

I am still somewhat atrophied from years of not being able to use my body the way I wanted, but the muscles are coming back almost as quickly as the memory. The mental fog is rapidly lifting, and I can now remember a phone number after dialling it once.

It has not made a big difference to the heat sensitivity problem, but I will learn to live with that. What it has helped greatly with is no more fatigue. I sleep like a baby through the night, and my cognitive function is vastly improved. My left leg and right arm are no longer nearly useless, and about as normal as they were as a youth.

I guess the thrill is just how 'normal' I feel. I will never go without my LDN.

My hope is that the MS Society will spend some of their massive research dollars on this cheap generic drug that is showing so much promise for thousands of MS sufferers, and that has no side effects.

I realize that the ABCR drugs help support the Multiple Sclerosis Society, but the Society is there to serve us, the MS patients - even if it means that the thousands that we all spend on expensive and scary drugs is cut way down by the use of this generic therapy that is cheap, safe and easy to administer either orally or topically with a cream that you just rub in.

I cannot thank my lucky stars enough that I lost my health insurance and found Low Dose Naltrexone.

### **63**

### Gary C, Australia 1993 - Primary Lateral Sclerosis (PLS) February 2004 – LDN, plus Antioxidants & Vit D3

I was diagnosed with Primary Lateral Sclerosis (PLS) when I was in my late thirties, after, in retrospect, about a year of symptoms. By then I was feeling very stiff but attributed that to a change of career to computer programmer about 5 years earlier and spending most of my time sitting.

A few months before diagnosis and thinking my symptoms were all due to lack of exercise I tried to start jogging, but the first time I tried I only took a half dozen strides before my legs got confused about what to do. Eventually I built up to the stage where I could manage about 3km down quite a steep hill, along a flat, pot-holed section and back up to home again. (At that stage we were on a 10-acre property out in hilly country.)

However, in other respects I was getting worse so went to see my doctor who decided there was a problem (possible MS or brain tumour) so sent me to see a neurologist who was also an oncologist! My diagnosis was done on the basis of clinical examinations and an MRI. Interestingly PLS and ALS typically don't show on MRIs (expect possibly the very newest ones -- MRS I believe). My MRI showed some abnormal signalling in the corticospinal tracts leading me to be diagnosed with PLS. In retrospect it was a very

brave call given some people take many years to be diagnosed, although mine did progress pretty rapidly.

There is nothing I have read in over 10 years of communication with other PLSers that has ever caused me to question the diagnosis. I had a follow up MRI in 1995, which was similar, possibly a little more abnormal signalling, but nothing since. I get very claustrophobic and no way they're getting me in one again unless it will lead to a cure!!

For the first 5 years after diagnosis I progressed relatively quickly for PLS, to the point of needing a walker to get around and having very poor speech. I did take various antioxidants (mainly vitamins C and E) at times during those 5 years, but never rigorously or consistently.

I then found a great website as the source of much of my info on antioxidants (<u>http://home.goulburn.net.au/~shack/</u>) and based on what I read there I decided to start taking a wide range of antioxidants consistently and rigorously. Steve Shackel, the guy whose site it is has Amyotrophic Lateral Sclerosis (ALS). He had actually improved after starting on all his antioxidants (before I did). The info on his site is oriented towards ALS, but also applies to things like MS and PLS. I worked up my list of antioxidants based primarily on what I found there. There is an almost overwhelming volume of info there now - 10 years ago there was far less.

Within 6 months of starting rigorously on a wide range of various antioxidants my progression stopped and for the subsequent 10 years now has been virtually nonexistent, except for my speech which very, very slowly continued to decline, though I feel that is more due to lack of use (because only my family could understand it even 10 years ago anyway). It can be extremely frustrating trying to make myself understood so I probably now only try to say maybe a dozen things per day, hence my speech muscles get little exercise and no practice.

I just wish I had found all the info on antioxidants earlier!! If I could stand beside myself 10 years ago then I would no doubt notice some decline but it has been so slow as to be virtually non-existent from my perspective.

Over 4 years ago I started on LDN after someone on PLS-FRIENDS said how much it was helping her. Within a week or two I was walking a little better (not miraculously better, but noticeably - feet were picking up better) and after about 9 months my urinary urgency (a scourge of PLS for many) dramatically improved. Again, I'd say that in the last four years I have held my slightly improved ground but it's hard to know for sure.

If there has been any deterioration I haven't noticed it. I still drive and until mid 2006 was still working full time. The only reason I am not working now is that my company lost the contract for the work we were doing and most of my group were made redundant.

I attribute the relative stability of my PLS to the antioxidants I started taking about 6 months before my progression basically stopped and the LDN is now the icing on the cake! Based on my own minor improvements with LDN, plus the results I've seen for some others with Motor Neurone Disease (MND), ALS and PLS, I believe 100% in the ability of LDN to help the body and there is no way I'd stop taking it. It's just that four years down the track I don't know how much of my lack of progression is due to the antioxidants, the LDN, or the combination.

In consideration of the six years before LDN, I have to say that most of it is possibly due to the antioxidants and that the LDN is an extra weapon in my arsenal now. From what I've seen, it's possible I could have achieved a similar result with LDN alone but I'll never know for sure because while I'm stable, I'm not prepared to risk what I've gained to test the theory.

Ten years after beginning on antioxidants and later LDN, I still can't take a step without my walking frame and maybe the distance I could manage is somewhat reduced, but basically I still feel my walking ability is much the same, whereas I feel sure if I hadn't started on the antioxidants I would have been permanently in a wheelchair many years ago. In consideration of the speed at which my PLS was initially progressing, I'd say I was very lucky to find Steve's website, then later LDN, and I wouldn't change either.

One thing I consider very important to point out. I got the impression from things I read long ago now that it was far better to take a wide variety of daily quantities of antioxidants rather than mega doses of just one or two and my results compared to a few people I've known who went the mega dose route would seem to bear that out.

My understanding is that using a wide variety is better; (a) because some work synergistically together so that the effect is greater than the sum of the individual parts, and; (b) and because using a variety allows you to take advantage of the different individual actions of each rather than relying on just one or two ways of working (not putting all your eggs in one or two baskets).

UPDATE – November 2008: I used to always get heavy head colds at least once or twice per year, followed by cold-sore(s) on my lips. In the almost 5 years I've been on LDN I've had one (about 2 yrs ago) which lasted about half as long as usual and the resultant cold sore didn't even get as far as blistering. From group discussions I've learned most people have similar results.

UPDATE – July 2009: Basically no change except for feeling stronger and walking more freely at times, probably due to combination of Vit D3 supplementation and fortnightly massage commenced Dec 2008, around six months ago.

#### Update April 2010

Yes, I'm still taking LDN and there's been no change since my last update (which is a bloody good thing given my first five years!!).

I'm holding steady, and the only difference to my regimen is that I started taking one teaspoon of coconut oil most days since early February. 'Something' yesterday may me feel better in walking than I had for a while, but I don't know if it was the coconut oil or just a 'normal' variation for me, which also happens from time to time. I really can't decide! I seem to be having more good days on average, but I'm not sure whether it's the coconut oil, or its combination with Vit D, or....???

Incidentally, a recent post made me realise LDN also seems to be helping maintain my eyesight! I can still easily manage with prescription reading glasses I had for a year or more before starting on LDN six years ago.

### **64**

### Gemma Y, UK 2004 - Relapsing Remitting Multiple Sclerosis (RRMS) Dec 2009 - LDN

It was Boxing Day of 2002 when I experienced the worst headache I'd ever had. I knew the pain of migraines and headaches... I'd suffered them since being pregnant with my son 7 years earlier, but this was a monster. I lay in bed most of the day. As the day drew to a close I noticed vision in my right eye had got a sort of blue tinge. I thought it was strange but just put it down to the headache.

The next day it was still there. I was worried, so I made an appointment with my doctor who told me I had sinusitis. I thought that was a bit farfetched but I had to take what he said. He told me to inhale steam. Well, I did as I was told to and, not surprisingly, to no avail. As the days went by, my vision got worse to the point where I was blind.

It was so strange. I could see all around the edges, peripherally, but not through the middle, if that makes sense. (I now know nothing makes sense with MS!) Eventually, an optician diagnosed optic neuritis. Over time my sight gradually returned, but I continued having rather weird things happen... On one occasion, and quite suddenly, it felt like an electric shock ran down my whole body. It left me feeling burning hot for days. I had no idea what was going on. I went to casualty and they did all sorts of tests but couldn't find anything, so I was at a dead end. I had no clue, nor did they.

It got to a point when my hands had constant pins and needles. At my wit's end I went to my doctor again, but this time I saw a lady I had never seen before. She read my notes and listened to what I had to say, then said very matter-of-factly, "I think you may have multiple sclerosis". My heart sank... I'm sure you know what it's like when you've heard of something, know it involves wheelchairs, but know nothing else about it. I said, "Well what's that?". All she said was "I don't want to go into it until we know for sure".

Now I understand why... because MS is difficult to explain in a few words. I walked out of the doctors' office thinking my life was over. I had visions of wheelchairs and not being able to do anything for myself. I was devastated.

I went straight for a blood test and waited for my first neurologist appointment. Because the wait was so long, and I was so worried, I paid to see the neurologist. Not knowing anything about MS, I just wanted answers and medication to get better (we all know it's not that easy, but I had no idea back then). The neurologist was quite matter-of-fact, saying it could be MS but even if it was there wasn't much that could be done about it.

He went on to say that the interferons (the approved medication for people with MS) weren't foolproof, and that there was only 30% chance of them slowing the disease progression or stopping another relapse... anyway, more about that later.

I asked if I should pay for the MRI scan (again, thinking the sooner I was diagnosed the better) but he said there was no point wasting money because if it showed anything he probably wouldn't diagnose MS anyway. Oh my... this takes some getting used to! I

walked out thinking I may as well have bounced my head off a brick wall.... still no answers!

To cut a long story short, I did my research on MS and realised it wasn't the end of the world and that I wasn't going to die... and once I knew that fact, I could accept anything. I had the MRI and went in for the results. Like I was expecting, it did show some lesions but not enough for a clear diagnosis. By now I was used to being sent away with more questions than answers!

Over time I still had what I like to call 'MSey' moments - pins and needles here and there, a numb patch there, etc.

Then came the day I could hardly lift my legs. They were so heavy that when I tried to walk down the stairs I couldn't pick up my leg, so I left it behind and fell down the stairs. I damaged my coccyx (tail bone). It was the worst pain I have ever experienced in my life... I thought, "That's it... I can't go on without any help".

I booked in to the neurologist again and finally saw him after a 6 month wait. All he said was that it was probably stress because all the usual neurological tests weren't showing him much. I asked for another MRI scan. He said okay, but he didn't think it necessary. So when I was called in for the results some weeks later I wasn't expecting much. But this time I was wrong. He did give me a diagnosis - Relapsing Remitting Multiple Sclerosis. Surprisingly, I was relieved... because I now knew I wasn't going mad. Sounds funny to be relieved about being told you have a chronic neurological condition doesn't it? But yeah... relieved is the right word!

The next step was considering whether to try DMDs (disease modifying drugs). I did mountains of research on them. I asked people in chat rooms. I read the MS society decision guide. I thought and thought about them, but no matter how much I thought, I always felt uneasy about using them. They scared me for a start, all the injections and side effects and injection site reactions. I thought, "Wow, they sound worse than MS!".

I went to the meeting with the MS nurses and there were about 10 other people with MS there too. We watched videos, asked questions, but I still couldn't convince myself it was the right thing to do. I had made my decision. I was the only one in that room that chose to walk out and away from DMDs and that was it.

I had one major relapse just after diagnosis in 2004. it was a bad one, and I couldn't feel one square inch of my body... it was completely numb. I couldn't walk, and my coordination was all over the place. I went to the neurologist again because I was so scared. He just passed it off as a 'moderate attack' and said to "Go home and wait till it gets better". No steroids, nothing! It was then that I really knew I was on my own. I had to cope with this any way possible. Though that relapse left me with chronic symptoms like vertigo and fatigue, I haven't done too badly.

At the back of my mind though, I continued to worry how my disease would progress. I knew I had a 50% chance of progressing on to the next stage; Primary Relapsing MS (PRMS); within 10 years, and the clock was ticking. But still I was determined never to touch the interferons.

Then my life changed. I wrote a piece on the networking site, Facebook, about why I chose not to go on to any medication and how I was coping alone, etc. I had one reply

from a friend who said I should try LDN. At first I said, "No way!". Just another drug that has more side effects than it's worth.

But my friend sent me some information, and I could hardly believe what I was reading; 99% of people taking it were reporting no new symptoms... and no needles or bad side effects. It seemed too good to be true. The only downfall was that it wasn't licensed for use at such a low dose for MS. But the more I read, the more I knew I had to have this, whatever it took.

I booked an appointment with my neurologist (not the same one that diagnosed me... times had changed!). I went along armed with as much information as I could. Luckily he'd heard of LDN, but unluckily, it made no difference as he was one of those doctors who were too scared to prescribe. He did listen to me, and he did say if I could get a doctor to prescribe he would monitor me, but he said even if he wanted to prescribe he'd have to get his over-heads to agree, and he knew they wouldn't... you know.... the usual story.

I decided I had nothing to lose by asking my own GP. I asked him and he was very interested and hadn't heard of LDN before. He went away to read up and to make up his mind. The next time I saw him he said "I don't see why not... it looks like it can't harm you so what do we have to lose?" I could have kissed him right there and then!! He had no idea what this meant to me. He wrote my prescription on the NHS and I sent it on its way to Dickson's pharmacy in Glasgow. A couple of days later my LDN arrived in the post.

It was strange... I was scared that night before I took my first dose... I think all the anticipation had built up inside me and I was actually scared! But I just thought to myself "You've fought so hard to get this! Now you have it... come on!!". So I took it and had the most vivid, surreal dreams I've ever had... I was expecting that because I knew the dreams could be a side effect for a few weeks after first taking LDN.

3 days later I stood in church with my eyes closed, and I had a feeling something was different. Then I realised... I was standing, balanced, with my eyes closed, and was not holding onto the chair in front of me or even peeping out to see if I was still upright! I was so excited!

When I got home I showed everyone my new party trick! "Look!! I can stand with my eyes closed and not fall forwards!" I kept doing it to see if it was some kind of fluke, but it was real... and more surprisingly it was after just 3 days and after only 1mg. It had already made a difference! Then as the days went on, I noticed I slept much better and didn't have to get up and use the bathroom 3-4 times a night... I don't even get up once now. It truly is amazing the change I have seen from just 1mg, and in just 3 weeks.

I am now waiting on 3mg for my second month. I can't wait to see what else LDN can give me back!

I lived my life with MS for so long without any medication. That was my choice I know, but even now I wouldn't have done anything different. I still maintain the interferons are not for me. As for LDN, I have to say it has changed my life... it is giving me my life back.

To my doctor who prescribed it, and to LDN I owe my life.

## **65**

#### Geraldine O, Ireland June 2006 - Multiple Sclerosis Dec 2007 - LDN

I was diagnosed with MS in June 2006, but my first symptoms appeared in early November 2005 when I lost strength on my left side. Initially doctors thought it might be a stroke, then after attending a Neurologist in December 2006 I was diagnosed with Transverse Myelitis. At that time, he told me if I ever had another episode then I would definitely have MS.

I had my second episode in May 2006 when I lost half the power of my right side, I had numerous MRI scans, high doses of steroids and was given a lumbar puncture and VER tests, resulting in my final diagnosis in June 2006.

I was prescribed Rebif a few weeks later with training from an MS nurse on how to do the injections and, although not very pleasant, I persevered with them for the sake of my health.

I had terrible nights on the 3 nights a week that I had to inject: I couldn't sleep, had terrible night sweats and rigors, kicked my poor husband out of bed on many an occasion, and was up constantly to run to the toilet, resulting in being exhausted all the time. I just put all these symptoms down to me having MS.

I had to have minor surgery for another medical problem in April 2007 so I had to come off the injections for a few days to prepare for that. I had the surgery and one week later was told I could recommence the injections. It was at that time that I discovered that most of the symptoms I was having were injection-related and not MS related, because most of the symptoms I'd been experiencing stopped when I stopped the injections.

I recommenced the injections, got a few injection-site infections within a week or two, then decided to stop taking the injections all together. I was given a copy of the book 'Up the Creek with a paddle', written by Mary Boyle Bradley about her husband's experience with MS and LDN, and that's when I first heard about LDN. I looked up everything I could on it, including how I could manage to get it.

My next appointment with my neurologist was in November 2007, and I asked him if he would prescribe LDN for me. He said he would, but he wasn't very happy about me taking it as he said I wasn't bad enough. I told him I didn't want to wait until I was bad enough! I got the prescription and started taking LDN in December 2007, and I really haven't looked back.

I didn't sleep great for the first two weeks, but haven't had any problems with it since then. During the first year I was able to do much more... attend all the MS physiotherapy classes, join the gym at work, work all day without suffering from fatigue.

Then early in 2009 I decided to sign up to do the MS Trek to Peru with MS Ireland and challenge myself. I took up hill walking in preparation, and I must say, after the first

attempt I thought I would never walk again... but I kept at it. I then attended the training walks with MS Ireland in the Wicklow Mountains and Dublin Mountains.

In September 2009 I set off on the adventure of a lifetime to visit Macchu Picchu and to trek. The trekking was very hard - 8 full days of approx 6 hours per day - but when we got to the Sungate and looked down on Macchu Picchu, it was the most amazing experience. I was overwhelmed... by the breathtaking view and my accomplishment. I hope to be able to do another trek with MS Ireland in 2010.

I know if I hadn't started on LDN I probably wouldn't have been able to undertake the trek. It is the most amazing drug, and I'm glad I came across it. I have a much better quality of life now than I had when I was taking the interferon.

## 66

### Ginger M, Canada 2000 – Multiple Sclerosis June 2009 - LDN

I have always been extremely sceptical about anything that doesn't come through my doctor or neurologist.

Before LDN, my health for the previous 2 years had been spiralling downhill fast and I knew the Copaxone I had been on for the last 5 years was not working.

I heard about LDN on the internet but was afraid to try it for fear of it being yet another snake oil treatment or worse yet, harmful to me. I then heard about Mary Boyle Bradley's book 'Up the Creek With a Paddle'. I read it and decided to try LDN. I asked my GP for a prescription, but he knew nothing about it.

I called my local MS clinic and they were as useful as two right shoes. I looked up Mary's email on Google and wrote to her asking where I could get it. In 10 minutes she had written back with a list of Canadian Doctors that prescribe it.

I started taking 4.5mg and it made me really ill. I was so wired I could not sleep and I was nauseous all day. I didn't want to stop it as I heard so many good things about it from the book and it was my last hope. I cut my dosage in half and was able to tolerate that. I slowly increased my dosage back up to 4.5mg over about a 2 month time period. I suffered no more ill effects when I did it this way.

By the end of month 3 I felt my exacerbations halt. It didn't cure my MS but it did, indeed stop the horrible downhill slide I was on. I have been on LDN now for 9 months and recommend it to everyone I can!

## 67

### **Greta T, UK** July 2000 - Multiple Sclerosis 1<sup>st</sup> October 2009 – LDN, plus Strict Gluten-free Diet

I was diagnosed in July 2000 and started LDN October 1st 2009.

In 2000 my daughter was married. At the wedding I noticed I was losing power in my legs. I was just over 50 at the time.

During the following week things really started to become a problem: I was falling, collapsing, tripping up, and unable to balance. I was virtually blind in one eye and incredibly sleepy all of the time. This resulted in being hospitalised for three days and undergoing all the standard tests to detect and diagnose Multiple Sclerosis.

The tests were positive. I was really upset for a day or two, but I never thought, "why me?". There are worse things than MS. Having worked for two years in an Intensive Care Spinal Unit, I saw many patients having to come to terms with paralysis, and I was just so relieved I could still walk (though I walked as if I'd been drinking whisky).

It is now nine years since diagnosis. I'd say that there are two things that have helped me reduce symptoms. Firstly, adopting a gluten-free diet. Secondly, taking Low Dose Naltrexone (LDN). I became aware that some people with MS have food intolerance to gluten, dairy, eggs and legumes. The immune system identifies some of the proteins in these foods as invaders.

Scientist Ashton Embry has a son with MS, and he explains this in more detail in 'The Best Bet Diet' featured on the website www.msrc.co.uk. I have noticed that if I eat gluten I get itchy on the head, face, and neck, become very sleepy, don't walk very well, and my MS symptoms get worse. It takes less than 24hrs for the symptoms to show, but 4 days of being completely gluten-free to recover from it. It's just not worth it to risk making myself ill.

My GP has prescribed me gluten-free bread for the past 9 years. I can eat eggs and don't seem to get a reaction from them. I have a small amount of dried skimmed milk and yoghurt, but no bottled milk, and I don't eat legumes.

Last year I seemed to be having a relapse that went on for about 10 months. I was really quite worried that the disease was going into a more progressive form. A major concern was losing more strength in my legs because I need to walk my dog daily and I live alone so cannot readily get help with tasks.

Then a friend mentioned she'd read an article in The Daily Mail about Low Dose Naltrexone (LDN).

I read up all I could about it on the internet and thought I would really like to try it. I had nothing to lose. Things were becoming intolerable at times, and I felt I needed help. I contacted the Multiple Sclerosis Resource Centre by e-mail, asking how I could get a prescription. They replied with download information on how to obtain it. It required a note from my GP to confirm that I had MS. This he gave willingly, saying that he thought the drug was 'interesting' but that he could not prescribe it as his hands were tied by the constraints of the NHS.

I followed the instructions to apply for a private prescription from e-med. They sent a 3month script to the chemist in Glasgow and they sent me the drug by post. I started it that night at 11pm. I can hardly believe how quickly it worked for me.

I awoke with no pain in my legs and during the day I had more strength in my legs and was able to balance better. Over the next few days I had no fatigue or misty vision and no cracking, stiff joints.

I can do my housework and shopping easily now, and walking my dog is a pleasure again. I've been taking LDN for 12 weeks now and I've had no side effects at all. I would never want to stop taking it. If proves to be the case that it can halt the progression of MS then what more could I wish for?

I have given the information to others in my local MS Society branch who are interested. Also, friends have asked for details as they know someone with MS. I met a friend this week that was diagnosed recently. She has a 3 month old baby and is really struggling with her first major attack. She now knows about LDN.

The best disease modifying treatment for me is definitely LDN.

### 68

### Hannah G, UK 1997 - Secondary Progressive Multiple Sclerosis (SPMS) 2006 - LDN

I've got Secondary Progressive MS. My MS started about 15 years ago but wasn't diagnosed until 1997. I am in my mid forties and am married. My husband and I were disinclined to start a family, particularly because after leaving college, I was showing the first and most frightening initial symptoms of MS.

Having always been healthy, I thought, wrongly, that I would recover entirely after suffering 4 episodes. I also suffered a short period of colour blindness for which I chose not to seek medical help.

I later suffered two 'petit mal' fits within 10 days of each other. Because of the fits I was given an M.R.I. scan and was treated with the drug Epilim. Fortunately the doctor who dealt with me was careful to make sure that the treatment didn't last longer than 6 months, as he had experience of epilepsy patients for whom the dose of Epilim continually went up. Great handfuls of my hair had come out already as a result of taking Epilim.

I first heard about LDN from a feature in New Pathways.

At around this time, my husband was doggedly tapping away on our laptop trying to discover if putting in 'LDN' and 'Scotland' might turn up any supplier within this country.

I ordered a Fact Pack from the MSRC and was glad to be able to place an initial prescription for a one-month supply of LDN at 3.5mg strength. I found the first order too expensive, so I placed my second order through an internet supplier. Following that, I placed orders through Dickson Chemist in Glasgow.

Since starting on LDN, I've been provided with private prescriptions from three different GPs at my local health practice. They were interested in the idea that I, as a patient, could present them with details of something they'd never come across before and a request a private prescription in order that I could get it!

The most noticeable immediate benefit for me was that I no longer had horrible reactions to heat. I remember how totally unbearable heat used to be before I started on LDN.

I wish taking LDN would help me walk! I'm taking 4.5ml of LDN on a regime of 10 days on, 2 days off, and have just learned that most take LDN every day without a break. I'm intrigued by that. I walk with two sticks, I take baclofen in tablet form when needed, and I take 10mg tamazepam nightly for sleep.

I have to stop and remind myself how dreadful I used to feel before I began taking LDN. LDN allowed me to feel a lot sharper mentally within the first month of taking it. Things used to be particularly unbearable in hot weather. I still find hot weather difficult, but far more tolerable with LDN.

## **69**

### Helen O, UK

February 1999 - Chronic Fatigue Syndrome, Myalgic Encephalomyelitis Feb 2009 – LDN

I started taking LDN about 6 months ago for CFS/ME. I had been under Dr Gilhooly's care since October 2008, and had made good progress on nutritional supplements, mainly high doses of omega 3, which I found reduced my pain levels a great deal.

Despite the improvements, in Jan 09 I was still having setbacks, or crashes, causing dreadful mental and physical fatigue, muscle spasms and twitching, lymphatic pain, all of which resulted in me being able to do very little, requiring help to even look after the children.

I started on 1ml LDN daily and over the last few months I have managed to get up to 3.5ml. I'm taking it slowly as I had a strange reaction when I went from 2ml to 3ml (my head felt as if everything was going slow around me).

The big question is, has it helped me? Yes, the first thing I noticed going was the muscle spasms and twitching. This stopped within a few days of starting LDN.

Gradually, over the last couple of months, I've noticed an increase in my energy levels... my brain fog is so much better... I remember my words now... and, in fact, I remember so much that my friends and family now struggle to keep up with me... which I find very amusing.

I can now walk over 2 miles at a time... and have not had any major crashes since getting the dose up to 3ml. I am hopeful of getting up to 4.5ml in the near future.

Exactly one year ago I was very ill. I was losing weight and in considerable pain every day, with no real energy. LDN has given me and my family hope, and I would very much like to help raise awareness in any way I can.

### 70

### Huw E, UK 2004 - Primary Progressive Multiple Sclerosis (PPMS) April 2009 - LDN

I was diagnosed with primary progressive MS in 2004.

This was the result of more than two years of investigation. Following diagnosis I was supported by an MS Team based in Cardiff. Their help, whilst appreciated, has been confined to 'approved' medical options which, in my case, consisted mainly of neuropathic pain blockers and physiotherapy.

Clearly the exercise involved in the 'physio' activity was helpful, however, the medication was less successful and resulted in very little pain relief and an adverse side effect of, what I can only describe as, a 'brain dead existence'.

In the early part of this year I was made aware of the use of LDN in cases of MS. I approached my local GP for the provision of a prescription. The initial reaction was very positive, the prescription was provided and, with great efficiency, Dickson's Chemist in Glasgow provided me with the liquid form of LDN.

At this stage, I feel the need to stress the importance of increasing the dosage levels gradually until the maximum recommended level is reached.

At the end of the third week of treatment I began to feel the senses in my feet for the first time in a very long time. This was accompanied by a better sleep pattern resulting from reduced muscle anguish in my legs. At this stage, you can imagine the optimism that was beginning to build up. However, it was short lived, because my attempt to procure a repeat prescription from my GP was refused.

There was no real explanation from my doctor other than to say that contact had been made with my local MS consultant. I can only assume that their conversation had

'reflected' on the non-approved status of LDN in the treatment of MS. This change of circumstance resulted in my continued use of LDN being disrupted until I was able to set up a source for private prescription. This was achieved through information obtained through LDN Research Trust.

I have now completed four months of continuous LDN medication and make the following comments:

• Noticeable improvement in sleep pattern (I have dispensed with the need for diazepam and baclofen to help with sleep and muscle relaxation).

• An improvement in the burning and anguished sensation in both my feet and legs.

• A very substantial improvement in mental alertness and 'feeling of well being'.

• The mental fatigue previously experienced has diminished to the extent that people who are close to me have commented on the difference.

• A flow-on effect from improved well-being has been a heightened sense of 'feeling positive', which naturally, leads to every day activities being much more pleasurable. I only wish there could be a more scientific way of measuring the level of improvement in order to convince would-be sceptics of this alternative approach to the condition.

• On the slightly negative side, I did experience a bit of a relapse when I reached the maximum level of 4.5mg LDN, however, at this juncture I am not sure whether this situation was influenced by an infection that I have recently been treated for. At this moment, I have reduced the dosage of LDN back down to 3mg without adverse effect.

In conclusion, it would be ridiculous to suggest that I could walk (or run) a marathon, but... the desire to tackle every day chores is approached with more optimism, even if it is achieved a little at a time.

I hope my comments will be of help to others.

### UPDATE April 2010

I am continuing with LDN, and am currently on a dosage of 3.5mg per day.

In general terms I can report ongoing improvement in mental alertness and a muchimproved feeling of 'well-being'.

As far as my mobility is concerned, there is a slightly deteriorating situation, however, the 'well-being' is a big help in improving and maintaining my positive outlook.

A few months ago I was taken into hospital with a condition described as hyperventilation, accompanied by a high blood pressure level. There was no clear diagnosis of the problem, but at the time I was taking 4.5mg LDN per day.

I reviewed some of the side effects of LDN and identified one as 'can result in increased anxiety levels', and did wonder about this. Consequently I reduced the dosage back gradually to 3.5mg per day. To-date I have had no further problem, though it is by no means certain the higher dosage level was the cause. I should add that tests carried out whilst in hospital showed no indication of infection of any kind.

I would appreciate your thoughts on this if there is any anecdotal experience of this reaction.

Thank you for your continued efforts on our behalf.

### 71

### Jackie B, USA 1997 - Hashimoto's, April 2006 - Cancer May 2008 - LDN

I was diagnosed with Hashimoto's in 1997, but I had suffered from it since the 1980s.

I was diagnosed with cancer in April of 2006, but I'm sure I had had that illness for twenty years minimum. The cancer is a slow-growing cancer that disrupts neurological and endocrine functions.

I don't have much of a story. I began taking LDN in May of 2008 to try and control neuroendocrine tumors, a rare cancer of the neuroendocrine system that plays havoc with most bodily functions.

Since then my symptoms have slowly receded, and my tumor markers are now normal.

My scans show no image-able tumors and no growth of micro tumors. My next labs and scan will be in August 2010 and I'll update then. Incidentally, I have Hashimoto's Thyroiditis and LDN has done not a thing for it.

### 72

### Jan A, UK 2007 - Primary Progressive Multiple Sclerosis (PPMS) September 2008 - LDN

I have Primary Progressive Multiple Sclerosis (PPMS). I had a very late diagnosis. I was eventually diagnosed in 2007, I think, after being told I had ME for about three years.

I first heard about LDN 2 years ago, and though I managed to find Dr Lawrence, I had to wait a while to get on to his programme.

I started taking LDN in September 2008. I felt no different, nothing happened. I didn't feel any better or any worse and that's still the case. That's why I didn't want to share my story last year, because I didn't think it was very strong.

It's now one year later, and I'm still very much the same, except that I haven't had a cold for two winters in succession.

What that says is that in 20 months I have remained stable, and haven't had to deal with any colds, which is another benefit.

Not the strongest story in the world but I will carry on taking LDN and will continue to recommend it to anyone who'll listen.

# 73

### Jane W, UK November 2009 – Primary Progressive Multiple Sclerosis (PPMS) 22nd February 2010 - LDN

For many years I complained to my doctor about various 'odd' ailments and feeling exhausted. Then in 1994 I had two weeks of being unable to walk due to severe dizzy spells, which were put down to an inner ear infection. I am now told this was probably MS. Over the last two or three years my right leg has become numb and my foot has dropped causing me to fall and trip. I have also had bladder and bowel problems and awful headaches.

In November 2009, after rigorous electrical tests and a lumbar puncture, I was diagnosed with Primary Progressive MS. I was told there was no cure and very little available to treat the symptoms.

I started taking Baclofen for the spasticity with minimal effect and soon realised my career as a Scenes of Crime Officer was not going to last much longer. I requested a physiotherapy referral and tried doing a little exercise as often as I could.

After a really bad spell being unable to do much at all for myself, or even get out of bed, I started searching the internet and various MS forums for advice and help. A friend had told me about somebody she knew who was on this medication called LDN and strongly recommended it. I noticed LDN popping up in each and every forum. I read with interest how many people had felt benefits within a short time of taking LDN.

I asked the MS Nurse about LDN and she was reluctant to talk about it. I mentioned it to my GP who told me I would not be able to get it anywhere but that he fully understood that I wanted to try it as there was so little he could offer to slow down the progression of my illness.

I managed to find a private doctor who prescribed me LDN and I had it sent down from Glasgow.

Within 2 days of taking it I felt better, but I put this down to the natural comings and goings of PPMS. However, it is now nearly 2 months since I started LDN (22nd February 2010) and I have not felt so well in years. I still get very tired and sometimes my leg goes stiff but nothing like it had been. I am now confident enough to go out to the shops on my own and have been able to be of some use at work again.

The Physiotherapist cannot believe how I have my mobility back in my leg and my GP is very pleased with my progress. I have read that some people say it is a placebo effect: Well, if it is, I don't care because I feel so much better. I can cope with PPMS with the help of LDN.

If anyone is thinking of trying it for PPMS, all I would say is... what else is available?

I hope that one day LDN is prescribed on the NHS for everyone.

### 74

### Janet T, UK 1986 - Multiple Sclerosis May 2004 - LDN

Six years ago, when we moved from the London area, I'd just had a two-week stay in a hospital because of a serious back problem. This resulted in me being on a concoction of drugs including very high dose morphine, which was certainly turning me into a zombie and probably was killing me. I had rejected the option of having my spine cut chemically. None of the drug treatments dealt in any meaningful way with the severe back pain resulting from the interaction of MS spasms with the separate back problem.

A local GP helped me to wean off the prescribed drugs and achieve some improvement with one of the now infamous Cox2 Inhibitor drugs.

This left me again in my right mind although still with serious back pain. I trawled for hours on the web to try and find some solution. I eventually discovered LDN and took some time to persuade my husband to research it as over the years we had looked at several 'miracle' cure treatments for MS. The only one we had tried was the Carrie Loder protocol, which I found to be totally ineffective.

I then persuaded my GP to write a private prescription for LDN in May 2004. Within four days my life changed completely. Having had difficulty travelling locally in the car and being virtually housebound, I could again travel freely.

It took us about six months to get the dose of LDN right and find an alternative solution for my back problem.

Since sorting out the use of the correct dose of LDN for me and resolving the back pain by separate mechanisms I have had NO further progression of MS.

In summary therefore, LDN has replaced a horrifying concoction of dangerous drugs that had turned me into a zombie and might have killed me by now. No doctor is now suggesting I submit to having my spine chemically cut.

My results with LDN seem to be typical of at least 90% of those or so who are currently using it.

For the newly diagnosed, LDN is very nearly a complete solution to MS.

### UPDATE March 2010

A resounding 'YES' to both update request questions.

Recalling how bad I was when I started taking LDN, I still want to give anybody with MS the chance to halt this crippling disease. My neurologist has now stated he only wants to see me if I want to see him as there has been no regression back to how I was in over six years.

# 75

### Janne, UK 1998 - Multiple Sclerosis 21 September 2009 – LDN

LDN has been a huge success for me. I started taking LDN on September 21, 2009 and have been taking 4.5mg at bedtime every night. It has now been over three months since I began taking it, and I'm thankful to God for how well I'm doing.

To give you some backround on me... I was diagnosed with Multiple Sclerosis in 1998 but had my first symptom at the age of 12. My first symptoms consisted of weakness of the upper right arm and right leg and blurry vision, which went away after two weeks... so I opted not to tell my parents, thinking it was because I got nervous and got a little paralysed. I convinced myself life can be paralysing!

By profession I am a Registered Nurse, since 1995, but I have not worked since the last crisis in November 2008, and the past year, 2009, has been very challenging. I have had extreme trouble walking and the balance was just not there, the most bothersome was the brain fog.

Let's get back to how LDN helped me... one day of LDN and my brain fog was 97% better - I could hardly believe it. I used to exercise daily and had not been able to for almost a year.

Before LDN I could barely do the treadmill at 1mph for one minute, but finally struggled and got up to 3 minutes at 1mph. Now with LDN, I can do 1.5mph for 20-25 minutes (holding onto the sidebars, naturally). I do this once a week or once every other week. Considering I have been in bed practically one year this is awesome.

With the brain fog gone now life is so much easier, but I have to remind myself not to overdo it because I feel like superwoman at times. I have to remember to slow it down and not forget my daily afternoon naps, as an afternoon nap is still essential to my sense of well-being, strength and coordination.

For me the key has been to set limits – more, but not too much - and prioritise the things I need or want to get done. It's also crucial to not get worked up, upset or anxious.

I'm thankful for once again having a quality of life. I highly recommend anyone to start with Naltrexone and just see for yourself if you too find a renewed energy and focus.

My husband says my stamina is much improved, as are my eyesight and my memory... I actually remember where my keys are now!

My mother tells me she can understand me better when I talk, so my speech has improved, even though it's difficult to construct sentences when I'm suffering brain fog. My mother also noticed I've been coordinating tasks better and have been less anxious.

I'm not yet where I used to be, but I'm heading in the right direction, and I sure am enjoying life again with LDN!

# **76**

Jay D, UK 2001 - Multiple Sclerosis Oct 2002 - LDN

I'm still taking LDN, and it will be my 7th anniversary this October. I've been getting my LDN on the NHS for around 5 years.

I had my first attack back in 1993. I lost the use of many things for a little while - my vision went blurry, balance left me, hands were very weak etc. After 4 months of symptoms, one week in hospital and IV steroids, I came back to 99% wellness and stayed that way until I got pregnant in 2000. That was when my legs started to go numb again. I was officially diagnosed in 2001, and it has been a slow, steady decline since then.

I first read about LDN in New Pathways magazine in 2002, so I thought it was worth a try, especially as a GP was taking it. It seemed a fairly safe risk. I started buying my LDN from Dr Bob Lawrence in October 2002. I didn't suffer any side effects, and within a week of starting it I noticed some subtle improvements - my legs felt a little stronger, my bladder a little more controllable, and I had a little more energy.

But by far the biggest improvement was that my legs stopped 'buzzing'. Since my 1st attack I'd been left with residual tingling in my legs, which meant I found relaxing very difficult. Then I started LDN and the tingling went! It was so nice to be able to sit 'quietly' and relax properly!

Although I have not had massive improvements on LDN, I still continue to take it. I am still tingle-free and I attribute LDN for being my own personal firewall. I don't seem to get half as many colds, bugs and viruses, which is a real bonus being a single mum to 2 school age kids!

When I first started on LDN, I visited my GP and told him I was taking it, so my notes could be updated. A year later he offered to prescribe it for me, but at the time there wasn't a pharmacy in England compounding it in 4.5mg capsules, so I had to decline his

offer. Later, Martindale's started compounding it in the right dosage, so I went back to my GP and have been lucky enough to get it NHS prescription ever since.

I support the need for LDN trials as I believe it to be one of the best drug options out there for MS right now, and it's suitable for Secondary Progressive as well as Relapsing Remitting, so I believe everyone should have the opportunity to try LDN.

# 77

### Jayne T, USA 2000 - Relapsing Remitting Multiple Sclerosis (RRMS) February 2009 - LDN

Throughout my life, I've had many blessings, the love of my parents, 4 beautiful children I raised on my own, and grand, supportive friends. The only one thing that has made a mess of my life was being diagnosed in 2000 with multiple sclerosis.

After a series of 'symptoms' that were dismissed by my GP at first, I demanded to be sent to a neurologist and went through the series of tests that determine whether or not you have 'it'. The diagnosis? Relapsing Remitting Multiple Sclerosis. I was told I had probably already had MS for about 8-10 years.

Shock, denial, anger, mixed emotions and many, many tears held on to me for months. My mother had MS, and as a child, I witnessed her deteriorate. I was scared as hell, and the last thing I wanted was for my children to go through the same thing my sister and I did.

The first thing I did was to Google everything and anything about MS. This was the WRONG thing to do. Everything I read was very depressing and of course, not of an optimistic outlook. I considered the CRAB meds, but after much research on the long-term effects of them, I decided NO. These meds only mask the disease, they do not cure. After they stop working, you are still left with your MS, and damaged organs. In short, I chose the natural approach, with diet, exercise and vitamins... and it worked. I continued to work full time, sometimes 50 hours per week.

In June of 2004, we, as in the children and I, moved into a cute little house, that we thought was ideal, but within six months I went from working and enjoying spare time with my children, to being carried to bed by my son. By January 4/05, I could no longer work. The fatigue, spasticity, brain fog, and weakness in my right leg happened very quickly. By May of that year, I had drop foot on the right side.

I tried everything and anything to 'cure' myself, trying products on the internet, trying new protocols. Nothing happened and the reason for that? Black mould was in the house. Black mould attacks your immune system and that causes you, of course, to deteriorate. So, we moved and moved again, until I was able to get subsidized housing. Through all this, my children, were greatly affected emotionally. All my children had to witness a physically and emotionally strong woman become what I considered to be a pathetic, useless human being. Life can be so cruel.

So, my journey in life continued. Through the meeting of extremely positive people and pushing away the negative, I stopped feeling sorry for myself and embraced my spirituality. I watched 'The Secret' and read, read, read. 'Optimism' was now a new word in my vocabulary.

Despite spending 10 weeks in the hospital after an exacerbation, I looked forward to delving into more research when I got home. So many supportive nurses told me stories of how they had patients that were bedridden and were now walking and carrying on a full life. So, I decided that was my goal. Never, never, give up.

I subscribe to Dr Mercola's weekly email. He gives advice and information on health issues and the proper way to treat your body. The header of one particular email was, Cure for MS? Well, I did what anyone would do. I read it. The more I read, the more excited I got. Could this be the answer or just another hoax?

Well, the Googling started again, and everything I read was so very supportive. I joined a couple of online groups that support LDN and made contact through Facebook with fellow MSers who were on it, then made my decision.

I gathered all my info, and armed with said info under my arm, went in to see the doctor. I told him of LDN and what it does and gave him the websites to look at. He was so impressed with my research that he signed the script right then. Even now, I remember how ecstatic and lucky I felt to have such a supportive doctor! That was four months ago.

I found a compound pharmacy in Toronto and asked them if they could compound it. My filler is acidophilous, and I started at 3mg per day. I know that some recommend starting at 1.5mg, but being me, I couldn't wait for that. The first night after I started to take it, I couldn't sleep at all. Lesson learned. I then took it just as I was going to bed. The next night, I slept like a babe and had the most wonderful, real dreams!

Side effects? Yes. In the first week, my spasticity increased. As stated in all the LDN groups, sometimes the worst symptoms may be exacerbated, but they do not last long. My energy level increased almost immediately and I stood! I am in a wheelchair, and have been for about one year, so that one simple thing to the average person, enthralled me!

I continued to make strides, until my one doctor put me on Baclophen. It did not sit well with me and turned me into a pile of mush. So, back to square one. Now, since then, excitedly as I report this, my speech is back to normal. (I had no idea my speech had been affected until my friends, point blank, told me how good I sounded now.)

Personally, ugh... my bladder and bowels are back to normal and the brain fog is almost non-existent. My eyesight is getting better. And fatigue? A thing of the past... but I listen to my body, just as any average person should!!

I believe in LDN so much. I tell everyone who has any autoimmune disease about it. It's not just for MS. I created an LDN page on my Facebook, to provide information, and now I'm writing this letter in full support... I've also started a petition requesting governments worldwide to help with funding of clinical trials of LDN, to make physicians and pharmaceutical companies more aware. This petition will be joined with another, to get the numbers higher.

All LDNers believe strongly in this magical little pill. Not only does it work, it is very cost effective at less than \$35 per month as opposed to millions being spent by the government on meds that are questionable, to say the least. Instead of investing in more weaponry, how about investing in saving lives?

So, four months after I started, and only four months, I have not felt this well, in ages. Is this the end of my story? No, it certainly is not. I will not give up the LDN, will keep up with the physio and when I am walking again, never again will I take for granted those little things that a 'normal' person can do. Walk or run to the store, go for a hike, put on my own shoes, reach that box of cat food way up on the top shelf... the list goes on.

I will thank my beautiful, supportive children by walking beside them, and thank my lovely supportive friends. Oh and importantly, Dance!!!!

#### Update – February 2010

When I went back to my doctor two months after he first prescribed LDN, he was shocked and said I looked like I had taken a glow pill. The haggard-ness was gone, as was my dysphasia. My fatigue level was almost non-existent, and my mood was, well, plain old happy!!!.

Now, my bladder is the best it's been in 5 years, my brain fog is 98% better, and my strength is building up every day... I wish I'd known about LDN earlier because then I could have halted the progress years ago. I wouldn't be in this chair (which I will be out of one day), and my children wouldn't have gone through hell watching me go down hill, physically and emotionally.

I started on LDN 12 months ago now and have not looked back. LDN has changed not only my life, but also my children's lives. They have lived in fear of me deteriorating, and that they might get MS themselves. Now I have improved, and they know there is LDN in their corner if they should need it in the future.

### **78**

Jean M, USA
May 2000 - MS
March 2001 - LDN

My symptoms first began in 1997 when I experienced loss of hearing to the point of deafness, but I was not diagnosed with Multiple Sclerosis until May 2000.

LDN has been of great benefit to me, but particularly so in the last twelve months, during a major upheaval in my life and a continuing period of stress that would put most healthy people to the test.

Last May 2009 I was served with papers to leave the home I had shared with my partner, the father of our child, for almost 12 years. Apparently he no longer wanted to

be a 'family man', and wanted instead to 'enjoy' his life. His words, not mine, because that's what he stated in front of myself and our daughter who was age 11 at the time.

We had no place to go to, so I had to leave our large home with garage and yard and move into Government Housing. I told the government bureaucrats that I needed have my dog with me because I had hearing problems, MS, and was totally disabled, but I had to leave my dog behind because the bureaucrats failed to advise me of my rights as a disabled person under the 'Americans with Disabilities Act, Title 2, Fair Housing Act 1988' and the 'Rehabilitation Act 1973'.

I had a nervous break down, going from 163lbs down to 118lbs by August 2009, before I finally started feeling like myself again.

But no MS FLARE.

LDN DOES WORK.

Now they are evicting me, even after I gave them documentation from my doctor. The Judge has given me 10 days to get out, or as it was told to me, "You will be bodily removed and all of your possessions will remain in the apartment". These people have violated my rights by categorising my Service Dog, Star, as a pet.

Thankfully there has been one light on my horizon: I dated Bill 20 years ago for 18 months. We parted, but stayed friends and have always kept in contact. In July 2009 he called and asked if he could come over to talk to me, and we fell back in love. I guess we never stopped loving each other, and I proposed in October. We announced our engagement the week before Christmas.

Then the Child Protective Services began knocking on my door.

Last May 2009 the man with whom I'd had a 17 1/2 year relationship did not want to keep our daughter, but now I have been falsely accused of Child Abuse and Animal abuse and the partner who left me has filed for full custody of our daughter. After all this time!

My family has become dysfunctional since my Grandpa passed away in 2003. I was so very close to him and am still very close to my mom, but I have 2 sisters that have basically turned their cheeks to me because they're jealous of the closeness my mom and I share.

I hope this gives you an idea of how much stress I've been under, and yet, how well LDN has been working for me.

### Jeanette M, UK 1998 – Relapsing Remitting Multiple Sclerosis (RRMS) September 2009 - LDN

I was diagnosed with RRMS in 1998, by a GP, and this was confirmed in late 1999 by a neurologist. My first symptoms were blindness caused by Optic Neuritis, and numbness in my fingers.

I was offered Beta Interferon as a treatment but as soon as the Optic Neuritis cleared, I had no symptoms that impacted on life, and, not being a fan of drug treatments that are so toxic I refused. Things carried on much the same with only fairly minor relapses, but crushing fatigue was constant.

In February 2009, I had a serious relapse that laid me in bed for about a month and was very slow to improve.

I went back in to the system for scans and to see a neurologist after being away for 7 years. Immediately, I was overwhelmed with appointments with continence nurses, contact with the MS nurse, steroids, and DMD treatment...

I found this approach overwhelming and unwelcome. One size does NOT fit all. I was coping with coming to terms with MS all over again and I kicked back at this unsympathetic approach and started using some of my University training and did some serious research and reading. I'm a Chartered Librarian/Information Scientist so I found the research easy and interesting, and I found LDN!

In September 2009 I spoke to my GP and showed him the information sheet from the website. He immediately wrote an NHS prescription for me.

Since starting LDN my fatigue and bladder problems have massively improved. I feel better and am coping very well, even though it's been a terribly stressful time. Since starting LDN in September 2009 I've lost my mother in law, two much loved pets, and finally, in January of this year, my own mum.

In the past this amount of stress would have kicked off a pile of symptoms, but it hasn't, and for that I thank LDN. I only take the minimal dose of 1.5ml and have so much to be thankful for.

I'm not properly over last year's relapse yet, and walking is not as fluent as it once was. I can manage a mile or so in the morning with the dogs though! It used to be 3 miles, and I hope once the stress is lifted that may come back.

#### Jeanette M, USA 1987 - Multiple Sclerosis 30 June 2009 - LDN

I am writing to LDN Trust to express my gratitude for the opportunity to experience LDN for my illness of M.S.

I was diagnosed in 1987, in my late 20s. I was halfway through graduate school in psychology, and had just had a baby. Upon diagnosis, I was given tegretol, noretryptiline (antidepressant), and solumedrol, just to name a few. After continuing on this track for a few more years, I turned my focus to herbal medicine with fairly good results.

But then, three weeks ago, I read online an interview with Dr. Burt Berkson, M.D., describing the benefits he has seen in patients with LDN. The article convinced me to request from my local doctor a prescription for LDN. For the first time, I feel like my life could possibly brighten (maybe a lot!) regarding present symptoms - my gait (a limp), cognitive ability (aiding my short-term memory loss), and fatigue (which is most of the time).

I think this drug could change people's lives. This is day 14 for me on LDN, so I'm thinking (hoping) it's still in process. I'm not sure how long LDN takes to kick in. If it has completely already, I'll have to go for a long walk and see how my leg does as well as other symptoms. If it takes longer, I'll email you back in two weeks or so, and let you know.

# 81

### Jeannine E, USA August 2000 - Multiple Sclerosis March 2009 - LDN

I have been on LDN for 6 months now.

I didn't expect to feel any difference for at least a month, but in the first week my fatigue was a lot better.

I didn't even notice it at first until I realised everything I was doing was easier to do and accomplish.

Then the spasms eased... I went out to dinner with friends and got up from the table by myself and started walking out with my cane. I stopped, because I then realised that no one had to help me walk out! I am usually all cramped up and can't straighten my legs.

I am not in pain anymore at night with my spasms. I still get them but they are easier to deal with now. The last time I saw my neuro he wanted me to do Rebif as well. I have spent the last nine years on Copaxone, Avonex, Rebiff and IVIG infusions and have been very, very sick.

I feel like I have my life back now so I said "No"... I don't know if LDN slows MS and I don't care. My day-to-day life is so important. I can now work 3 hours from home as well as go out, see friends, go to the grocery store, etc... I would rather have this and enjoy the ride than be sick all the time and have no life. I had 15 lesions while I was taking all the standard MS meds.

LDN is working.

## 82

### Jeni S, UK 1997 - Diagnosed plaque psoriasis April 2009 - LDN

I've had plaque psoriasis all over the place, including my face, for about 12 years now and in the past have used mainly dovonex, dovobet, and other sticky creams. I've also used UVB a few times, which worked well the first time but not so well after that.

I've been taking LDN now for about 4 months. I started at 1mg per day and gradually increased the dose. I'm now at 3.5mg. I didn't really notice much of a change for the first couple of months, but the psoriasis has definitely faded over the last month or so and I can even see skin on my knees (total novelty!).

My face has also completely cleared up. Obviously this has also coincided with summer, so the sun may have played some part, but it is better than it has been for a long time, so I feel that the LDN is definitely helping. Hopefully it'll continue to improve. I've had no side effects from taking the LDN and it's reassuring to know that the drug has been on the market albeit at higher doses for other uses for quite a few years.

## 83

### Jennifer F, USA 3 June 2009 – Relapsing Remitting Multiple Sclerosis (RRMS) 26 June 2009 - LDN

My journey into the world of MS began suddenly; like many others. There were no signs, no symptoms, no forewarning.... Just WHAM!

It was January 31, 2009. I was sitting on my couch looking out the window at a woman walking her dog and then suddenly, there were two women and two dogs. I shook my head and my vision cleared slightly, but then went back to double. Throughout the next few days I dealt with it; then finally gave in and went to the ER. I was admitted immediately and the staff began running tests, concerned I'd had a stroke. A stroke, I thought... but I'm only entering my 40s!

In the middle of the night, as usually happens in hospitals, I was visited by the doctor making rounds. I vaguely remember her saying something about a spot on my Medulla, and mentioning (quite casually) a term I'd become intimately familiar with; Multiple Sclerosis. The next day, anxious to be discharged with a trip to Hawaii pending in a few short days, I listened to the doctors explain that, what most likely happened was that I had dislodged a small particle of calcium from my inner ear, causing blurred vision. I thought, 'but it was double, not blurred!'. But off I went on my merry little way. The double vision resolved itself within 12 days, and I thought it was behind me.

Two months later while visiting my Aunt and Uncle, I was gazing off into their fields enjoying the view when it happened again. Two fields, everything doubled. Ugh... I knew then there was more to the first episode than the doctor's originally believed. Three days later, I went back to the ER and the doctors immediately informed me they suspected Multiple Sclerosis. 'What the hell is that?', I thought.

Over the course of the next three days, I was poked and prodded in every way possible while my doctor, a resident intern, tried to decipher the cause. I left the hospital with a vague diagnosis... "It may be Multiple Sclerosis, it may be Myasthenia Gravis, or it may just be a virus", the resident advised me. That's one hell of a virus, if that's what it is, I thought to myself. But once again, I was happy to get out of the hospital; they just make me uneasy. So off I went, into what turned into a two-month nightmare.

Within two days of release, I started to experience my first real taste of Multiple Sclerosis. It started with my legs; I couldn't keep them still. I've never had restless legs before, but I sure have empathy now for those who suffer from it chronically. Then it exploded into a plethora of new symptoms; tremors, ticks, slurred speech, balance and coordination problems, severe optic headaches, nerve pain, and on and on.

I remember calling the intern who was handling my case to advise her of what was happening. She laughed and advised me there was no way for me to be experiencing that many new symptoms for the illnesses they were considering. I'll never forget that phone call; I was beside myself after I hung up. Generally speaking, I don't fluster easily. I consider myself well-grounded and not prone to hysteria. That phone call took me to a whole new level. I realized that I was at her mercy.

Later that day I began calling some of the top docs in NYS. By evening, I had made appointments with 3 Neurologists; the head of NYU's MS Center; the head of Mt Sinai's MS Center; and a local doctor in upstate NY. Even though I hadn't yet been given a diagnosis, I was pretty sure I knew what I was dealing with. The pieces all fit, and I didn't need the intern to tell me what I already knew.

As many of you know, focusing on anything in the midst of an episode is far from easy. I knew though that standard medical treatment is not always the best avenue. We are all unique, each of us responds differently to different treatments. I don't subscribe to one standard treatment for any given ailment. I believe there are many options; it's just a matter of finding what works for you.

I'm also a researcher at heart, and the internet is my playground. So I started to play... and the more I read about the accepted CRAB's, the more unsettled I became. Thirty percent was the number that stuck in my head. It slows the progress of the disease by 30%. Really, I thought, 'Not very good odds'. I kept looking. Then I stumbled on it by accident, Low Dose Naltrexone. I began reading everything I could about the drug.

"Anecdotal", my father said; "There needs to be double-blinded clinical trials to prove the efficacy." I didn't care what anyone said. It is my body, my choice. Plus, the thought of sticking my body willingly with a needle several times a week did not set well. What was even more disturbing was what was in those needles! Interferons? Who wants those in their body? Not me! I had become familiar enough with the prospect of LDN that I decided to find a doctor who would prescribe it to me; and I did. They were 3 hours away.

In the meantime I had my other 'top' Neurologist appointments. Each time I went in, they gave me the same diagnosis. I would explain that I wanted to 'try' LDN before a standard CRAB. With each time I mentioned LDN I received that polite pat on the head, and the, "That's just internet nonsense" response. So I left each appointment with literature in hand, Rebif starter kits, and MS Support Group information... but no prescription for LDN. I still had a few weeks before my appointment with the Neurologist whom I knew would prescribe me LDN.

I drove 3 hours to see the doctor who is now my current Neurologist. I immediately thought he was a godsend. He spent 3 hours with me on my first consult; discussing my 'new normal' and explaining his recommendations for treatment. I called it my 'new normal', because despite the fact that my episode had ended, I still felt off, fatigued, plagued by nerve pains, weak, cloudy... just not 'right'.

Anyone with MS knows what I'm talking about. When I advised him I wanted to try LDN before any other treatment, he explained that he would let me guide my own course of treatment. I realized then that he wasn't as enthusiastic about LDN as I was, but instead was the kind of doctor we all should have; he let me make my own decisions.

I left with my script in hand, happier than a fox in a henhouse, but not as hopeful as I was when I got to his office. I thought if this doctor doesn't think it will work, and my dad doesn't think it will work, am I just fooling myself that it will? I filled the prescription immediately anyway and took my first 3mg dose that night, 26<sup>th</sup> June 2009.

The next day I woke up and thought, Okay, it's only been one dose and one day, I can't expect anything yet. And then one day turned into two, then three, then four... and before I knew it, the fatigue was gone. The fog also lifted, but the nerve pains remained. Then after one month, I increased my dose to 4.5mg.

It's now early January 2010, nearly five and a half months since I started LDN. The nerve pains did eventually subside, and now are almost non-existent. Once in a great while I'll get them, but nothing like before.

There are days I completely forget that I have this disease, something I didn't think would ever happen for me. Goodbye 'new normal'! I finally do feel normal again. I may still have Multiple Sclerosis, but as a wise MS'er once said, "Until there's a cure, there's LDN".



### Jennifer F, Australia May 2009 - Ankylosing Spondylitis (AS) June 2009 - LDN

After years of CFS/ME Hypothyroid diagnosis, I undertook tests in May 2009 for Ankylosing Spondylitis (AS).

I started LDN in June 2009 for Ankylosing Spondylitis, a type of arthritis, as well as high CRP ESR Inflammation levels. Following my doctors instruction I took 1.5mg LDN at night, which was to gradually increase until I reached a maximum dose of 4.5mg.

I experienced no vivid dreams or insomnia that I had read others had experienced and had mild easing of hip and thigh pain in the first week. Now as a very gentle and eventempered person with a huge sense of humour, I was surprised when I started to become irritable and snapping at everyone. If I had a dog I would have been growling at the poor thing.

I increased my dose to 3mg and had the benefit of 50% pain relief, able to stand straighter and stronger. I had previously only been able to stand for 3 minutes. I was particularly relieved to find that I could breathe easier and deeper.

During this time I needed afternoon sleeps from 2pm, and the need grew. I was now feeling totally exhausted all day long, having to force myself to shower.

I didn't make my bed or wash my sheets for 3 whole weeks. My exhaustion was so great I was becoming daily more and more depressed unable to function. Yet at the same time, I could visually see improvements, the deep redness between my ankles and knees was receding, open cuts were healing, and pain was easing, so I knew something good was going on 'inside'.

I increased to 4.5mg thinking this would be the answer and I would break through to the other side of whatever I was experiencing, however, my depression just got worse and worse. Unable to dress upon waking, forget brushing my teeth... far too hard... and now I can't wait to go back to bed to experience a deep sleep from 2pm until 6pm. Also keep in mind that I am sleeping deeply from 10pm to 7am each day.

I felt caught between a rock and a hard place, 50% pain gone and visual healing - yet severe depression and incapable of any activity.

Having decided after 4 weeks that this was NOT right, yet knowing I was healing 'inside' I decided to take a few days off LDN. Oh great - here is the pain whooshing back. So what on earth do I do now?

I had listened to an interview with Dr Zagon who said it didn't matter what time you took the LDN, and despite screams of 'night-time dosing only' from devotees, decided to go back to 1.5mg but take it in the mornings.

Pain went back to 50% relief after 2 days and I just got some 'buzzing' in my head (now gone). I was tired but not, 'can't get off this chair or stop staring into space' tired.

The exhaustion lifted, and I started to be able to function again. Sheets got changed on the bed YAY !!!!! Family came out of hiding, but now I have another fun experience.

As a London born Cockney now living in Australia, my cuppa Blitz tea has been my best friend in all of life crisis - and now it tastes like 'dishwater' and the sugar is particularly foul. I can't eat anything, as food now has this most dreadful taste. I had experienced this a few years ago after anaesthetic and couldn't eat or drink for a week - my gosh, what on earth is happening to my brain chemicals? The upside is that I should lose weight, it should be falling off of me any day now. Oh but to loose my 'cuppa tea' is like loosing my best friend...

One week on, I can again enjoy my cuppa, life has become much better and there is NO WAY that I am going back to night-time dosing. I did slip in a night time dose, just to see, and went straight back to 'can't move- can't function and I think I will sit here and stare at the clouds.'

I would also at this point mention the importance of having a no or low starch diet; that means, no bread, biscuit, potato, soy nor anything processed - you know the story. I ate some unsalted cashews (hidden starch) and the pain increased. So it is very important for me to make sure I help the LDN by not sabotaging the benefits by eating incorrectly.

Whilst I have read so many ultra positive, bordering on miraculous stories about LDN - my story is just a real world 'it was hard getting here' experience. I believe that we need to speak honestly of our experiences in the hope that we all learn something from everyone's situation.

I move on, confident that only good will come from taking LDN morning dosing combined with a low starch diet, and so I look forward to reviewing how far I have come in 6 months time.

And I have just noticed that the once huge ganglion cyst on my wrist has greatly reduced and is a tiny size I can only just feel now. It used to stick out... how good is that, and again, it makes me wonder what is going on inside where I can't see. It was there last week... and had been there for over 5 years... interesting.

I have stopped LDN as symptoms continued to deteriorate. Seems that mercury toxicity, confirmed by hair analysis, 1.44 (0-1) was being released, causing the symptoms, plus the metal taste in my mouth, tingling tongue and worsening headaches - just had to stop. I have been sicker than I have ever been in my life the last few weeks, but I put that down to the mercury trying to get out NOT the LDN

I am 'thinking' that the LDN started to throw out the mercury from the body but I can't find any references or past experiences by anyone so far as I search the forums. I think LDN is the bees knees and 'when' I have chelated all this mercury out of my body I will get back on it to re-heal. I have found suggestions that mercury is the core cause of Ankylosing Spondylitis (Andy Culter). Ah life is such an interesting journey.....

#### UPDATE March 2010

Despite two further attempts to take LDN, within just a few days I would start to sink into a psychologically depressed and extremely fatigued state.

### 85

### Jill G, UK 1970 - Ulcerative Colitis March 2007 - Multiple Sclerosis Sept 2008 - LDN

I started to take LDN in September 2008.

I didn't have immediate results, however over time I have noticed a marked improvement in my bladder. I have less spasticity & the tremor in my right arm has reduced.

My balance, coordination, and walking speed are better. So much so that I have adopted a rescue dog and we now go out on walks together.

Before taking LDN I had to make frequent trips to the bathroom due to urge incontinence, especially at night which disturbed my sleep.

My balance was very poor & walking difficult. This meant I didn't leave the house unless absolutely necessary.

After taking LDN my bladder is functioning a lot better, and I sleep soundly at night without being disturbed.

My balance and walking have improved considerably. This has given me confidence to achieve my goals in life, which before didn't seem possible. Thanks to LDN I now have an active & positive outlook.

#### **UPDATE March 2010**

I am still taking LDN and will continue to do so. I forgot to mention last time that I have had Ulcerative Colitis for 40 years. Thanks to LDN all symptoms have now disappeared. This truly is a miracle drug.

### Jody J, USA 2008 - Fibromyalgia November 2009 - LDN

I was officially diagnosed with Fibromyalgia in 2008 but have actually had the condition since 1991. The doctors were so ignorant and uncaring when I first got it that my neighbor, who was a nurse, finally figured it out in about 1998 or 1999. Doctors are really reluctant to give the diagnosis even if they have heard of Fibromyalgia. I don't know why. So, I had years of suffering before I even knew what I had.

Just a couple of notes on what I believe LDN has done for me...

The effect of LDN has been subtle, but I have noticed some changes. For one, I am not as intolerant of the heat as I was previously. I take LDN in addition to Mirapex for Fibro and between them almost all of my pain is gone. I believe the LDN has a subtle effect on me because the Mirapex was the first drug I took and it virtually worked miracles on me. In addition, I don't seem to have as much chemical sensitivity.

I ran out of LDN this week and the pharmacy is not that close. It took me 2 days to get there. After the second day off the drug, I began to feel achy and stiff all over, and I felt like I was burning up all the time.

I have also felt a little less of the depression that plagues us fibromyalgia patients.

I think the change happened gradually and was subtle, but when I quit taking it, I could really feel the difference.

Before taking Mirapex and LDN together I could do nothing but go from the bed to the easy chair all day. Now I am up and about and doing limited things, i.e., doing errands, taking on more of the housekeeping chores, and doing my hobbies all day long if I want (I am a miniaturist and a painter).

The two have given me my life back. I am still not able to do many things I used to, but I feel the quality of my life has improved considerably. I was hopeless before and did not have anything left to live for. I woke each day hoping God would take me. Now I want to live again.

### John D, Ireland

### August 2008 - Non Small Cell Lung Cancer, and metastasis to the Adrenal Gland December 2008 – LDN

It is now May 2010, and we have been achieving great success with LDN for Non Small Cell Lung Cancer.

My wife was diagnosed in August 2008 with 3 lung tumours, and metastasis to her Adrenal Gland. Jacinta was given 2 to 6 months to live and given 4 rounds of chemo.

The day after finishing chemotherapy Jacinta started taking 4.5mg LDN, because at the time no one I spoke to was sure if you could take LDN whilst underdoing chemotherapy. It is now believed the LDN will help alleviate the side effects of chemo if you take them together.

There was one large tumour in the right lung measuring 8cm, and we had to deal with that one as quickly as we could, so my wife underwent the Cyberknife procedure which reduced the tumour to a 3cm scar that was no longer a threat.

After 6 months on LDN alone, the tumour in the Adrenal gland had gone, and the other 2 lung tumours had reduced from 2cm to 1.3cm.

Then in June 2009 a tumour was found in Jacinta's brain and was removed surgically. We decided to start her on ALA, which crosses the Blood Brain Barrier (BBB), in the hope it would deter further brain tumour development.

While off LDN for 6 weeks before, during, and after surgery to the brain, the 2 lung tumours began to grow again, measuring 3cm. Jacinta underwent a second round of chemotherapy, but this time 10 rounds of a milder chemo combination along with LDN, and; when measured on 10th January 2010, the tumours had shrunk to 1.8-ish cm.

Since Jan 10th we've upped the game plan. From day one Jacinta's been taking 2 capsules of Sodium Bicarbonate to optimise her blood pH (acidity/alkalinity).

More recently, we began to add \*Sodium Bicarbonate to a nebulizer, which is used for 6 nights on and 6 nights off according to Dr Simoncini (\*<u>http://www.curenaturalicancro.com</u>). Jacinta has never needed a nebulizer. I just bought one for the purpose of the Sodium Bicarb.

We've also recently introduced alternating topical applications of; (a) DMSO and Colloidal Silver, which is rubbed over her back, and; (b) DMSO and hydrogen peroxide, which is rubbed over her front. We alternate these two topical applications, applying (a) one day, then (b) the next day, and so on.

My wife is not due for her next scan until June 2010, so I can't tell you first hand if this is working, but I have read a lot on the subject and it's well worth a shot as it's inexpensive, has no reported side effects, and my wife finds the massage comforting.

### John M, Australia 1991 – Secondary Progressive Multiple Sclerosis (SPMS) 18th June 2007- LDN

I was diagnosed with MS in 1991.

The primary symptom back then was a numb right leg.

I started on Copaxone. I could not notice any great response from this. The progression advanced over many years till about 2002. After an MRI, the Neurologist said I was in Secondary Progressive MS stage. Nothing really stopped the progression. I went on mitoxantrone. It worked well, however, I didn't want to take the full dose due to the side effects, and wanted to have a bit up my sleeve in case things went downhill rapidly at a later stage - as the drug can only be used once due to the toxicity levels associated with it.

I found out about LDN by talking to a few people. Reading the literature, it sounded promising, so I went to my neurologist and asked if he could prescribe some naltrexone. I started on the 18th June 2007. Within a week I felt as if things had halted.

On the 13th of May 2008 I learnt how to compound my own dose to give me more control over my dosage because the dosage I was on seemed to have stopped working. After talking to Ian Zagon, he said I was very sensitive to Naltrexone. Everyone's metabolism works at a different rate.

I cut my dose down to 2mg. It worked great. My progression stopped and remains this way today. The only thing that seems to be getting worse is the strength in my legs due to being inactive and in a wheel chair. Use it or lose it - but it's hard to time activities throughout the day for maximum use of your legs without getting too tired.

I call it the holy grail. No other drug has achieved these results.

### John O, UK

24 July 2000 - Secondary Progressive Multiple Sclerosis (SPMS)

February 2008 - LDN

I have secondary progressive MS and have been taking LDN for about 18 months now. It's fair to say that it has changed my life.

I am able to do so much more now and my quality of life has improved no end. I am able to stay at work and my colleagues have noted a positive improvement in my movement, etc. I am a police officer but sadly whilst it's good, the use of LDN hasn't improved things for me enough to allow me back to operational duties!

I was so enthused that whilst attending my MS physio class, I spread the word about LDN. Judging by my improvements (I was able to get on the floor and participate in floor exercises) a number of my classmates approached me on its availability and how to get it!! They now take the stuff!

Thank goodness for LDN.

### UPDATE March 2010

Yes, I still take LDN and am still reaping the benefits and long may it continue. I'm still singing its praises to friends/colleagues who suffer from MS, and sent details to a friend in Australia who was recently diagnosed.

# 90

### Jon C, UK 1986 - Secondary Progressive Multiple Sclerosis (SPMS) April 2009 - LDN

I have MS, diagnosed in 1986 and now secondary.

I took beta-interferon for 10 years until it became apparent that my MS had altered from RR to Secondary.

I have only been taking LDN for four months, having heard of it from a friend. There is no doubt whatsoever that it has improved my mental acuity, coordination, physical condition and wellbeing. I am certainly not an example of a 'miracle cure' but I have already derived definite benefit from LDN treatment.

I work as the Curator of a large collection within a major Stately Home and this treatment has certainly made it easier for me to work effectively.

Yes, I am certainly still taking LDN. Whilst not a 'miracle cure', it seems to be helping by preventing any deterioration in my MS condition. I feel noticeably better generally since starting to use it and my memory and concentration have definitely improved.

## 91

### Jon S, UK 1995 - Multiple Sclerosis July 2005 - LDN

I was diagnosed with MS in 1995. By 2000, I couldn't work full-time and had to rely on a wheelchair to get around.

I'm over 40 and a father of 3. Just getting going in the morning used to take up to an hour, and that's with help from my wife and children. At more than 6ft tall, hauling me out of bed is no mean feat.

Once I had got up, which itself could take half an hour, I was dragged to the top of the stairs because I couldn't bend my legs. I then had to shuffle down the stairs on my backside, like a child. Once downstairs, the ordeal wasn't over. I'm a writer, so I had to haul himself into a chair next to the stairs, which would then be pulled over to the computer where I'd try to focus long enough to write a few sentences.

One of the aspects of MS is not being able to concentrate and, with a family to support, that was very frightening. Also, illness takes its toll on family life. I have since split from my wife, but my children are still with me.

My neurologist only offered the two conventional types of treatment on the NHS: steroid injections which reduce inflammation, or the drug interferon, which works on MS patients' dysfunctional immune system. I wasn't keen to take more steroids as my dose was already high, and I disliked the flu-like side-effects of the conventional treatments.

I discovered a drug called Naltrexone on the internet. Anecdotal evidence indicated this to be effective in treating MS.

Within three months of taking it, I could leave my wheelchair and get about with a walking stick inside. My concentration also improved, and I got some independence back.

No drug company will apply to trial Naltrexone at a low dose for MS, because to do so they would have to invest millions to prove it's safe and works. However, the results of such trials would be of little consequence to MS sufferers like myself who don't need to be convinced.

I now move around the house on a frame and need the wheelchair only for longer outdoor trips. I hope one day I will be able to walk unaided again. Only time will tell, but in the meantime, LDN has given me something many with MS don't have - hope.

I've been getting my LDN from the USA via Dr Bob Lawrence since UK supplies of the tablets were interrupted for a while and became unavailable. My GP still won't prescribe it for me, despite endless lobbying by myself and Dr Bob. I can never be without my LDN.

More recently, I've been having Hyperbaric Oxygen Treatment at my local MS Therapy Centre, together with weekly physio, all of which I have to pay for. Currently, I cost the NHS nothing - bar one flu jab a year.

I still feel absolutely fine, but I now have to use a wheelchair every time I go outdoors. I can still drive, which means I remain useful as my youngest son's taxi service. I remain resolute in my dogged belief that not taking aggressive drugs like steroids and DMDs (disease modifying drugs) was the right choice for me.

### UPDATE March 2010

Yes, I'm still taking LDN, and yes, it is still benefiting me!

## 92

### Jonathan D, UK December 2000 - Multiple Sclerosis 4 January 2007 - LDN

From the mid nineties onwards there seemed to be something wrong. Being a sheep farmer, we suspected organophosphate poisoning as we knew of several cases in our area. I was without any rational explanation, was running out of energy with periods of very low spirits, and was from time to time suicidal.

I lost my father in 1996 and just didn't seem to pick up from that point on. There were various visits to the doctor, none of which did much good, but I do thank God that I binned the Seroxat after a few days.

It finally came to a head in the Autumn of 1999, a strange tingling on my right side and several unexplained falls, one of them on flat Tarmac. I went to the Doctor and demanded to see a specialist and was referred to a Neurologist.

I paid to go private and saw him around the 6-10th December 1999. He said, after a lengthy pause, there was definitely something wrong but he could not say what. In mid January 2000 I was admitted to the Neurology ward at The University of Wales Hospital, Cardiff. After around a week of tests, I was diagnosed with Syringomyelia and was introduced to a Neurosurgeon, Dr Vafidis, who sent me home wanting to operate as soon as possible with instructions to ring in if anything changed.

After a very hectic weekend with my children running us ragged, by the Sunday evening I found I was unable to speak. On the Monday Morning I phoned his secretary. I was admitted by 4pm and underwent a Foramen Magnum Decompression operation in February 2000. My symptoms improved greatly for a couple of months but then started to get worse again.

By August/Sept 2000 I was in a state of collapse and was carried into the University of Wales Hospital in Sept 2000. The usual range of tests ensued, such as; MRI scan, Lumbar puncture, urine retention, and one I don't remember the name of which tested my visual fields and reactions, and there were probably more that I have forgotten.

There was the customary delay in informing me that I had MS (I was told in December 2000), and then the Neuro sent me away to get on with it.

Beyond this my memory fades, a lot of water has passed under the bridge since 2000.

From the outset I was astonished by the attitude of the Neurologists who just seemed to want me to go away and get on with it. I had already had acupuncture and used essential oils for healing, I knew there were options out there to help with the MS so I went about finding things that helped me feel better and slowly made progress against the MS.

I won't detail all of the things that helped and instead will jump to December 2006 when somebody (Andy) phoned me up out of the blue, told me all about Low Dose Naltrexone (LDN) and how it had worked for him. Determined to try it, I noticed Dr Bob Lawrence's name on the internet and as he was close-by, I got in touch.

I started LDN on the 4th January 2007.

For a couple of days I was a little groggy, but almost immediately after I found my head began to clear, and hence, the brain fog of jumbled thoughts began to ease.

I didn't notice much more for a few weeks but then found my legs, which had been very wooden, were coming back to life and all of a sudden, sexual function returned. In Easter 2007 I led some French friends on a country walk in to the waterfalls country. It's quite a long walk and something I thought I would never do again. I had gone from struggling round town on two walking sticks to boldly striding out across country.

I remain fit although the MS does give kick now and again, especially if I forget to take LDN as occasionally happens, or if I overdo it. I still seem to have a problem with hot weather, so I still hide indoors when it's hot.

This description did not work out as brief as I'd hoped, but I do hope it goes a fair way to describe the most wonderful thing in my life - Low Dose Naltrexone.

Update – January 2009: I'm still doing well on LDN.

I received a letter today from my GP declining to prescribe LDN on the National Health Service - so I will be buying it on a private basis now.

#### Update – May 2010

You bet I'm still taking LDN.

My health is good, the occasional bad day and I suffered some 'winter blues', which as usual was treated with acupuncture.

I find myself now only remembering LDN every few days, even getting careless about it.

### Joyce C, USA 2001 – Hepatitis B July 2007 – LDN

I'd been waiting for years to become a mother. When I learned that within a few months I'd be flying on a plane to Asia and would finally be united with my new, wonderful 11 month old daughter, I lay awake at 3 o'clock in the morning excited about what the future held, and thinking about how to decorate my future daughter's bedroom. I wanted her to be surrounded with a special room in her new home-to-be, constantly reminded that she is loved and a precious gift from God. I remembered a picture I had just purchased with 3 Angels dancing and rejoicing with the inscription 'The Angels Danced the Day You were Born'.

That message became the inspiration for her bedroom. I wanted to write those powerful words into the wet paint on the walls of her room - symbolic of drawing those meaningful words into the fresh canvas of her heart and life. However, I had never tried cursive writing in wet paint before and did not know if it would succeed. But what did I have to lose, and it could actually work - so why not at least try it and see the results? Well, I tried it and it worked beautifully! My experience with hand painting my daughter's room is something similar to my experience with Low Dose Naltrexone (LDN), as I will share in our story of great 'Grace & Hope'.

After arriving home, my daughter Grace (not her 'real' name), underwent normal adoption blood work to check for HIV/AIDS, Hepatitis, parasites, etc. The doctor called back a few days later and asked me to sit down because she had some news to share on Grace's lab results. She had tested positive for Hepatitis B (Chronic Active). How could that be, I wondered? She had been tested for Hepatitis in the orphanage and had a clean health record. After the initial shock, I realized that she was truly a gift and we would face this disease with hope and prayers for a healing miracle.

While Grace's Hepatitis B had very little impact initially in our lives (besides routine lab results), Grace's food allergies and eczema continued to spiral downwards. From 2002 onwards, she'd developed a new food allergy every few months - and feeding her became very challenging. She became allergic to all diary, corn, soy, nuts, egg, wheat, and other fruits and vegetables. Additionally, her eczema was so severe that her skin was constantly raw and red. In 2005, I became desperate.

The conventional treatments offered by her Pediatrician, Allergist, and Dermatologist had not delivered improvement, so I started to investigate and use Complimentary and

Alternative Medicine (CAM) protocols to see if we could heal the underlying causes of the food allergies and eczema. Based on my research and additional consultations with a Functional Medicine practitioner, we concurred with adding Antioxidants, Probiotics, Essential Fatty Acids (EFA's), and liquid vitamins/minerals to her diet. (Note: Functional Medicine uses both Conventional & CAM approaches to holistically treat patients - (www.functionalmedicine.org).

These combined efforts finally started to improve my daughter's food allergies and eczema, but we also saw another benefit. Her immune system started to recognize and fight the Hepatitis B virus.

In children, due to their immature immune system, the body is often not able to mount a successful attack to totally eliminate the Hepatitis B virus. When the body's own immune system starts to fight the virus, very often the liver enzyme levels (the ALT and AST particularly) begin to rise. This is known as the 'Immune Clearance' Stage because the body's immune system is trying to 'clear' the virus.

If the liver enzymes are raised for an ongoing period of time, it can damage the liver with inflammation and scarring. It's a paradox that the good the body is doing while fighting the virus is also damaging the liver.

My daughter's liver enzymes and viral load started going up in 2006, and her liver biopsy result in Spring 2007 rated both her 'Inflammation' and 'Scarring' scores at 2 (mid-range in the scale 0-4). Her Gastroenterologist wanted to begin either Interferon treatments, or enrol her in a Pediatric Anti-Viral drug trial for a new drug, Entecavir, that was commencing within 6 months. Her doctor contacted Johns Hopkins (Baltimore, Maryland, USA) and together we determined my daughter would be a good candidate for the upcoming Entecavir Pediatric drug trial that was starting in the near future.

While waiting for the Entecavir drug trial to start I went back to the medical professional who had helped us so much over the past two years with Grace's food allergies and eczema (the Functional Medicine practitioner). She was excited about my daughter getting into the Entecavir drug trial, but when I asked her if she could think of anything that might help boost Grace's immune system prior to the trial, she mentioned 'Low Dose Naltrexone' (LDN). She'd recommended LDN for other medical conditions where the immune system needed further stimulation, with success, so she proposed LDN as a possible solution. She said I should research LDN at <a href="http://www.ldninfo.org">http://www.ldninfo.org</a>, to see if it was something we wanted to try, and left the decision to me.

For approximately 2-3 weeks, I poured over the Idninfo.org website, which had a wealth of information. LDN had been used by many patients with various conditions; Cancers, Autoimmune Diseases, and HIV/AIDS. All the info indicated it helped the immune system function properly (which is exactly what I was looking for to combat the Hepatitis B virus).

The website briefly mentioned that LDN had been successfully used in Hepatitis C patients. I also reviewed other medical research, including the National Institutes of Health (NIH) PubMed website, into the growing area of research into how opioids and opioid antagonists can positively or negatively affect the immune system (depending upon how they are used and dosage levels). I've included some of those NIH/PubMed studies at the bottom of this story as a reference, particularly those relating to the liver and Naltrexone.

One concern I had was the 'black box liver warning' for Naltrexone. I did further research into the liver warning and found the warning was based on very high doses of Naltrexone, at 300mg per day, where some liver anomalies had occurred in obese patients.

Dr Jaquelyn McCandless and other doctors had been safely administering minuscule doses of between 1mg and 3mg per day (a tiny fraction of the maximum safe dosage) to treat children with Autism. We rationalized that since LDN had been so helpful for other immune related illnesses, and the side affects were minimal (transitory sleep disturbance when starting LDN being the main side affect), and it was so inexpensive (less than a \$1 per day), that we'd like to try it. I grew eager to start LDN before the Entecavir study (to see if maybe the two together would help her).

What did we have to lose in comparison to what we might gain? But, before we started LDN, I wanted to ensure being on LDN would not preclude Grace from getting into the Entecavir Study at Johns Hopkins (because back then, we had no idea how good LDN would actually prove to be).

I spoke with our Pediatric Gastroenterologist in June 2007 to check he was okay with us trying LDN (especially as he was not the prescribing LDN doctor) and to make sure he was aware of our attempt to prime my daughter's immune system with LDN before the trial. While he didn't know if LDN would do any good, he didn't think it could do any harm, since he had other liver patients on a higher dose of Naltrexone for pruritus (severe itching caused by other liver conditions). To maintain eligibility for the trial, we agreed we'd stop the LDN once the Entecavir study actually began. I also consulted my daughter's Pediatrician to ensure she was also aware of our plans. Both doctors concurred with us trying LDN.

In July 2007 we started my daughter on a very minimal dose of 1mg Low Dose Naltrexone (LDN). Within one month of starting LDN, in August 2007, we had liver laboratory tests completed to see if LDN was having a positive result, and it was. The doctors couldn't believe how good the results were, and ordered more tests to confirm.

LDN in July 2007. We saw a remarkable decrease in liver enzymes, from ALT 196/AST 203 in May 2007 to the normal range of ALT 26/AST 38 in August 2007. Her liver enzymes were the lowest ALT/AST results we'd seen since her diagnosis in 2001.

Additionally, we saw a significant viral load reduction from 59.2 million in February 2007, to 53.3 thousand in August 2007. At that point we no longer even qualified for the Entecavir study - yippee! The Advanced Practice Pediatric Nurse who prescribed the LDN was ecstatic with the results.

Incidentally, I called my daughter's Pediatric Gastroenterologist when we got her lab results in mid-August 07. I said to the doctor, "Isn't this good news"... He responded..."No ... this is GREAT news!" We discussed that LDN appears to be resulting in similar responses as can be achieved with other anti-viral drugs.

The doctor said he had one teenager on Entecavir and this patient also saw dramatic results within the first month (similar to my daughter's impressive viral load decrease). However, the advantage of LDN was that since it wasn't an anti-viral Hepatitis B drug, but instead helped her own immune system to fight the virus, we didn't have to worry about the anti-viral resistance that can be a problem with other anti-viral drugs.

Also, if at any point the LDN stopped working in the future, we always had the option of starting anti-viral drugs (without the worry of her already building up Anti-viral drug resistance). The Gastro doctor was not the prescribing doctor of the LDN, but he said to keep on doing what we were doing because it appeared to be working!

Between the Sept 21, 2007 and Nov 15, 2007 lab results we'd stopped giving Grace some of the antioxidants we were previously using for food allergies and eczema (since those conditions had improved significantly). Because we felt this change may have accounted for the slight increase in Viral Load in Nov 2007, we resumed all supplements, and increased the LDN dose to 1.5 mg nightly.

In February 2008, 7 months into our LDN/Antioxidant protocol, Grace had Seroconverted, going from HBeAG (e Antigen positive) to HBeAG (e Antigen negative), and she'd gained the HBeAB (e Antibody positive). This was an outstanding result! These same treatment outcome results only happen in approximately 30% of children on Interferon treatments, so the above treatment may possibly compete with Interferon!

It is now July 2008. Grace's liver enzymes are still in the great range. She has maintained her HBeAG (e Antigen) seroconversion to HBeAB (e Antibody). Her Viral Load has very slightly increased from the undetectable range on 8 Feb 2008 to 551 (but this is still very, very low compared to the 59.2 Million in Feb 2007).

Over the past year (since beginning LDN in 2007), we've achieved excellent results below the max 3mg dosage level (at 1mg and then 1.5 mg nightly). While my daughter has done extremely well, we're going to increase the dose to 3mg a night, effective 17 July 2008, as she's grown considerably over the past year. The 3.0 mg dosage is believed to be the optimal dosage for children. (Note: For adults the optimal dosage target is 4.5 mg nightly to obtain the maximum benefit to the immune system.)

Besides our blessing of healing for Grace's Hepatitis, we have also seen fantastic results in her eczema and food allergies due to the multi-pronged approach of LDN with the Antioxidants, Probiotics, and Herbs we commenced in 2005. Grace has no more eczema - her skin is now like silk for the first time in her life. Additionally, her digestive tract has been healed, thus eliminating the extreme responses she had to various foods. She is now able to eat every food (in moderation) with no more allergic reaction. That is a real miracle, and as her body is better equipped to absorb nutrition from what she eats, this bonus has contributed to her improved health.

It appears that my daughter's body may have entered into the 'Immune Clearance' stage with the Antioxidants, Probiotics, Herbs, etc. we began in 2005. When LDN was added in 2007, it helped further stimulate her immune system to dramatically fight the virus. In clinical studies, Naltrexone demonstrated an increase in the body's Natural Kill Cells (which fight viruses). Therefore, I believe that LDN might also help jump start the immune system and take a child from the 'Immune Tolerant' stage to the 'Immune Clearance' stage in a safe and effective way!

The LDN website (Idninfo.org) is full of information that you can print out and give to your doctor. Also, the website has a link to the main LDN Yahoo Group where you can learn about other people's success with LDN, and find out about other 'splinter LDN groups' like mine that focus on specific diseases that LDN has benefited.

Clinical trials of LDN for other diseases (Multiple Sclerosis, Crohn's, HIV/AIDS, Fibromyalgia, etc.) have been completed (or are currently being completed) that indicate

the immune modulating effects of LDN. At this point, controlled clinical trials need be undertaken by the medical community in order to prove the efficacy, safety, and dosage recommendations for children and adults. Only when clinical trials are undertaken, will we be able to 'prove' scientifically that LDN really helps to boost the immune system in fighting the Hepatitis virus. However, we need to ask the National Institutes of Health (NIH), FDA, and others in the Medical Community to fund clinical trials for LDN and Hepatitis.

This is one of the end goals of the Yahoo Group that I recently established, 'Hepatitis Children and CAM Alternatives'. Our focus will be on informing other group members, but also documenting our treatment stories in enough detail that we can give it to medical researchers. Our group welcomes both adults and parents of children with any form of Hepatitis (B, C, Autoimmune, etc.) to join us in our journey of healing.

My daughter's Gastroenterologist, Pediatrician, as well as the prescribing APRN are all very excited to see the results we have achieved!! Her Gastro believes that there is definitely merit in conducting controlled clinical studies in LDN in Hepatitis in order to scientifically document the efficacy, safety, dosage recommendations, etc of LDN in fighting the Hepatitis virus. He will be discussing our case study with local Gastroenterologists (including a Gastro from Johns Hopkins) to discuss this possibility of initiating a clinical study. Yippee!

Also, Dr. David Gluck, who is the editor for the official LDN website (Idninfo.org) has seen my Treatment Success Report (i.e. a similar copy of this report indicating our Seroconversion, undetectable viral load, and great liver enzymes). He is going to forward our report to Dr. Leonard. B. Seeff at National Institutes of Health (NIH)/ National Institutes of Diabetes, Digestive and Kidney Diseases (hepfi.org/learning/authors/seeff.htm). In the future, when there are other LDN / Hepatitis Treatment Success Reports for other patients posted on the new Hepatitis Children and CAM Alternatives Yahoo Group, I will forward them to Dr. Gluck, who in turn will then forward them to Dr. Seeff at NIH.

I spoke with a Gastroenterologist from Johns Hopkins Medical. While her original intention was to tell me the bad news about the delayed Entecavir study that my daughter was enrolled in last year, I was happy to be able to give her the great news about our successful seroconversion. I was very grateful the doctor was willing to talk to me for 10-15 minutes about my daughter's Low Dose Naltrexone (LDN) case study, as well as the exciting research being conducted by Pennsylvania State University (PSU) / Hershey Medical Center into the impact of opioids/opioid antagonists on the immune system. She also indicated NIH is looking to do clinical research on Hepatitis and I suggested LDN as a candidate of one of the trials. So I'm willing to advocate in any way I can to get the necessary funding to research this exciting area!

I also spoke with one of the researchers at PSU / Hershey Medical Center who assisted in the LDN / Crohn's Phase I study (ncbi.nlm.nih.gov/pubmed/17222320) and is assisting in the current Phase II LDN/Crohn's study (The Effects of Naltrexone on Active Crohn's Disease) and the Pediatric LDN/Crohn's study (The Efficacy of Low Dose Naltrexone Therapy in Children With Crohn's Disease). She works in the Gastroenterology Department and was very interested in our LDN/Hepatitis B case study. They are also working on other therapies (besides LDN) for Hepatitis C.

Dr. Jill Smith is one of the prime researchers, along with Dr. Ian Zagon and others at the Hershey Medical in how opioid antagonists can help the immune system. Dr. Smith had

great words of encouragement in her following statement, as part of their Crohn's Disease Clinical Study (medscape.com/viewarticle/555290):

"... "We do not understand the entire mechanism by which the opioid antagonists work to help Crohn's disease, but our basic science studies suggest that the low dose naltrexone increases endogenous enkephalins and endorphins, and these in turn improve (rather than suppress) immunity and cause healing of ulcerated mucosa," Dr. Jill P. Smith from Pennsylvania State University College of Medicine in Hershey told Reuters Health ... Dr. Smith added, "I believe the main point for physicians and patients is to have hope that perhaps a new era of treatment may be on the horizon, an era of biotherapy that may improve and restore health and healing to the bowel and not at the expense of harming the body's natural immunity." ... '

I have forwarded an email to the doctor at Johns Hopkins, the researching doctors/nurse at Hershey Medical Center, and my local Gastroenterologist trying to garner further interest in initiating a clinical trial for LDN. I included a number of web links to sites discussing LDN.

Additionally, we have sent our Case Study to National Institutes of Health, Johns Hopkins, and Pennsylvania State University/Hershey Medical Center in order to further spur interest in LDN and Hepatitis research.

We are truly grateful, appreciative, and awestruck by this miracle and have been blessed by God's mercy in this welcome healing! I personally believe LDN may be a safe, viable alternative to the current limited drugs that are available for children (as well as adults) with Hepatitis and other immune related diseases.

Every day my daughter is reminded when she enters her room (with the hand painted walls) that she is a precious gift and 'The Angels Danced the Day You Were Born'. I'm glad that I was willing to try something different - her room turned out beautifully. Maybe you could say I 'saw the handwriting on the wall', and chose to try something different (LDN) to help her immune system. LDN's results have also turned out beautifully!

Update: June 2009: We have continued our success on LDN with my daughter's Hepatitis B – her sero-conversion of the 'BeAG' 'e' Antigen) and gaining the 'BeAB' e Antibody) has been maintained over the past 18 months. Additionally, her viral load is undetectable, and her liver enzymes are in the normal range.

On the Hepatitis\_Children\_and\_CAM\_Alternatives Yahoo Group, we now have 121 members. Of these, 10 Members with Hepatitis C, 2 Members with Hepatitis B, and 1 Member with Auto-immune Hepatitis have started using LDN. Thus far, every person who has tried LDN has seen improvement in their condition once lab results have been taken after starting LDN (either by reducing liver enzymes and/or viral load). We are excited with the possibilities that LDN offers to the Hepatitis community...

I will continue to advocate for funding for LDN and Hepatitis...it offers a great possibility as an alternative, affordable treatment in our fight to slay the dragon!

I went to the Hepatitis B Foundation Patient 'B Informed' Conference on 26-27 June 2009, shared this Hepatitis B case study among patients and doctors, and promoted the need for LDN trials. Additionally, I shared the LDN success of two other members of the Hepatitis\_Children\_and\_CAM\_Alternatives Yahoo Group who have seen dramatic results in the liver lab results for their Hepatitis C.

Three Cheers for Answered Prayers & LDN! ~~

### Update April 2010

I'm working a lot more now so by the time I get home I don't have much time to write.

My daughter is still doing well and is still on LDN, but also because she's been well, we haven't had to have lab tests done over the past year.

It is time for us to do them again, so I hope to get them done within the next couple of weeks.

## 94

Judy H, USA October 1995 - Fibromyalgia 21 January 2009 - LDN

I was diagnosed with Fibromyalgia in the fall of 1995. I woke up one morning and was in so much pain I couldn't move. I was very lucky however, because my physician was familiar with Fibromyalgia and diagnosed me right away. Unfortunately, all the medications he put me on either gave me bad side effects or didn't help at all.

I think I may have been predisposed to have Fibromyalgia because of genetics, but I know the stresses of life and various illnesses may have contributed also. My mother was a type 1 diabetic when she got pregnant with me. She had been diagnosed when she was 18 and was 24 when I was born. That meant that I weighed 9 lbs 10 oz and was born insulin dependent. Memories of my childhood include many times when mom would pass out because of difficulties with keeping her blood sugars level. Later a doctor actually asked her if he could tell her story at a medical conference because of the type of diabetes she had. He explained that sometimes her body would produce insulin and sometimes it wouldn't.

Even with all her health problems, mom tried to be a good mother. And my father, a minister, tried to be a good father. Unfortunately, I was still sexually abused by a friend's grandfather when I was five. I remember my parents being shocked when I told them, but nothing was ever said or done about it again. I felt as though I had embarrassed them by saying anything, so the second time I was sexually abused, this time by a cousin when I was eight, I didn't tell anyone. It was also around this time that I caught diphtheria and nearly died. The doctor gave me penicillin, but I had an allergic reaction to it. Somehow, however, my fever broke and I recovered.

When I was a teenager and began having my period, I would have terrible pain with it. I was also very irregular and would have them only once every two to three months. Later I found out this is a sign of endometriosis and Poly Cystic Ovary Syndrome. I've had a fighting battle with my weight all my life, but by heavy dieting and exercise I was able to get pregnant with my five children. Unfortunately, that caused a lot of yo-yo dieting which gradually made my health worse. I eventually had pancreatitis and had to have

my gall bladder removed. Then I was diagnosed as hypothyroid and put on Synthroid. I also had high blood pressure and was treated for that.

About a year after I was diagnosed with Fibromyalgia, I was diagnosed with Restless Legs Syndrome. I started taking Mirapex, which did help a little. Later a sleep study would show that I also have Periodic Limb Movement Disorder. However, the constant pain all over, numbness in feet and hands, twitching of muscles and total exhaustion of my fibromyalgia, made it nearly impossible for me to do anything. So in 1997 I applied for disability. I was turned down. I appealed. Again I was turned down. I asked for a hearing before a judge. He ordered a psychiatric examination, which I must have failed because I finally got my disability.

By the year 2000, I had gained another 100 pounds, putting my weight at over 300 pounds. I hated it and decided to have gastric bypass surgery. I did lose about 100 pounds, but the weight loss didn't help the pain from the Fibromyalgia. The extra weight had already done its damage though, and I had to have surgery on my back for spinal stenosis. Also, because of constant fever and sore throats, my tonsils were removed. Later that year, I had the endometriosis and Cystic Ovary removed.

Every time a new drug would come out for Fibromyalgia, my doctor would try it on me. It seemed, however, that the side effects always outweighed any benefits. And I had to constantly alternate pain medications because of stomach upset or other problems. Somehow I kept going, though, mostly by taking a lot of Tylenol. Unfortunately, it never did more than barely take the edge off the pain. I think I probably also had Multiple Chemical Sensitivities, but my doctor never confirmed it. And then, because I couldn't be very active, I started to regain much of the weight I had lost from the bypass surgery. Even though it seemed as though my health continued to deteriorate, I didn't give up. But I did decide I would just have to learn to live with my life the way it was.

In 2007, I nearly died from double pneumonia. It really scared me. I determined I had to do something more about my health. I went on the internet and tried to learn everything I could about the new advances in Fibromyalgia and healthy living. About this time I heard about phytonutrients and began to take a supplement that contained them. I started to feel a little better. Next I started the Atkins diet program and totally changed my diet, cutting out gluten and sugar. I finally began losing some of my excess weight. I even began to feel better as the devastating pain wasn't quite as bad and I seemed to have slightly more energy.

Unfortunately, by this time my spine had started to deteriorate. I had two disks that slid out of place and pinched my spinal cord (Spondelolisthesis). The pain became so severe that I was put on Tramadol (Ultram). Unfortunately, I had a severe allergic reaction to it. I started sleeping 18 + hours a day, and I was so out of it when I was awake, I didn't know what was going on around me. Then my eyes and face started to swell. I tried to go cold turkey, but thought I was going to die.

My doctor's office said I would have to wean myself off Tramadol because it was an opioid drug.

Again I went on the internet, and in the process of learning how to come off Tramadol, I came across a drug called Low Dose Naltrexone.

When I discovered that Stanford University was doing a trial of LDN in Fibromyalgia patients, I printed out a stack of information about it and took it to my doctor. While he

had never heard about Naltrexone being used for Fibromyalgia, he did agree to read about it. Since I was seeing him at the time for my back problem, he said he wanted me to have my back surgery first.

I had my surgery December 4, 2008 and was finally able to walk again. When I went to see my primary physician in mid January 2009, he agreed to write a prescription for LDN. **He said he couldn't discover anything about it that would harm me.** I thus started a dose of 4.5 mg LDN at bedtime on January 21, 2009. I was hopeful that this time I had found something that would help, but I'd been disappointed so many times in the past, I was determined not to get too excited about it.

The <u>first night</u> I did fine. No dreaming, but then I couldn't remember dreaming for a long time. I did wake up a couple of times, which isn't that unusual with my Fibromyalgia pain, but I went right back to sleep. I didn't notice anything different when I got up the next morning. <u>Second night</u>, again woke up a couple of times, but this time it took about an hour each time to get back to sleep. Was having a lot of pain in my pressure points. I messaged them until they eased up, then fell back to sleep. Again didn't notice anything different during the day.

<u>Third night</u>, I woke up sweating profusely at around 3am and threw off the covers. I started to chill again after about fifteen minutes, so I pulled up the covers and went back to sleep. I wasn't sure if it was a hot flash or from the LDN. Later that afternoon, I did notice that I seemed to have more energy during the day.

On <u>day four</u>, I again woke up sweating around 3am, but it wasn't as severe as the previous night. When I got up in the morning I realized I didn't have as much stiffness as I usually do. Also, I realized that while I did still have some pain, especially in my pressure points, it wasn't as sharp.

The <u>fifth through seventh days</u> I didn't feel too bad during the day, but by evening I was totally exhausted and I started sleeping 11 to 12 hours at night. I didn't wake up in pain as many times during the night, but I did realize that I was dreaming. I didn't really remember what the dreams were about, but just remembered that I had actually had a dream.

Around the <u>tenth day</u> I realized that my morning stiffness wasn't as bad as before. And I definitely had more energy and less pain. I never expected to notice any changes so quickly.

On the <u>18th day</u> I woke up between 2-3 am and realized I had been dreaming. And this time I actually remembered the dream. I did stay awake a couple of hours afterward, but finally went back to sleep. When I woke up I felt so good, I ended up overdoing it. I actually straightened the living room and vacuumed the floor. I haven't been able to vacuum for I don't know how long. I've always had to ask my husband to do it for me. He still moved the furniture around, but I actually did the vacuuming. Of course, later I started to notice a lot of pain and exhaustion. It continued through the night and I woke up every time I turned over. However, when I woke up the next morning, I again felt pretty good. If I had tried that before, I would have been in bed for a couple of days at least.

At <u>one month</u>, I couldn't believe how much my life had changed. I had so much more energy and I felt so much better. I still had some pain but had been able to cut back on pain meds, taking them just when I needed to instead of around the clock. I still had

days where I felt exhausted and awful, and some nights where I felt like I hardly slept at all. And then there were other days where I woke up feeling like I had the best sleep of my life. Some days I didn't think the LDN was working, and then other days I was so excited because it actually felt like it was.

I could get up and not have to hold onto the wall for support. My morning stiffness and pain were at least 50% better.

One thing I didn't expect was with my restless legs. That started to get better also. I had been taking 1 mg Mirapex at about 3-4pm and then another at bedtime. Gradually, I started to forget to take it until later and later in the afternoon. So I cut that dose in half. Then I didn't need to take any in the afternoon. Then I cut the evening dose to .75 mg and finally .5 mg.

That is something I never expected to ever happen. And I think I'm even more excited about that then how I felt about my fibromyalgia getting better. The Mirapex has some very undesirable side effects, but the relief from symptoms did outweigh the problems.

Another thing I noticed was that my mind seemed clearer. I didn't have as much fibrofog as before. And most of all, I actually felt like doing things again. In fact I had to watch that I didn't overdo, because I'd start something like cleaning out a kitchen cupboard and forget to take a break.

There was an incident that happened around the <u>beginning of the second month</u> that made me really realize how LDN works.

I caught a very nasty bug of some kind. When I was at my sickest, I woke up two hours after I went to bed and it would feel as though my body's immune system had completely closed down. I felt horrible. I'd stay awake for a couple of hours and then finally drop off to sleep. When I woke up I felt so much better, like my body was fighting off the infection and I was mostly just tired. Then, gradually through the day, I would start to feel worse again. This happened for about 4 days in a row.

My husband kept telling me I should go the doctor, but every day I kept saying I didn't really feel that I needed to. Usually, I would have to get antibiotics when I had something like this, but this time I didn't need to. Amazing. Of course I loaded myself up with vitamins and drank lots of fresh juice, too.

As I write this, I've been on LDN for almost six months. I have come from having daily pain levels of 5-7 to 2-4. I still have to pace myself, but I have so much more energy. In the last 2 months I haven't had to use my walker once. I usually sleep through the night, waking normally after about 8 hours. I had fasting labs drawn that said my liver, kidney and thyroid function are normal. I rarely need to take any pain medication. I would have to say that I feel 70-80% better overall.

For me, I can't say anything bad about the LDN. I think everyone with Fibromyalgia should definitely give LDN a try. What do you have to lose?

### UPDATE April 2010

Yes I'm still taking LDN, and yes, I am still feeling the benefits.

After one year on LDN I have 80% improvement in all my Fibromyalgia symptoms. My

pain levels have dropped significantly from a daily average of 6-8 to 0-2. When I began LDN I was taking 4 other medications. I've been able to eliminate two of those drugs, and of the remaining two, I've reduced my dose to one half and one quarter respectively.

I call LDN my life-saver.

## 95

### Kacey J, UK 2003 – Multiple Sclerosis 2003 - LDN

From homeless drug addict to having my work hung in the Tate Modern art gallery, and meeting Prince Charles!

My name is Kacey and I am in my early thirties. To look at me, you might not guess that I have been a drug addict. You might not guess that I have been in trouble with the police in the past. You wouldn't think I met HRH Prince Charles either.

I had a great childhood until my parents split up when I was 10. My sister, my brother and I had to move with our Mum to an area in London where we didn't know anyone. My Dad and I had been very close in the past, but when this happened it broke that fatherdaughter bond we had.

I was pulled out of a school I loved where I had loads of friends and placed into a school where I was the 'new kid' and I stood out like a sore thumb because I was so much taller than anyone else. I was bullied- for my weight, and also because I had learning difficulties.

So I tried to fit in with people by playing the joker and giving the teachers at school a hard time. Being the class clown stopped most of the nasty comments - at least from the other kids. The teachers were another matter. My teachers 'encouraged' me by saying stuff like, "Why can't you be more like your sister?" My sister and I are two very different people. She was always the 'good one'; the one who was destined for 'big things'. What did they predict for my future? 'Encouraging' things, such as "You will be dead by 18".

I felt like I was nothing. By the time I was 11 I was smoking cigarettes to fit in with the older kids that I was hanging around with, and because someone told me they would make me lose weight. Not long after that I moved onto smoking cannabis because someone told me it would make me forget what was going on around me.

One bad drug leads to another and I went on to experiment with more illegal drugs as well as getting alcohol poisoning when I was 12; although thankfully that put me off it for life! I ended up getting kicked out of school permanently, and by then, I was so far off the rails no other school in the country would take me. Social services thought it best to put me into the care of Barnardos.

Barnardos had a place in Wokingham in Berkshire where there was a school in the middle of the grounds and six houses that were called units where the kids would live. I lived in a house with 11 boys and 2 girls. The staff at Barnados had me figured out in a positive way from day one and helped me discover a lot of my talents such as photography. They even got me work experience at a local newspaper.

I left Barnardos when I was 17. I didn't go back to London because I didn't want to fall into the traps of my old life. There was nothing there for me anymore. I started my independent life homeless. I was in a hostel for young homeless people and claiming benefits. I got £65.00 every two weeks to survive on.

I started going to college. It was costing me £25.00 a week to get to college, so I was left with only £15 every two weeks to buy food, buy cigarettes and whatever else I needed. Even if I had managed to find a job, I would have had to pay £100 per week rent for the hostel and council tax of £50 a month, not forgetting all the other things, such as food - but who was going to employ me? I felt trapped, so I stopped going to college and once again fell back into my old habits.

When I was 19, I decided to get away from the area and its problems completely, and moved to Bedford... but I knew nobody so I was back to being 'the new kid' and once again found myself hanging around with the 'wrong kind' of people. I was homeless and sleeping on the streets. Sometimes if I was lucky and there was a bed available I slept in the night shelter, and sometimes I slept under a bridge.

By now I had developed a habit of developing a habit to try to escape what I was going through, but this time I turned to a much harder drug; heroin.

Drugs like heroin don't come cheap and I ended up getting into trouble with the police and went to court for a burglary. I was lucky because I should have gone to prison but didn't. This really woke me up and I got myself into the YMCA in Bedford. It was like a second chance really. It scared me enough to sort myself out. I got myself clean. I have been clean for 10 years now.

I got myself a flat and then even got into a happy relationship. I felt I took a lot from society when I was on drugs and wanted to give something back, so I started raising money for the NSPCC and took an active role in PLANB (Peer Led Active Network Bedfordshire) - going into schools. I was also an active member of the Pilgrims Housing Association residents' board, arguing for better social housing conditions.

Then I got involved with the Princes Trust and went on a 'Sound Live' music course, working with people who have worked for the really big names, like Tina Turner and the So Solid Crew! I was also given a development award, which funded my first 'proper' camera and started my photography career in earnest.

The Princes Trust also helped me with putting together an art exhibition called 'Running with the Herd', which was about drugs and how they have affected people in Bedford. One of the visitors to that exhibition invited me to meet her at her office - she turned out to be the owner of a large, well-known recruitment agency and provided the funding for me to produce my booklet 'Running with the Herd'!

Life was suddenly good! I started talking to the trust about setting up a business as a photographer and they gave me a grant to do this. I was so grateful that I wrote to

Prince Charles thanking him and I also cheekily asked if I may photograph him. Can you believe, he wrote back within a week! He wrote 'yes, he would love to meet me'.

In November 2003, I was granted a private meeting with the Prince and was allowed to take his photograph for my portfolio!

Life went from good to great! The following month, in December 2003, one of my photos was displayed in the Millennium Commission exhibition at the Tate Modern. I didn't know at the time that the Tate Modern is a famous art gallery and that work by artists like Dali, Monet and Picasso were in there! The exhibition was created to celebrate the projects which had been achieved with National Lottery funding ... Ms Jones used her award to create a photographic exhibition and website promoting drug awareness' (quoted from BBC news website)

Because of all the attention in the press I was getting, I was invited to the MoBO awards to take photos. I told you life was good and great, but there was, however; some bad news for me at this time... something that was going to change my life forever.

In the last months of 2003 I was diagnosed with Multiple Sclerosis. Multiple Sclerosis (MS) is the most common disabling neurological condition affecting young adults. Around 85,000 people in the UK have MS. MS affects the ability of nerve cells in the brain and spinal cord to communicate with each other - symptoms such as being tired all the time, having problems with co-ordination, and memory lapses (among others) will affect me for the rest of my life...

Despite this major set-back to my health, I continued in my quest to change my world.

In May 08 and 09 I was an 'Adult Achiever' finalist at the annual 'Pride in Bedford' Awards. Many were nominated because they have shown great bravery, the ability to care for others above themselves, or their desire to improve their community whatever the odds.

In November 08, I released my first track on download, called 'Tightrope'. It went straight to No.1 and stayed for 3 weeks!

In conclusion there is so much more to my story. The next project I would like to do is to help raise awareness of LDN, a medicine that has helped me back on the road to recovery, and I plan to write, record and release a single in the near future for The LDN Research Trust. It's something I feel that is very important to share with the world as I believe it would benefit others.

### Karen G, UK June 1996 - Multiple Sclerosis June 2009 - LDN

Approximately 20 years ago, in my mid twenties, I was diagnosed with optic neuritis. I was sent home from Moorfield's eye hospital in London and told to "stop wasting the doctor's time", and to "go home and clean your eye with a cotton bud". But I was fortunate to have private health care where I worked and was soon booked in for a CT scan.

I had regular check-ups from then on at Moorfield's, but Multiple Sclerosis was never mentioned as a possible diagnosis, and although my left eye was affected, I was neither worried nor concerned.

At the beginning of 1995 I was having a lunch break at work, and I can remember telling a colleague that my feet felt weird. It's hard to explain the sensation; I was walking in a perfectly normal way, but my feet didn't feel as though they were touching the ground. I took this as a one-off thing and gave it no further thought at the time.

Within days however; areas of numbness had increased and the episodes lasted longer. I saw my GP but it was totally useless: She stuck needles into my legs and said there was nothing wrong with my circulation. As time progressed, so did my numbness. After several months of seeing my GP, my legs had begun to weaken and would often be without feeling from my knees to my thighs. On my last visit to my GP I insisted to be referred to my local hospital as I'd had a couple of experiences of my tummy being numb.

My first hospital appointment was in December 1995. I had wasted 9 months with a hopeless GP and 2 months waiting for my hospital appointment.

I saw a really nice (shock, horror) neurologist who suspected I had something wrong with the back of my brain. I remember my mum and I laughing – we thought it was funny! I had some blood tests and was booked in for an MRI scan later that month.

In January 1996 I was sent for an Evoked Potential test and was told I would get all my test results at an outpatient clinic in March '96.

At this time I still had no serious concerns, although my legs were getting weaker and they sometimes gave way on me. I naively thought that if there was anything seriously wrong with me, there would be some form of medication prescribed to me.

Shortly after the Evoked Potential test I received a letter telling me that my March appointment to discuss my test results had been cancelled and had been rescheduled for June '96. Although I was annoyed, I still had no worries; after all, if there was something wrong my appointment wouldn't have been cancelled...

On 8th May 1996, my mum had an operation at the same hospital I was under the care

of. She had breast reconstruction surgery after having lost a breast to cancer many years ago.

On Friday, 10th May my whole world was turned upside down by one phone call. My lovely, wonderful mum, my best friend, had suffered a massive heart attack due to a pulmonary embolism. Somehow I got to the hospital where I spent the next 30 hours with my mum whilst she was on a life support machine in intensive care.

On Saturday, 11th May, my mum's machine was switched off. She was severely brain damaged. She was just 59 years old.

Around 3 weeks later I had to go back to the same hospital for my neurological results. To say how difficult it was to enter the hospital cannot be described. I couldn't think straight and felt zombie-like after the sudden death of my mum, and my recollections regarding this particular appointment are pretty vague.

I do remember, however; that the neurologist was very arrogant and somewhat rude. He asked if I lived alone, if I had children or close family, then flippantly told me I had MS. I'd heard of MS, but I didn't know what it was. The neuro looked serious so I asked him if it could kill me and he said, 'Yes, it can'.

He mentioned a lumbar puncture (LP), which he wanted done at the same hospital. I recall sobbing uncontrollably, trying in between to explain that I'd recently lost my mum in that same hospital and therefore, flatly refused to have the LP. He gave me no further information, but said I had to have some x-rays. I realised how serious the situation was and became angry, demanding to know why my original appointment had been cancelled. Didn't they think it was important enough to tell me I had MS? Why did my appointment get put back by 3 months?

I know without any doubt that if my mum had known I had MS she would never have gone ahead with her operation.

Unbeknown to me at the time, this was to be the beginning of 14 years of hell of dealing with neurologists. From then on it was the same with every neuro I had the displeasure to meet. Their manner and extreme arrogance never failed to amaze me, and every appointment would result in a heated argument and/or me leaving in tears.

In 1999 I was offered Beta Interferon, but as I was trying to conceive this had to go on hold. I was told to return for another appointment in 12 months regardless of whether I'd fallen pregnant or given birth in that time.

In 2000 I gave birth to my gorgeous son and I was the happiest person in the world as I'd always wanted children. Sadly it wasn't easy for me to conceive, but luckily I found the best fertility doctor one could wish for, and we remain friends to this day.

My happiness was heavily edged with great sadness; how I wished my mum could have been with me when my son was born.

At this time I was still able to walk, albeit not brilliantly, but I managed with the help of a walking stick, pram, or someone's arm.

When my son was 2 months old my MS flared up tremendously. I was unable to walk at all and had to crawl everywhere. I telephoned the hospital to see if I could begin taking

Beta Interferon only to be told that it had been banned by the PCT (Primary Care Trust). The reason? It was too expensive. Instead I had a 3-day course of steroids administered via an IV. This treatment didn't help in any way at all. In time I did regain the ability to walk but could only manage short distances – I couldn't walk unaided.

So life went on, and by no means was it easy. I was a single parent, and although my son was a happy, contented baby, he was diagnosed with having glue ear in 2002.

In October, 2002 I underwent a full hysterectomy. That was when I found out my son had glue ear in both ears and not just one as thought previously. Three weeks after my operation I took my son to a private consultant in central London. The consultant told me within seconds that he was 50% deaf and he was livid that my GP had refused to refer him for treatment earlier.

Had it been left any longer, it would have caused permanent ear damage. Fortunately, I only had to pay the consultation fee. The consultant was kind enough to do his ear op on the NHS, and what a great job he did!! Within one hour of the grommets being inserted my son was talking! It really was music to my ears!

In 2003 I met my present partner and happily moved from London the following year. We live in a bungalow and so have no stairs to worry about!!

Then in August 2006 I foolishly travelled to Rotterdam for stem cell treatment, which I now know was a money spinning scam by a lying, greedy conman. I'm unable to comment any further on this as the so-called 'doctor' is currently under investigation by the GMC. Suffice to say, this man has made my life a misery along with the others he has conned. It beggars belief what some people are prepared to do to desperate, vulnerable people.

This now brings me to LDN...

When and how I heard of LDN I really can't remember, but I can only presume it was through the internet.

One thing I DO know is how much it has helped me in the 9 months I have been taking it. In fact I can't stress enough how good it is. It's absolutely fantastic and I could not face life without it now.

My GP still flatly refuses to discuss it and will not prescribe it to me, whereas my pharmacist has been dispensing it for several years and says it's 'simply brilliant'.

Prior to beginning LDN I often wished I could simply die in my sleep. My quality of life was at zero, but, as I'm a mum I'd resigned myself to the fact that... ok, I couldn't walk, but I could see my handsome son every day, watching him grow, watching him learn etc.

My son is now 10, and my having MS has, without doubt, affected him a lot. He has no confidence, very low self-esteem, and is a very deep thinking child. He worries about me as I worry about him.

I used to fall frequently and was constantly covered in painful bruises. I tend to bruise and bleed easily due to the medication I take since being diagnosed with APS – Antiphospholipid syndrome in 2007. I've lost count of how many times I've called an

ambulance to get me off the floor. At one stage I called 6 ambulances within the space of 2 weeks. Worst of all, 90% of the time, my son was around to see all this.

I am now happy, pleased, proud, in fact over the moon to say that since taking LDN I haven't fallen once!! For somebody whose legs were like jelly, that in itself is a major feat.

I am now able to STAND UP, with only the support of my scooter. My legs no longer collapse from underneath me or shake uncontrollably. It's great because I feel so tall. I'd lost any perspective of my height after sitting for the best part of 4 years.

I'm 5ft 7" but feel like a giant when I stand. In the past week I've managed to get off the toilet by myself with no problem whatsoever. I haven't been able to do this for about 2 years, so to me it's a major feat. I also have the feeling of general well being. So many people have commented on how much better I look. I quickly tell them it's all down to 'my little wonder drug'... LDN!!

For any sceptics reading this, I can assure you this is NOT a placebo effect. I know what my body is and isn't capable of doing. Nobody who suffers with progressive MS can make their body do something it hasn't been capable of doing for such a long time.

I am a great believer in LDN, not only because of the improvements I've been lucky enough to have but for all the other people it helps and there are so many others. I have read countless stories and they are so inspirational.

It's wrong and sad that NICE will not pass LDN as a licensed drug, not only for MS sufferers but for those with many other illnesses. Considering it's such a cheap medication with only good side effects I think NICE should definitely be renamed.

Why are we being denied something which is cheap and effective?

It's 2010... why can't we say what medication we want? I suspect it has a lot to do with the big drug companies – of course they do not want to miss out on making ridiculous amounts of money. A proportion of the blame must lie with the so-called experts, those calling themselves neurologists, whereas the government must be held accountable for the final decision.

LDN has proven effective for too many patients for too many times to be ignored any longer.

Paracetamol hasn't been proven in any medical trials but I don't know of anybody who hasn't used it.

I wrote this account a couple of days ago and was going to end by saying that I am confident I'll be able to take a few steps within the next 6 months.

Well I'm ecstatic to tell you that tonight I WALKED 2 STEPS!!!

### 97

#### Karen H, USA July 2005 - Rheumatoid Arthritis (RA) October 2009 – LDN

I started having problems right after having moved into my dream home in St Louis, MO and finding out 3 weeks later that I had to move to lowa or loose my job. I was told my company was closing down the site that I had just transferred to. Also, at that time my partner of 7 years started drinking heavily again and I had to call police several times to get him out of my home. Long story short... I sold my home, made several trips to lowa, found a sort of suitable home, and moved in the middle of an extremely cold winter.

I never wanted to live in Iowa, found I'd moved into a 'bad' section of town and was terrified due to noticeable drug activity in the neighborhood. After about a week of living in my new home I started having excruciating pain in my legs. It was so bad that I would scream out loud in my home because the pain was so bad (I do not usually show such high emotions).

I even called the ambulance once, but by time they got there the pain had subsided and I felt stupid. A few days later I drove to the hospital. They did a doppler and could see I was in pain. My blood pressure spiked. My pressure began to return to normal after the pain subsided. No one could figure out what was going on with me. This went on for a few weeks, then disappeared as mysteriously as it had come on.

Then a few weeks later I was blow drying my hair. Somehow my hair was blown into my eyes and it hurt/stung pretty badly. The pain subsided and I went to work. My eyes felt a little weird but I went on without thinking too much of it. The next morning I woke up with a bad pain in my eye and noticed that I was having trouble with light sensitivity. I thought maybe I had pink eye (because I'd never had any problems with my eyes prior to this). So I found an ophthalmologist, who in turn said I had 'Iritis'. She sent me to a GP who ran lots of tests to see if I had an autoimmune disease.

It took about 4 months of steroid drops and loads of trips to the doctors and the ophthalmologist, but the Iritis was cured and I didn't have any signs of autoimmune disease. I chalked it all up to stress and went on with my life.

I never liked lowa so I transferred back to St Louis as soon as I could find a job there. I had to find another home, did, then settled into my new job. At the same time my Aunt (who lived about 150 miles away) became extremely ill and had to be hospitalised at a local hospital. Since I was the only close family member she had, I made loads of trips to the hospital after work and took time off for her surgeries etc.

This wore me out completely. I found a great Cardiologist and GP. They listened to all the symptoms I was having: I felt fatigued, had muscles jumping all the time, couldn't sleep, had joint pains, swollen ankles, an unbelievable amount of stress for the last several years, and on and on the list went.

I was worried he would tell me the same thing all the other doctors told me... that it was

just depression. I knew I wasn't depressed as I still went out. I didn't sleep too much but I loved getting out... just didn't have any energy and was gaining weight even though I wasn't eating much.

I told him I thought I had Fibromyalgia (two family members have it). He said he thought it was Rheumatoid Arthritis (RA). Sure enough the tests revealed RA. He referred me to his colleague in the same practice, and she put me on the so-called easier drugs of asulfidine, and something else.

Well, the asulfidine turned my skin a beautiful shade of red within a few weeks and caused liver damage. I also began to find out what having RA meant, and I was terrified. I could not find any information on how to help it naturally, so I felt that I had to try to trust my doctor and follow her advice. My Aunt died around that time as well.

It was all so much for me, being away from my partner, being many miles away from any living family members, no friends since I had just moved here, a stressful job, and finding out that I had a crippling disease for which I had to take deadly medicines... it was all just too much on top of each other.

I went out on disability for 6 weeks. I also started taking methotrexate (a chemotherapy drug), and steroids, and my doctor wanted me to start taking Humira shots as well (I am deathly afraid of needles). I resisted taking the Humira shots and began researching all that I could about RA. I read about an anti-inflammatory diet and began that. But my pain was getting worse on the chemo and steroids, so I started having acupuncture and found a wonderful chiropractor.

That helped some, but I was spiralling downward fast, so I started looking at disability websites and tried to find senior housing because there was no way I could continue to take care of myself, my cat and the house. I felt like I was 50 going on 85. I even started taking anti-anxiety drugs to help me get through the days.

At one point I was seeing 3 different doctors and counsellors each month, getting labs at least once a month, and taking approximately 7 or 8 different medications, many of which were to counteract the Methotrexate and steroid side effects.

Then my lung partially collapsed, and after that I fell the day after having a minor surgical procedure and broke my hand. I had never broken a bone in my entire life! Tests on my lung showed I had several lung nodules, and I found out I had sleep apnoea, and had gained a lot more weight. This just kept getting better and better. When would this madness stop? I had to find another way to deal with this disease.

I read about Dr Brown's Antibiotic Protocol, and was surprised when my doctor agreed to give me the antibiotics. As I had to have another surgery, I had to wean off the Methotexate and steroids, which was convenient. After surgery I didn't go back on the methotrexate or the steroids, but instead followed Dr Brown's protocol and the recommended diet.

That worked for quite a while. I was feeling much better than on the other drugs and my pain was very manageable. Unfortunately, I still had huge issues with fatigue. I began to think I also had chronic fatigue syndrome. Instead, I was diagnosed as having Candida.

I found an Environmental Doctor who said I had a deep case of Candida and put me on

Nystatin and a Candida diet. That was in November of 2008. I was still taking the antibiotics up until February 2009, then stopped because it was interfering with getting rid of the Candida. The doctor then put me on thyroid medications and they helped clear the mental fog I'd been having. I began to process thoughts better and was better able to comprehend things. I understood much more than I'd been able to for years.

I'd been so bad I wondered how I'd managed to stay employed during that time. I had always been rather sharp but the last few years I could barely carry on a conversation. I forgot words, couldn't remember anything, missed appointments, and my chemical sensitivities were getting worse.

The newspaper bothered me. Anything artificial bothered me. I started avoiding most stores, especially shoe stores and tyre stores. I couldn't walk down the laundry detergent aisle, and god forbid if I got anywhere near the pesticide aisle in the supermarket... I'd get really sick. Even though I was lonely I didn't have the energy to meet people, and when I did meet people I liked, I didn't have the energy to keep up a friendship.

Anyway, as I said, getting on the thyroid meds made a big difference, but by now I wasn't doing anything for my RA disease, and that bothered me. I wasn't having a lot of pain, but it was getting somewhat worse and my fingers had started to turn... so I was worried that the disease would cause them to become more deformed. Plus, the hips and shoulders were bothering me much more.

Unfortunately I also ran out of money, and the Environmental Doctor did not take insurance, so I found a homeopathic/naturopath on my insurance plan who agreed to keep me on the Nystatin and the thyroid medications. She also gave me some homeopathic drugs to help with the pain, and B12 shots.

About that time I stumbled across the LDN website. I read up everything I could, printed out information, then called the Naturopath to make an appointment. I told her what I had read about, and as I started to hand her the papers she said she had a patient on it and he was doing well. Oh joy!!!

She wrote me a script in August 2009 for 1.5mg LDN. LDN has made all the difference in my life! As at October 5 2009 my LDN dose was raised to 3mg after almost 2 months on 1.5mg. So far many of my co-workers have stated that I look like I am getting well! I tell you, I have looked like death warmed over for at least 5 or 6 years! So this comment is a great compliment to me!

My grey hair seems to be getting darker... don't know why, but it is. My mind is much clearer than with the thyroid medicines alone. My energy levels are much better. I'm no longer having fits trying to stay awake at 2 or 3pm each afternoon.

My ankles don't swell anymore! My feet don't look like swollen sausages, and there are spaces between my toes! I have lost almost 20 pounds without even trying. I don't have as much pain, I don't get out of breath like I used to. I feel like a human being. I haven't had any problems with vivid dreaming or nightmares. The swellings under my arms are going down. I don't feel like my body is toxic anymore.

I kept telling my doctors that I felt toxic all over, and they looked at me like I was nuts. But I don't feel that way now. I do have some issues with being unable to fall asleep, and with constipation, but compared to a collapsed lung and liver damage I can

handle these 2 minor side effects. I did notice that my symptoms got worse when I first started the drug, but I was aware that might happen and did not worry. It occurred again for a few days when my dose went up but I was ready for it.

I feel like a real human again. I'm out every night now running errands and doing things after work that I only dreamed about before. I can walk longer than I have been able to in years and I don't pay a price for it the next day. My stamina is not where I would like it to be but I have been inactive these last 6-7 years, so I know that will build with time. I just have to keep building my stamina up little by little, day by day. I'm no longer fighting sleepiness in the afternoons, and I'm happier than I have been in ages. And... I'm beginning to have confidence in myself again.

My house is cleaner! Yeah! I don't wake up stiff anymore. The real test will be this winter. The cold has been pure hell in previous years. I feel warmer this year already, probably due to the thyroid medications, but I'm very hopeful that I will get through the winter much easier than before.

Oh and the best part... I only take the LDN and my thyroid medicines. I don't have to see 3-5 doctors every month and Lab tests are not prescribed every month, because LDN is not toxic to my system. I'm saving money because the LDN is way cheaper than all the other medicines I've been on. The hard part is finding a compounding pharmacy that can make the LDN. The nearest pharmacy is about 40 miles from my house but I gladly make the trip once a month!

I'm so grateful to this drug and to having my life back! I hope you too can use this successfully. I know it isn't a very long time that I've been on this drug, but even my Naturopath said at our last meeting she could not get over how good I looked! She said up until the last visit the fatigue was written all over my face! She is as excited about this as I am!

As a January 2010 update, I'm taking 90mg porcine thyroid, 900mg ALA, a multivitamin, Vit D3, magnesium, and calcium daily along with the LDN.

I still have some pains in hands and elsewhere occasionally; however, this has been the easiest winter I have had since diagnosed. Usually I am in such pain I can't do much. But I have been out hiking looking for eagles, replaced my bathroom sink all by myself (I couldn't hold a wrench in my hand before), my house is much more tidy. I've been going out after work and enjoying myself, and I am happy.

Before being diagnosed I used to do all kinds of things around the house but with this disease I would hurt way too much and was so exhausted I didn't even want to try. Now the only thing that is holding me back is that I still have to build up my strength and stamina, but I am making progress everyday. I actually was able to use my leaf blower for over 2 hours and wasn't exhausted or in pain afterward.

I think back to the days that I had to ask someone to please open the plastic surrounding the spoon at the cafeteria, or use scissors to open the energy bar that I wanted to eat. Or how I could barely get dressed every morning without thinking how much I wish I could just crawl back into bed. Now I am on the go all the time and have the energy to stay on the go. I know that I do still have limitations due to this disease but it's not nearly as limiting as before.

The Rheumy stated that there is no way that LDN could help me and that he would highly recommend that I take Enbril or start on some other standard protocol for RA. I told him that I was really sorry he felt that way. I had hoped he would be willing to work with my Naturopath in keeping my disease at bay more naturally. But since he could not fathom that idea that I would continue just seeing my Naturopath as she is the only one who has helped me get better. Oh, and did I mention I have lost over 20 pounds since starting on the LDN?

It feels great to have hope for my future and to know I can have a life in my own home. I haven't looked at any more nursing homes since November! And I am not reading up on how to qualify for disability! Instead I am looking at classes on how to lay tile flooring, which will be my next project in my home! I know I will have the energy to do the job and my hands will work well enough to be able to do what I have to do.

I have been on the LDN now since October 2009 and am still feeling well. I went to see a new Rheumatologist who did not believe I had RA because upon a thorough exam he could not find any physical signs of the disease! Yeah!

### 98

#### Kathryn R, UK Jan 2005 – Multiple Sclerosis 10 February 2009 - LDN

Life before taking LDN was becoming virtually impossible. I am now 62, and it is dreadful to think how young people cope with it.

I have had a very good life, but it was becoming increasingly difficult and even though I could see no future, I WOULD NOT GIVE UP.

I was diagnosed with Multiple Sclerosis around the end of 2004, beginning of 2005. Around that time I had begun to see an herbalist in desperation. He was very good, but he was unhappy with my walking ability.

He asked me to go back to my GP, who sent me to the hospital I'd worked at for 10 years as a Phlebotomist. I attended the clinic there several times, but it was an older Irish doctor who sent me to WALTON in Liverpool. There I had a lumbar puncture and Multiple Sclerosis was discovered.

Before taking LDN I was obviously deteriorating, but since taking LDN there has been a vast improvement. At the time of writing, I've been taking LDN for 7 months. I'm still wheelchair bound, but I'm hoping to be able to use my walker to go into the garden, and then I'll really feel I've achieved something.

I was taking the liquid preparation, but now I take the compounded capsules because they're more convenient. It's expensive for me as a pensioner, so I'd like to see it available through the NHS. I have to go to e-med to get a prescription, and the LDN is sent from Scotland. Life could be made easier if my GP and Neurologist would prescribe it, but I feel I must continue taking it as it has been improving my health.

It is now late January 2010, and as at 10<sup>th</sup> February, I'll have been on LDN for one year. I'm still here. My husband pays £90 per quarter for the LDN privately. It's a disgrace. Obviously, being 62, I have no time to lose. It's definitely helping. Though I'm still wheelchair bound, I now do 100 exercises every morning, which I could not have done before LDN. I'm hoping this year to be able to get out into the garden with my walker!! Positive thinking... ALWAYS. Never give up. I'm confident they will find a cure. If I wasn't on LDN, I know I would be much worse.

### 99

#### Kathy R, UK Sept 2001 – Primary Progressive Multiple Sclerosis (PPMS) July 2006 – LDN

I started taking LDN approximately 3 years ago, after reading about it in the 'New Pathways' magazine, then researching it on the internet. My doctor initially prescribed, and continues to prescribe, Naltrexone in the full 50mg dose. My husband crushes a 50mg tablet to fine powder between two spoons, then divides it into approx. 4.5mg doses, each of which he wraps in marzipan. I take one every night just before bedtime.

I have PPMS and since taking LDN my condition has remained stable, I suffered terribly with 'restless legs' at night. Now my restless legs are a thing of the past. My balance has also improved. I used to fall almost daily, and sometimes more than once.

## 100

#### Kelli B, Australia 18 Sept 2006 – Relapsing Remitting Multiple Sclerosis (RRMS) 16 May 2007 – LDN

I was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) on 18th Sept 2006, after 2 confirmed 'attacks' that took place 2 years apart... then had a 3rd attack about 6 months after diagnosis, around March 2007.

On the recommendation of my Neurologist, soon after diagnosis in October 2006 I began Immunotherapy, specifically; Betaferon, which wasn't as bad or 'painful' as I'd expected but was extremely uncomfortable. I didn't stay on it long though.

I had booked a trip to Thailand for December of 2006. I was aware that it was quite safe to travel with my medication, providing I had a letter from my neurologist and my medication was stored below the correct temperature at all times. But I honestly could not be bothered with the hassle of arranging another Neurologist appointment (how hard are they to organise quickly, right !!?). Then I would have had to ensure the medication was always stored correctly in Thailand - not exactly the coolest place. Then there was the prospect of explaining it all to my travelling partner - who did not know of my diagnosis.

I will deal with it on my return, I thought... At the time I also began to think there must be something better than this. I felt as if I'd been delivered this blow and then told, "You only have a handful of under-performing treatments to choose from, none of which will really do you much good, but we have to be seen to be doing something for you"... HA!

My natural curiosity and investigative streak saw me doing my own research online, and I very quickly came across Low Dose Naltrexone...

I don't remember how, but I began talking to several people about it and those who were taking it from around the globe. The more I discovered about LDN, the more I could not believe that it was being kept a 'secret' or frowned upon by medical specialists - the very people that are meant to be helping me to get better, NOT keeping me sick. Then it dawned on me... if I was 'sick', my neurologist would keep me as a patient... but if I was 'well', that would be one less patient for her and no 'kick-backs' from the Immuno-treatment I wasn't taking!!

I found a wholistic doctor near to me that prescribes and believes 100% in LDN, and so my LDN journey began on 16 May 2007. There's not much to tell since then, as I've been (touch wood), great... no further 'attacks' and generally feel healthy.

I have made a few simple lifestyle changes - which everyone should ultimately do anyhow - changing my diet ever so slightly to cut out wheat products wherever I can, limiting my alcohol intake (a struggle but I got there !!), and the most important - NOT sweating the small stuff.

I have experienced a few instances (and I must stress these are less than minor) where I felt a slight tingling, almost a prelude to an attack (as like my 2nd - numbness of left side of nose) for a few minutes and then it disappeared. I am convinced that is the LDN 'kicking in' and doing it's job at stopping the attack.

So, to conclude my story so far... I have never missed a nightly dose of my LDN and my compounding pharmacist now knows me by voice and sight every time I collect my prescription... What better friend to have!!!

## 101

#### Kim S, UK 1990 - Multiple Sclerosis 2009 - Secondary Progressive Multiple Sclerosis (SPMS) 20 March 2009 - LDN

I was diagnosed with MS in 1990 after a long period of illness and many months in hospital suffering from seizures (I have MS with seizures).

Following that first major flare, my MS settled into Remitting Relapsing - until 2 years ago when I started to get worse and the seizures returned.

I had pain in my spine and increasing loss of sensation in hands, feet, and legs. My ability to walk was impaired. It was incredibly difficult to walk without constantly stopping. Pain and cramps were waking me late at night and early in the morning, my eyesight was worsening, and I was generally on the road downhill... !

I was at my computer one morning in March 2009, feeling rather low, my future looking bleak, contemplating at some point perhaps the unspeakable, and a possible necessity for me... when I came across LDN purely by chance - and this 'chance happening' has turned my life around in a very short period of time.

I called Linda Elsegood (an Angel helping so many of us in need of her compassion and knowledge of LDN), and I started LDN on the 20th March 2009.

I noticed a change within 24hrs! It is an amazing drug that does not cure MS, but has an almost homeopathic effect, in that our own bodies fight the effects of the illness. In the first week I noticed incredible results. My balance improved 100%, and there was no pain when I awoke. I had less fatigue and could walk again for long periods of time without stopping.

I kept diary of my first few months, writing down the amazing changes. In the first week my senses improved. I could smell, touch and taste better. Perhaps when we have MS, we are unaware of just how much it affects all of our nerves until we're lucky enough with LDN to experience the 'before and after' effect.

After 7 weeks and 3 days, I could wiggle my toes in bed and in shoes (still can!). I was able to walk to the supermarket, carry home my shopping bags, then walk up the stairs unaided!

After week 1, I was able to stop taking 1 dose of the clonazepam that I take for seizures, and I could get in and out of the bath with absolutely no problem and even wash my hair.

My balance is now excellent. It's greatly improved, and I'm going to join my Gym again!

Just before the Glasgow conference I shared my improvements with one of the neurologists at the hospital I attend, but I did not get much response. I also told my GP,

but she also did not say too much except that she could not prescribe LDN for me, then asked, "Were there any Doctors at the Conference from England?!"

I gave her some literature to read and I can only hope she did.

Not that long ago, I'd received a letter from my Neurologist confirming I have Secondary Progressive MS. I can only be thankful that LDN came into my life before I got any worse.

LDN is not a cure. I still have MS symptoms, but it has dramatically improved the quality of my life, and I have already become more accustomed to these 'normal' feelings.

During the first six (6) weeks I felt euphoric, because the changes were so dramatic and so quick. I am still in awe of the changes this little drug dose brings, but I no longer feel I need to shout it from the rooftops, or tell absolutely everyone I meet (because they look at me as a deranged woman).

I went to Brighton and was able to go on 'Water Logs' and 'Dodgems' with my young son... a huge achievement!

I notice in times of extreme stress I now experience minor symptoms (compared to pre-LDN). My son was in hospital for 1 day and put under general anaesthetic. I temporarily increased my dose to 4.5mg, which worked, and after 1 week I went back down to 3mg.

I think this is one of the many reasons we need trials done for LDN as the dosage is so important and there are times you just have to be brave and try things out. All of us on LDN are on a rather lonely path in the medical world and those who are not on LDN, but are in great need of it, are being terribly forgotten by the Medical world.

I thank Linda, and I thank the doctors and pharmacists who are brave enough to stand up and help us all. I'm thankful for my good fortune, my favourable co-incidence, and I can only hope that soon everyone who needs LDN will also be given the chance.

I just got back from Algeria last night and this year we had a lovely holiday. I was so much stronger and feeling much more well than last year!

#### **UPDATE March 2010**

This year I'll be travelling on my own, my sister is still on the interferon drugs, she will not go near LDN, I'm afraid her Neurologist does not agree with LDN (I'm still not exactly sure why so many doctors are against it?). Her MS nurse told her there are terrible side effects????? I have been taking LDN for almost 12 months now, and yes, 100% it helps me immensely. I would not be able to get out of bed in the morning without the help that the LDN gives to help my body deal with the pain and mobility problems of MS. I can only say that any one who has similar problems should always give LDN a trial as it has had such positive effects on the symptoms of my illness and changed the quality of my life incredibly.

## 102

#### Kristie S, USA February 2002 – Multiple Sclerosis March 2008 – LDN

Imagine being the sick child in the family, with tonsils removed at age 6 and having to take liquid nerve medicine because of tummy aches. Imagine always getting a virus!

Imagine as a teen not eating pizza because of stomach pains, and being told all other pains are called growing pains even though you only grew to 4ft 11 ½ inches tall. Then as an adult hurting with muscle spasms, and after trying to find out why you want to sleep so much, hearing the doctors say, "You did too much", or "Maybe you're depressed".

I've been through Gall Bladder removal, cystitis, hysterectomy and always having 'Inner Ear Infections', and losing balance for weeks. My eyeball hurts so bad at times I wished I could just take it out for a while. My vision would come and go and the docs would say it's low blood sugar.

I'd wonder why my Mom and Grandma had so much energy and I didn't!

Then in my forties my feet decided to go to sleep! The next day my leg would go to sleep and hurt so bad I couldn't sit, stand, or lie down. I'd have to keep moving to make the pain tolerable, only I'd stumble and couldn't regain my balance again!

So I'd go to my doctor, almost convinced by now that he was right and that it was just in my head, or thinking, 'This is a fine time for my inner ear problem to act up!'.

And again, the doctor would dismiss my concerns with, "You probably pulled something in your back or hit your leg. If it doesn't leave in 6 weeks come back", forcing you to beg him for at least some pain medicine so you can sleep!

You go home to sleep some and then awaken to a major decision. 'I'm getting another doctor!!!'

And you call a doctor who a friend recommends in the next county and they work you right in. That doctor is very concerned and pats you and says, "Honey we're gonna fix your problem. It's not in your head!"

A week and a half later you've had tests that confirm Multiple Sclerosis (which was the easiest diagnosis the neuro had ever made due to so many lesions showing on my MRI). The spinal really wasn't needed but it was done also.

I was so thankful to hear it was M.S. That may sound odd, but the truth is, of all it could have been, I was thankful it was MS and not something worse. Plus, I was NOT crazy after all! I suddenly knew why I couldn't think of things I was trying to say sometimes, and why I had all the other problems in my past.

I agreed to start on Copaxone injections, then later switched to Rebif, then to Betaseron shots. I was tested again, because for some reason my MS was progressing faster than expected.

I had Solumedrol I.V. every 4 months for exacerbations. (Since I have so many medicine allergies, new meds are really scary for me and for my doctors.) When Tysabri and the other new meds were mentioned I said, "No", because I was not ready to take the risks involved in taking them long term.

Then I discovered a treatment called Low Dose Naltrexone (LDN). I found it when searching on the internet. As I worked in a cardiac unit years ago I understood to be very wary of internet claims for medicines, but this intrigued me and made sense.

After studying it for 2 months I asked my Neurologist to check it out and see what she thought. She wanted to make sure it was safe for me and she studied it too. After 4 months she said she was ready to try the LDN for me, if I still wanted to try it. "YES!" After all, by this stage, I thought what can it hurt?

I was her first patient on it. The second was a nurse from another county who works for a cancer doctor. That doctor was so impressed he put a Pancreatic Cancer patient on it and her blood levels dropped dramatically!!!

Now my doctor calls LDN 'Kristie's Medicine', and says she is getting known as the LDN Doctor here in my home state. She gets calls almost daily for new patients who want to try it.

I've been on it a year now and I have not had a single exacerbation, nor balance problems! My cane and walker have been put away!

Everyone - my family, my friends, my doctors, my pharmacists, and me - are amazed at how well I'm doing! LDN should never be hidden from patients. I talk about it anywhere and everywhere I can to anyone who'll listen!

Later in 2009 I will have my first MRI since starting Naltrexone.

Guess what I did recently ... I played teeter-totter and ran with my grandchildren! It sure feels good to feel young and healthy!

As an update, I recently went for a check up with my neuro (took all of 5 minutes! LOL) I asked how her other patients on LDN are doing and she said pretty good. She also said one male patient developed antibodies to LDN. But he feels better on it than off it, so he decided to keep taking it.

No other meds work for him and when he went off LDN he reverted back to his previous state and was doing worse. I told my neuro about where I read that for some reason some men do better at a lower dose at 2.0 or 2.5. She said she may try that with him to see.

#### UPDATE March 2010

I'm sorry I haven't updated before this but I've been enjoying life so much!!! I'm still on my LDN at 3.0mg. I have not had another MRI since I started on it because so far I

have not had another exacerbation! Heat and cold does not bother me at all. I have great balance. I do not sleep like I did before LDN.

I went to my first Nascar race last weekend with my Grandson and his Mom. (I did the driving which was 6 hours getting to it and 11 hours coming home because of the heavy traffic.) I got sunburnt because of the heat there... I came back home to decorate a wedding chapel and reception for a friend's daughter's wedding the next Saturday. It was beautiful. Today I watched 3 girls (age 1 1/2, 3 and 4 yrs old) and they wanted me to jump on their new Trampoline with them! I was concerned I'd get dizzy but I didn't! I jumped and bounced with them and loved it!

My Neuro says some have come off their LDN, but she says no-one seems to do as well as me! Meaning that I amaze her...LOL. My Neuro still prefers to give the Crab Medicines first then LDN as a second option. I hope that she will soon change and encourage her patients to try LDN first! I don't see her often now because I am doing so well.. I call her occasionally to tell her things I have done. (The last call I made to her office is to let her know I installed my new Kitchen Cabinets all by myself.)

So you see I am doing GREAT on LDN and telling everyone I come across how great it is! Most are amazed that I have MS when they are told I have it.

Please feel free to post this update anywhere you want. I will never stop my LDN!!!

Prayers and Love to all of you who let me know of LDN.

### 103

#### LarryGC, USA 31 July 2002 - Relapsing Remitting Multiple Sclerosis (RRMS) 17 April 2003 - LDN

My name is Larry. I was diagnosed with RRMS on 31 July 2002 and I started taking LDN seven years ago on 17 April 2003.

Before LDN. I'd been through 11 years, 10 flares, 9 snares, and a whopping killer, knockdown, drag-out exacerbation that made previous bad exacerbations in '78 and '81 look mild. The killer flare was in March 2002, and hopefully, it was the last major one ever.

I've had none since I started on 3mg LDN with Avicel filler from Skip's Pharmacy in Florida, USA.

When I began, I took 3mg for 300 days before increasing to 4.5mg, but I wasn't able to stay on the higher dose. Within 14 days of taking 4.5mg I was ready to go back down to 3mg but I stuck with it for 38 days before reducing my dose back to 3mg. I tried to increase the dose again a few months later but only lasted 12 days before going back down to 3mg. 3mg works for me, so I decided to stay on 3mg.

I still get my script filled through Skip's Pharmacy because I know the quality is good and consistent, and with such a low dose, it's important.

I experienced a lot of symptom improvement after starting on LDN, but not without some hiccups along the way.

Three months after I started taking LDN, symptoms that had first developed in 2002 (my newest symptoms) returned - and scared the heck out of me! Then they eventually faded away. One year, four months after starting, I then experienced symptoms that had first developed in 2001, and they too went away. That was followed by going through symptoms I'd first experienced in 2000.

When the double biinguinal hernias I developed in 1999 started hurting I really freaked out because I hadn't done anything to cause pain there! After a few days that pain went away too. Then my 1998 symptoms came back, but only for a few days, then went.

The rolling series of symptom re-occurrence was truly bizarre! What did my hernias have to do with MS? Even more strange, my hernias have NOT bothered me SINCE those 3 days!

As you might have guessed, I keep updated diary records, but, it wasn't until I was one day contemplating the totality of all these experiences that I realized something: All my symptoms had returned in Reverse Order! What was going on with me? It was like the body had a checklist and was checking off each symptom or sore spot in reverse chronological order to the order in which it had arrived.

I should clarify that not all symptoms returned, and of those that did, they were a lighter version, an annoyance rather than a pain.

One of the 'problems' with LDN not being mainstream, especially so for people with MS, is that things like this ignite their 'fear factor'. Many don't have doctors with LDN experience monitoring and supporting them, so they can get scared off LDN before benefiting from it.

I'm glad I never got scared off it. The last 7 years have been great compared to the years prior.

I don't remember what my dreams were like before LDN. I always thought they were vivid and sometimes lucid before LDN, but definitely after. I also began to sleep more 'peacefully', and better than I had in 20 years.

My allergies have also improved. I had the allergy prick tests done in February 2003, a couple of months before starting on LDN. Chocolate was amongst the culprits, but I already knew that. Going back to the 70s, long before I was diagnosed with MS, chocolate had caused problems for me.

I've run some tests along the way and I seem to tolerate chocolate much better now, where before LDN, chocolate would trigger a flare of MS symptoms. In November 2005 I ate some chocolate after Halloween, and though I noticed an effect, it didn't lead to a flare. I tried it again in July 2006, and again, it didn't trigger a flare.

In September 2007 I had the allergy prick tests done again. The full results are in MyStory, post #16 (<u>http://www.larrygc.com/mystory</u>). According to those tests I am No

Longer allergic to ANY food items. I'm still allergic to the Environmental items, but not Trees. An Amazing change.

I also used to get headaches before big storms. I was a human barometer, and I could tell people when storms were coming, but not any more. During the winter of 2009-2010, however, I did get 3 of those headaches. The storms that buried my car for days and weeks at a time gave me reminder headaches. I knew they were going to be big ones when I got those headaches.

My hair and nails now grow twice as fast and are much stronger. I remember when I was in primary school I sweated a lot, but that changed as I got older. Since being on LDN I sweat more than I used to before LDN. At first it seemed odd, but then I realised I wasn't sweating any more than I did when I was in primary school.

My metabolism's also changed. It's more like 'the good old days' when it was faster. It slowed down a lot back in 1992, following the 2nd of 10 annual attacks in 11 years (maybe there's a correlation there somewhere - interesting).

My weight has benefited from both LDN and lifestyle changes: I weighed 135lbs when I was researching LDN. Seven months after starting LDN I'd dropped to 124lbs. A year after that, in 2004, I was 127lbs, and I stabilized around that weight until July 2005 when my weight suddenly dropped to 114lbs, then dropped again in March 2006 to 110lbs.

In April 2006 I weighed 108lbs. I stopped smoking completely. By May 2006 I was back up to 129lbs, and I've remained fairly stabilize in the range 129-131lbs.

Everyone with MS has problems with their internal thermostat and LDN has not helped that. Mine is still messed up. I'm still colder than I should be when it's cold, but now my underarms are wetter than they used to be before LDN!

Basically, more parts of my body are 'working' now than were working before LDN. They're doing things they should have been doing, but weren't.

When I got a staphylococcus infection in October 2004, LDN helped me battle it for 6 weeks before I had to resort to 2 doses of Levaquin to force it into retreat. I was given a full course, and I took the full course as prescribed, but the staph was beaten within 2 days. The podiatrist was amazed how quickly it cleared after only 2 doses. He said that in 23 years of practice he had never seen anything like it.

The doc was also impressed. He showed me a referral he'd written to the hospital for my 48 hour revisit. He had fully expected me to need hospital admittance.

What did that experience teach me? Stay on LDN, whatever comes my way. It had orchestrated my immune system so those other infrequently needed drugs were able to do what they were supposed to do.

And you don't have to take my word for it:

On 19 April 2007 I had a brain MRI that was compared to my baseline closed Tesla 1.5 brain MRI performed in August 2004. There were no new lesions, and the 2007 MRI was virtually identical to the MRI of 2004.

I also had a Cervical and Thoracic MRI on 20 April 2007, but the previous C&T set was taken five years earlier in August 2002. The April 2007 Thoracic showed my T5 'area of sclerosis' was healed and no new Thoracic abnormalities.

The April 2007 Cervical showed two C5 lesions present in July 2002 had healed. It also showed the development of MS in my C2/C3. They weren't evident in the August 2002 MRI, but I believe they developed during the 8 months following diagnosis, during which I was not taking LDN.

My chiropractors confirmed this when they said I had the C2/C3 issues before starting LDN.

I believe in the 'KISS' (Keep it Simple Stupid) principle. I take no other medications apart from LDN unless it's absolutely necessary (as with my staph infection).

I take a couple of vitamins: 100mg Vitamin B1/Thiamine daily, and every 3rd day I take 500mg Magnesium and a Super B Complex (that also has 100mg of Vitamin B1 in it).

I'm a shift worker so I'm awake and working most nights, but I still take my LDN and vitamins at night, and I take them all at the same time.

I started taking B1 regularly on 1 July 2005, and on 14 July 2005 I stopped using my cane. May be a coincidence, but I haven't stopped the B1 to see. All I know is I was having to use a cane a lot before that. In January 2008 I bought a new cane, one more comfortable to walk with, a straight, not curved handle and started to use it when necessary. Now when I go shopping I park near carts and use them to walk around the stores.

I eat a healthy diet. I used to have oatmeal for breakfast and a salad for dinner. I found when I ate oatmeal and salad daily, everything keeps on moving. Before introducing oatmeal and salads, I often relied on 750-800mg Magnesium daily for 3 days to get everything moving. I have given up on the oatmeal over time. It is definitely a winning combination, but the salads work well enough. I've added a lot to my salads since starting. It's usually my main meal of a day when I'm eating alone.

I don't think people would be as cautious about LDN if they were told it was FDA approved, \$1000 a month, had a long list of side effects, long-term risks to internal organs, and their doctor insisted they take it.

Ampyra (a sustained release formulation containing of 4AP) is a great example. People are flocking to it. Many people have been getting 4AP compounded, not as a manufactured medicine, for about \$1100 less per month. Sure, insurance may cover much of it for many, but there's still a huge difference in costs and providing the dose is accurate, no difference in Effectiveness.

If you do try LDN, be patient, don't expect too much too soon, and don't give up on it too soon. Give it at least 6 months because the benefits of LDN creep up on you until the day you remember 'oh, that's right, I used to have pain there and I don't anymore'. And for that reason, please keep a diary record because you will forget. I knew I would, so I've maintained a running record here: <u>http://www.larrygc.com/mystory</u>.

### 104

#### Laura, UK May 2008 - Multiple Sclerosis April 2009 – LDN

It started with optic neuritis in my left eye in May 2007. I then got optic neuritis in my right eye in September 2007. My brain MRI in October 2007 was clear.

I started December 2007 with numbness and pins and needles down my right side. In April 2008 I had another MRI, and this time they scanned my neck too. I was found to have two lesions on my brain and 'several' on my neck.

I was given a course of steroids, and diagnosed in May 2008.

In June 2008 I had a severe relapse affecting both legs, which left me unable to walk for a fortnight and off work for 10 weeks. I started Avonex in August 2008.

In October 2008 I had another course of steroids after both feet went completely numb. I continued to have a relapse every 2-3 months. My MS nurse, GP and Neuro are all saying, due to number of relapses, they think I've got a more aggressive form of the disease, but I have not formally been diagnosed with SPMS or PPMS to date.

I continued on Avonex until March 2009. Due to continued regular relapses I was told that Avonex wasn't strong enough for me and that I needed a higher dose of the drug. Therefore, I was started on Rebif. But after only two weeks on Rebif I had to stop as had a bad reaction.

I managed to get LDN prescribed through my GP and started taking it in April 2009. I'm lucky as my father is a GP and it was him that recommended LDN as he has a patient on the drug and knew how much it had benefited her. He spoke to my GP and together we persuaded him to prescribe me.

I'm currently in the middle of another relapse (6 weeks in), again affecting all down my right side and this time there's a new symptom - the terrible 'MS Hug', which is horrible every time I move my neck. Recently, I accepted a further course of steroids after four weeks of no improvement. I stopped taking my LDN on the advice of Dickson's Chemist whilst I was in hospital and for a few days afterwards. I have just started taking LDN again in the last fortnight.

Immediately prior to this last relapse I had a period of about four weeks when I felt really well on the 4.5mg dose of LDN. I remember feeling better than ever, far less tired and no pain.

I think this recent relapse occurred as a result of me catching some sort of virus. I'd been on holiday and my LDN was not delivered before I went away so I had two weeks of no LDN and then caught a virus upon my return from holiday. Rubbish!

I'm still taking my 4.5mg of LDN every night. Unfortunately my MS continues to be really

active, the last three weeks has seen my left leg go numb. It's really quite painful, incredibly sensitive to touch. My MS nurse has referred me to the pain clinic and I've been prescribed some cream made from capsicum chillies. I'm also due to start weekly acupuncture next week.

I've got an appointment arranged with my neurologist in three weeks time. My nurse has suggested that I may be suitable for Tysabri, given that my MS is active and that Avonex didn't reduce my number of attacks. I'm open to discussion regarding treatment options, but am worried about coming off LDN if my neuro recommends Tysabri...

# 105

Laura W, Ireland 2006 – Relapsing Remitting Multiple Sclerosis (RRMS) January 2008 – LDN

When I was 18 years old I fell in love with a man, and we had our first child when I was 19. We then went on to have a second child when I was 20. We were married that same year and started to plan our future and all of our plans started falling into place.

Then one evening I realised my legs felt numb. It was funny at first, I was laughing and saying pinch me I can't feel it. I genuinely thought it was maybe a trapped nerve in my back as I had been working out pretty hard trying to get back to my pre baby body.

As a week or so went by and the numbness was still there, my family became concerned (I was never one to worry about anything) so for their sanity I went to the doctor. I was pretty shocked when they said I'd have to stay in for testing and I (against doctors advice) left the hospital. I mean I didn't have time for all that. It definitely wasn't anything serious and the stupid doctors were over reacting, right?

After some stern words from my husband I went back that same night and agreed to have some tests done. So, bloods normal, and lumbar puncture normal. Okay, MRI time - not normal. I was later sent to meet a neurologist. To be honest I didn't even know what that was or what they did. I was 21 years old with my whole life ahead of me, and I had 2 very young children. I mean, my life was just starting.

He said we think you have Relapsing Remitting Multiple Sclerosis (RRMS). "Okay", I said, not knowing what that was and without any idea of its seriousness. I was alone in the office and I think he must have seen that I had no clue how serious what he had just said was.

He gave me some information and told me it was very important for me to start treatment immediately. 'MS, what the hell is that?' I thought on my way home. I got home and goggled it. Oh shi\*t! So that's what I've got. So I had to decide how I was going to deal with this: I could curl up in my bed and feel sorry for myself and let my family fall apart, or I could fight. I chose to fight it.

So, for the first year I did a lot of research. I had one more episode but thankfully, like the first, it went away by itself. I decided that I would try Interferon, only because it was the treatment with the least injections (and I hate needles). That, for me, was the worst time in my life that I have ever experienced. Reality hit home. This was serious, and it needed serious treatment. I stopped Interferon after 6 months as I just couldn't continue with it.

I then discovered Dr. Swank and started that diet at the start of 2007. I made myself very physically fit as I believe that the stronger I am, the better I'm able to fight against this thing. After several months of the diet I was feeling much better - not so much fatigue and my hands were less numb, but I still felt that I could be doing more to fight against.

I again started researching treatments. One day while browsing on the Dr. Swank website, I came across one man's story about how he had found a fantastic new medicine that had taken him from being stuck in a wheelchair to walking again. LDN it was called. I immediately started researching it and found lots of great information, all good. Wow! How can I get this, I thought.

I knew I would be wasting my time going back to my neurologist as he is a 'strictly by the book' kind of doctor, and as LDN isn't approved for Relapsing Remitting Multiple Sclerosis. I knew he wouldn't give it to me. I went back to the Dr. Swank website and asked if anyone knew where I could get it in Ireland. I was told to contact my local MS society. I called them and they gave me a number.

Turned out to be the wrong number. Amazingly, when I said, 'May I speak to Dr O' Flaherty', the man on the other end of the phone said sorry you've got the wrong number, but I see a doctor by that name and I could give you his number if you like. The man on the phone was a patient of the doctor I was looking for, and he also had MS, was on the same diet as me, and was taking LDN - and he lived about 10 minutes from my house (oh my god!).

He had only good things to say about LDN. I called the doctor and went to see him that same week, he gave me 4.5mg of LDN and I started that night. I had a little difficulty sleeping for the first few nights but that passed, and it was the one and only side effect – nothing when compared to Interferon.

After a week or so I noticed my mood improving. I had been suffering with everchanging moods, that is; I could be depressed one minute, happy the next, and then back to depressed. I was also very easily aggravated. Finally, I was getting back to my old self!

No more fatigue, and to my delight, I could play again for hours with my little boys without being exhausted afterwards – and the numbness in my hands was completely gone.

I'm now in my early 20s, and I've been taking LDN for 18 months without any complications.

I have recommended it to many people and I hope and pray that one day it will be available to all MS patients. I truly believe this is the best treatment for all new MS patients.

I'm now in my early 20s, and I've been taking LDN for 18 months without any complications.

#### UPDATE March 2010

Yes, I'm still taking LDN and am still in perfect health!!

## 106

#### Leslie J, USA August 2009 - Multiple Sclerosis November 2009 - LDN

I am a woman in my early sixties who was diagnosed with MS 8 months ago.

Eight months ago, with no warning, I started having issues walking. When I finally went to the hospital a few days later, I was totally paralysed from the waist down. The neurologist at the hospital put me on 5 days of intravenous steroids, and I was in the hospital for a month after that, relearning how to use my legs.

When I was ready to leave the hospital the neurologist said that since I had Relapsing Remitting MS, I should start immediately on Copaxone injections daily. He sent me home with a DVD about Copaxone, which I watched. I studied the Copaxone statistics in the printed material and on the DVD, but I was not impressed. My understanding was that they had a hard time keeping people on the Copaxone, but that those who stay on it have fewer exacerbations... maybe.

I had the Copaxone shots for a month. I had met my insurance deductible so I did not have to pay the \$2600 per month, but the shots gave me tremors for a couple of hours after each one, which meant I could not even walk with my walker. I was worn out after the tremors and would be dreading the next day's shot. After a month on Copaxone I called an holistic doctor I'd been a patient of 20+ years ago and told him I could not tolerate any more shots. I asked him what I could do.

He suggested I could go to the Low Dose Naltrexone (LDN) website and read about the treatment, then if I thought this was something I wanted to try, to call him and he would write a prescription.

My husband and I immediately spent hours researching and reading everything about LDN. I also used the Grillo Center (an organization in my town that responds to health related questions by accessing specialized medical databases to find current, scientifically-based medical information related to the topic) to research LDN, and we only found positive information on LDN.

I got a prescription immediately and started on LDN. At the time I was doing outpatient physical therapy 5 days a week.

Since LDN is taken at night, I started it on a Friday night. When I went back to physical therapy the following Monday after 3 doses of LDN, my therapist immediately wanted to know what I had done since the previous Friday to be in so much better physical shape. Of course my response was that I had stopped the debilitating (for me) Copaxone shots, and had taken 3 doses of LDN.

I have now been on LDN for 6 months and I am doing incredibly well. I now go back for outpatient Physical Therapy at monthly intervals, just to get new exercises to do. Eight months ago I was paralysed for a whole month. I can now jog again, ride a bike, do everything I was doing before I was diagnosed.

As part of my complementary lifestyle regimen, I eat only organic foods, mostly vegetables, and use a homeopathic remedy recommended by a homeopath who specializes in MS. I have a Far Infrared Sauna daily, and I visualize healing of the lesion that caused this issue daily.

For me, taking LDN has been the right answer, and the bonus is that I do not have to dread an injection. I'm taking a drug that has no bad side effects (yet as far as I can tell, every FDA approved MS drug does have bad side effects).

My outlook on life has changed to one of being very hopeful... life is wonderful again on this inexpensive 'off label drug'. LDN with shipping from my compounding pharmacy only costs me \$30.00 a month. I am so glad I found LDN, and that it is the right drug for me.

# 107

#### Linda C, USA 1991 - Multiple Sclerosis May 2005 – LDN

I'm in my sixties and I was diagnosed with MS in 1991. Prior to that I spent 20 years going through 26 doctors trying to get a diagnosis for my illness!

The doctors suggested Betaseron as my first trial medication, to the tune of \$1200 a month! After six months of infections at injection sites and NO relief, I quit Betaseron!

Not being someone who gives up easily, I then tried Avonex but I experienced the same disappointing results, plus something new, exhaustion. On top of that, I was sick and tired of the 'money drain!'

I came across LDN on the internet and printed out everything I could find about it for my doctor to read (the doctor was my Internist because I'd given up on Neurologists!). He read everything and told me it sure couldn't hurt me, and it might just help! At that time, I was in a power wheelchair and my speech had deteriorated to garble. I sounded like I had a language all my own!

Two weeks after getting my prescription my story began to change dramatically.

By the end of two weeks of being on LDN, I was back walking with my Labrador Service Dog, Toby, not tired at all, and speaking to anyone who would listen! That was five years ago today, and I'm still the same... still enjoying life, still driving, still walking most of the time except when shopping (I use a sport manual chair, and I can get in and out of my car with one hand!)

I have to admit to being a braggart and telling everyone who will listen or knows someone who might be a candidate. Of course this is all in vain, people like to hear my story, but they sure don't have the brains to try it! They are more willing to spend \$1200 a month in comparison to \$38, hoping to get the same end result. The total exhaustion is gone and is now just a memory. I still couldn't work though, because I do take occasional naps. The day after a really busy day is usually a rest day.

Am I happy on LDN? You bet your life I am. I remarried nine years ago but was a caretaker for my ex-husband until he passed away in 2007, took care of my 93 year old Mother till she passed away last December, and am now taking care of my husband's Mother who is 90 years old and quite a handful!

I am a happy, upbeat person with a sincere love of this refreshed life that LDN has given me.

Do I regret that I didn't continue to pursue the accepted MS protocols? NO. I know what each day will bring, and I give sincere thanks to the doctors who discovered that a medication used for detox could be employed in smaller doses and give me back my life.

## 108

#### Linda Elsegood, UK

Oct 2000 – Relapsing Remitting Multiple Sclerosis (RRMS) Oct 2003 – Secondary Progressive Multiple Sclerosis (SPMS) Feb 2004 – Relapsing Remitting Multiple Sclerosis (RRMS) 'in remission' December 2003 – LDN

Hi! I'm Linda, and after months of being asked, this is the first time I have written my own MS/LDN story.

Perhaps thinking that it was so incredible, I guess I didn't want to tempt Fate, but here goes.

I was born partially deaf, which wasn't all bad. I learnt to lip read. The major operation I needed for this was complicated on a small person so I had to wait until I was at primary school. The operation restored most of my hearing, and my adenoids were removed at the same time. After that I could hear but never at 100% (lip reading skills still come in today sometimes).

I had all the normal childhood diseases, but I was plagued with repeated ear infections and earache and was always on antibiotics. I also had repeated tonsillitis but my doc was reluctant to take them out.

I was young when my periods started and had menstrual problems from onset. I took steroids and other hormone pills almost from day one, until I went on the birth control pill when I married in 1976.

In 1969, at the beginning of my teen years, I had Glandular Fever (Epstein-Barr virus). I was seriously ill and away from school for six months. After that, strange things started to happen to me - trapped nerves here and there, what used to be called 'slipped discs' - you know how the story goes.

Then in my late teens I started to have regular urinary tract infections (UTIs).

Meanwhile, menstrual problems had resulted in my having my first Dilatation & Curettage (D&C) by the time I was 20, and after years of taking antibiotics, they finally took my tonsils out in my early 20s.

I had a stillborn baby boy in January 1979. I gave birth to my eldest daughter in 1980, but then miscarried twins during Easter 1983. My youngest daughter was born in 1985.

In 1998, due to recurring UTIs, a Urologist used a camera to see inside my urinary tract. He told me that I was one of those women for whom it was normal to have infections monthly, and he suggested taking a low dose long-term antibiotic, but I refused. (UTIs are a known MS symptom.)

In 1988 I was diagnosed and treated for cervical cancer. I remember I was also experiencing strange leg weakness at that time but it only lasted a matter of weeks and disappeared. I also had a trapped nerve in my neck that sent electric shocks down my arms to my finger tips (this symptom is called L'hermitte's).

In the ensuing years, I was focussed on being a wife and mother to two beautiful girls. I loved family life and thankfully, my health seemed to 'level out' a bit.

I returned to work and everything, though much busier than before, was still manageable and my health was still stable.

Then, during Christmas 1999 my mother had a serious heart attack and the trauma affected me badly. I was working full time, travelling two and a half hours every day AND running the home.

January 2000 I had a bad bout of flu resulting in two weeks off work. Then followed gastro enteritis. I was already at a low ebb and it took me three weeks to recover. I had a tooth abscess resulting in having a good tooth out.

I apparently slipped a disc causing pins and needles in my right leg. My energy levels were falling rapidly: I was finding it hard to cope and I had to sleep so much.

Easter 2000 I decided I had to break this cycle of ill health. I took a week off work and with my younger daughter Laura, went to Portugal. The day before leaving I felt I had burnt my tongue on the left hand side. I thought I had eaten something like hot melted cheese but could not remember.

Portugal was unbelievably wet, cold and windy: the wind made the left side of my face numb with pins and needles. Back home I went to see my G.P. who thought I had a trapped nerve in my neck. He said I should see a neurologist. The earliest appointment was August.

I worked for three weeks, managing the drive into work, giving one hundred per cent while there, driving home and going straight to bed. In May 2000 my eyesight began to play up. I went to see the optician who said nothing was wrong. Two days later, to my horror, I had developed double-vision. Around this time I also developed cognitive problems.

I had no choice but to listen to my body and stop work in July 2000. Over the next few weeks I lost my balance and the left side of my face, head, tongue and nose were numb with pins and needles. When trying to stand up I either fainted or fell over. I lost one hundred per cent of the hearing in my left ear.

Every day I lost some ability: the pains and fog in my head were terrible. I slept twenty hours a day which was the only saving grace because when I was asleep I felt nothing.

At this point I was really too ill to care. I had a three-day course of IV steroids: These did nothing for me at all. I had an MRI scan, lumber puncture and twenty-eight blood tests. By November 2000 I'd developed optic neuritis and it was feared I might lose my sight and hearing.

Six weeks later I was given another course of IV steroids and I began to feel a little better. Multiple Sclerosis (MS) was then diagnosed. The company doctor at work said I had completely crashed and no one knew if I would ever function properly again.

I spent the next year mainly in bed. I was having an attack every six months or so and it was taking months to get over an attack only to have another. My husband Marcus had to learn, after twenty-six years of marriage, how to iron and cook, both of which he now does very well.

In August 2002 the company doctor gave me a thorough examination and reported back that I was unemployable for the foreseeable future. Being a workaholic I was dumbstruck. Getting back to work was my goal.

In February 2003 I was assessed to go on the interferon trials. In my heart of hearts I didn't want to do this, but my family thought it was the only thing available to help me.

On the Expanded Disability Status Scale (EDSS) I scored 2.5, which I was told was very good. I then had the scale explained. A score of 0 was fit for someone with MS, and a score of 10 meant you were dead! So at forty-six I was a quarter dead. Wonderful.

I started taking Rebif in March 2003. The first liver function test I had was over the acceptable level. The results of each successive test were higher than the last.

I was told to carry on taking it. My health was such that '10' was getting closer all the time. I had to use a wheelchair more and more often, and even bought an electric scooter. The toilet and the bed became my best friends.

In September 2003 my elder daughter Sara got married and I doubted whether I could attend the ceremony. After getting showered and dressed I had so little energy left that all I wanted to do was go back to bed. I did struggle to get there, but came home as soon as I could. This disease didn't hurt just me, it was hurting those I loved too.

By October 2003 I was falling to pieces. I was always in hospital – and the urologist, the gynaecologist, the consultant treating bowels, stomach and liver respectively. My health was such that my GP thought I would only score 6 on the EDSS scale. I saw the neurologist at the end of the month and he thought I had 'progressed' from Relapsing and Remitting to Secondary Progressive. There was nothing more that could be done. No Plan B.

I had had enough of our health system by November 2003. I was so worried over how I would be in a few months that I couldn't even think of the next year. I was deteriorating rapidly and things I could do one week I was unable to do the next. My 'Normal' was becoming weaker and weaker.

I had read a lot about the Low Dose Naltrexone (LDN) treatment and I contacted Dr Lawrence. I stopped Rebif and Provigil and started a special diet plus a regime of vitamins and supplements. I discussed LDN with my GP and she - I had a new one - agreed to monitor me. The results of liver function tests were so high that I was worried what taking Naltrexone would do to me.

In early December 2003 I started LDN, and the results were amazing. By Christmas I was functioning again, and the liver tests were back to normal. I felt like 'me' again (OK, a me with MS) but that didn't matter.

In February 2004 I had to be assessed again on the EDSS scale. The deal when I started the interferon was that I was to be monitored for ten years, even though I had by now stopped taking it. I scored a magnificent 0, even though the neurologist wouldn't recognise that it might have something to do with taking low doses of Naltrexone (although that was all I was taking). It was confirmed that I had reverted to Relapsing and Remitting and was 'in remission'!

Thanks to LDN and Dr Lawrence, I have a life again, and hope for the future. I can plan things AND do them. I founded the LDN Research Trust in May 2004. It is the most exciting thing I have ever done. I am able to give many hours a week to the Trust, helping people to obtain naltrexone and trying to raise funds for a clinical trial of naltrexone for Multiple Sclerosis. A successful clinical trial would result in LDN becoming an accepted treatment for MS and help others.

My head is clear, energy levels up, greater muscle strength. Balance, vision, hearing, bowels and bladder are good.

In March 2005 I was re-assessed on the EDSS scale and achieved another 0. Throughout the last year I have had no relapse. To sum up, I know I have MS and I haven't been cured. I'm not back to the old me, but if I can remain like I am now (a major improvement in symptoms and no further progression) I will be more than happy.

Update - July 2008: 1999 started off being a good year.... My husband Marcus had been made redundant after 18 years working for Anglia TV but was managing well in the freelance 'sound' world.

My elder daughter Sara was happy living away from home.

My younger Laura was 14, and had asked to go to boarding school to take her GCSEs to cut down on travelling, she wanted to spend the extra time studying.

As for me, I had the job I wanted working for the Virgin One Account (banking). The family were happy and well and life was good.

Until... I came home from work the Monday before Christmas, my friend was already there cutting Marcus's hair and she was telling me to get my coat off and my hair washed as she was almost ready to cut mine.

Then something happened that had never happened before, my father called me, he doesn't hear well and hates talking on the phone. He said "Your Mum's had a heart attack and they are now taking her to hospital."

That statement was to change all our lives forever!

I'm an only child so had no siblings to share this difficult time with. I arrived at the hospital about 8.30 pm, mum was in ICU. I was too scared and frightened to sleep for two nights, I thought if I slept mum would slip away. I was very tired, stressed and worried, I also had the added worry of my father who is wheelchair-bound. Little did I know what the trauma would do to me.

Mum survived, even though a third of her heart died and they both had to come live with me for a while. Mum's heart attack was due to hereditary high cholesterol; this was when I found out my cholesterol level was 9.7, which resulted in me having to take pills daily.

I carried on working, feeling so very tired; the 60-90 minute drive to work every day was killing me. On my days off I was cleaning, doing food shopping, and other housework. My life was work, cooking, cleaning and spending as much time as I could in bed.

Between Christmas 1999 and Easter 2000, I had a tooth abscess that resulted in having the tooth removed, a slipped disc, flu and gastroenteritis. I had never felt so ill in all my life; I felt I couldn't cope anymore. I said to Marcus I wanted to go away on holiday and come back a new woman. He said he was unable to take any time off, so Laura and I went to Portugal for a week.

The day before we left I took Laura shopping for shorts and T Shirts. I had an odd feeling on the left hand side of my tongue, it felt like I had eaten food that was too hot and had burnt my tongue. I spent some time trying to remember what I had eaten that might have caused this, but gave up and carried on.

Portugal was very wet, cold and windy. We had the choice of sitting in the apartment or making the most of being there-going out and getting wet. I thought it very strange that the cold and the wind were making the left side of my face numb with pins and needles.

When we got home, I returned to work and made an appointment to see my doctor. After a week away I was feeling even worse than when I left. I was giving work 100% but was collapsing in bed as soon as I got home, and I stayed there until I had to have a shower and go back to work.

My GP thought I should see a Neurologist as he was unsure what was wrong with me. I also had to rethink working, as I simply couldn't manage the hours. It was agreed that I could work part-time and have 3 days off a week. I managed to do this for a few weeks until I developed double vision, at which point I had to listen to my body, stop work and rest.

All I wanted to do was sleep; I thought it was best to let my body heal; not knowing that short-term would turn out to be about a year.

I now had the problem of not working, hence not getting paid. We had Laura's school fees to pay on one salary. Marcus worked out we could afford for me to have 2 months off work. It was fortunate that at the time we didn't know I was never to return.

I was sleeping more and more, going to the toilet more often. The numbness was spreading from my face and down my left side. The hearing went in my left ear, muscles were twitching, and my thighs were burning as if sun burnt. Balance was a thing of the past, fainting and vertigo was becoming the norm. Trying to get to sleep at night my legs would thrash about and when I tried to get out of bed they felt as if they were made of rubber, I would bob up and down and more often than not I would fall over. I became a master of falling asleep either while talking myself or while other people were talking to me.

Marcus at this point of our married life hadn't learnt to cook, clean or use the washing machine, and the iron was a mystery to him. He had a crash-course and had to learn quickly. Life wasn't easy for him either, when he works he's away and he couldn't afford to stay at home looking after me.

Each day something else in my body didn't work properly, I was having really bad problems with 'exploding' bowels. I was unable to put a cup to my lips, I was walking holding on to furniture but was unable to go through my front door without help, let alone shower.

My parents would come over on Saturdays to visit me, mum would sit on the bed and talk to me and I would alternate between sleeping and awake. Sometimes she would try and help me get up and sit in the lounge but it took so much out of me that she would have to help me back into bed. I was sleeping 20 hours out of 24, but it was a blessing as I felt nothing while asleep. I wasn't living I was surviving.

At this point it was killing me to see the sorrow in people's eyes when they looked at me. I knew they all wanted to help me and felt inadequate, as did my doctor.

The pains I was experiencing in my head slowly got worse and unbearable. There was a trade off, I could either suffer the pain or take strong painkillers and feel very nauseous.

I finally saw a Neurologist who thought I had either, had a mild stroke, a tropical disease, brain tumour or MS. I didn't like any of these choices to be honest but had to wait for the results of a lumber puncture, MRI, evoked-potential tests and 28 blood tests.

While I waited for the results I was given a 3 days course of IV steroids. Six weeks later my condition deteriorated to the extent the Neurologist was concerned that I would loose my sight and hearing completely and recommended another 3-day course of IV steroids, even though the first course did nothing. I then developed optic neuritis. It was after this Relapsing and Remitting MS was diagnosed.

Marcus was away working, Laura was at school, my next-door neighbour was keeping an eye on me and the doctor came out to see me. He let himself in, brought me some more painkillers and fetched me a glass of water. I asked him when he thought I would start to feel better, and he replied; "If you were going to, you would have by now" and then he left. I felt so ill, I couldn't do anything let alone achieve anything and I was in a lot of pain. I couldn't bear what all this was doing to my family, and our friends had stopped visiting.

I looked at the painkillers and thought if I were to end it all, it would be a shock to everyone, but I felt they would understand and eventually life would carry on for them. I then had to think it through, things like, who would be the person to find me? It would have been Laura, how could I do this to a 15 year old. The answer was simple. I couldn't do it. It was then that I decided I would show my doctor he was wrong and that I would beat this MS if it killed me!!!

The biggest problem I had was cognitive problems, suddenly I couldn't retrieve my vocabulary or if I did it was very slow and often I said totally the wrong thing and thought I had said it correctly. I feared I was losing my mind. I spoke slowly and it was often rubbish!

I was having a relapse every 6 months, and it was taking about 4 months to start to recover from a relapse only to have another start. I went for an assessment at the interferon clinic and started on Rebif. This was something I didn't want to do but my family thought it was the only thing available to help me. My liver-function tests hit the roof on Rebif, but even so, my Neurologist wanted me to stay on it. He said it would settle down, but it never did.

It was during this period Sara brought home Darren, her future husband. We didn't know they were coming and I managed to drag myself out of bed but couldn't manage to get dressed. He must have wondered what kind of family she came from.

I was spending a lot of time at the hospital seeing a variety of consultants, for my bowels, stomach, and bladder. I had cervical cancer when I was 32, around the time of the first MS symptoms, had a series of follow-up operations and was told I needed another but they couldn't operate again until I had been free of steroids for 6 months. This was extra stress I didn't need. I then became type 2 diabetic, diet controlled.

I went for a medical assessment with my company doctor, who after examining me announced that I was "unemployable for the foreseeable future". For a workaholic it was devastating news, the thought of going back to work one day had been keeping me going.

Sara and Darren planned to get married September 2003, I managed to get showered and dressed and then needed to go back to bed and sleep. I told Marcus I couldn't go to the wedding but for him my staying at home was not an option. We went and I only managed due to the fact I used my electric scooter. As soon as the speeches were over we left, which was upsetting for all involved.

Though my last relapse was back in May 2002, my MS had been progressing to the extent the strength in my left leg went, and it was at that point I was told by my Neurologist that I was Secondary Progressive and there was nothing more that could be done for me. So, no plan B: We would see about that.

When I needed the toilet I would struggle to get to the PC and I would then sit for a short time, squinting with one eye and try to find out what other people were taking for MS. I eventually, after a few weeks, found LDN and people already taking it with great results.

I printed everything and took it to my new doctor, the original one had retired. I now have a great young lady that could have been a school friend of Sara's! I asked her to read the documents and tell me what she thought and could she prescribe it. I went back two weeks later and she said the partners in the practice wouldn't allow her to prescribe LDN for me, but she said if I got it privately she would be more than happy to monitor me so that is what we did.

I contacted Dr Bob Lawrence who suggested that I change my diet, take supplements and start LDN. I started LDN 3rd December 2003. After just three weeks things were improving and I started to feel like the old me again. This continued for about two years and then I stabilised.

Before starting Rebif in March 2003 I had a 2.5 score on the EDSS scale. Three months after starting LDN in December 2003 it went to 0, where it still is today.

Ok, I know I have MS but life is good. I can set targets and achieve them; I once again have goals and aims for the future. I'm not troubled by my old symptoms apart from fatigue and hot weather.

After my success with LDN I wanted everyone to know about it. I formed the LDN Research Trust in May 2004 and I spent all my time trying to help other people who are in the same place I used to be in, whilst trying to raise funds for LDN clinical trials.

My biggest blessing is having my grandson Leo; I can be the grandmother to him that my mum was to my girls, something that wouldn't have been possible before LDN.

Life isn't the same as 1999 for any of us, things have changed but then nothing stays the same in life for anyone. I now am not afraid of what the future holds....

Update – July 2009: The only thing that has changed is that I was very ill with diabetes at Christmas. I have Type 2 Diabetes and I was no longer able to control it with diet. I had to start taking a slow release metformin. I also had to loose weight so I halved my meals and have lost 40 lbs since Christmas!

MS wise, I had flu just before Christmas, which was the cause of my diabetes playing up and my MS symptoms starting to return (in the form of chronic fatigue and leg weakness). Once everything settled down, so did the MS symptoms and I'm the same now as I was this time last year :)

#### Update April 2010

Yes, I'm still taking LDN and it is still benefiting me.

Everything remains the same.

I should add though that last winter from October 2009 to January 2010 I was sick: I had laryngitis 4 times, a chest infection, and a UTI that took 5 courses of antibiotics to clear up. Although I felt very ill, my MS behaved itself and I put this down to the LDN.

In consideration of the workload associated with the first International LDN Awareness Week, I think it was to be expected to some degree. I'm being more careful in the leadup to the 2010 Awareness Week, trying to pace myself and spread the workload evenly.

### 109

#### Lisa C, UK January 2009 - Multiple Sclerosis February 2009 - LDN

This is my story about how I came to be taking LDN and how it has affected me. In January of this year, 2009, I woke up one day and noticed that my feet felt kind of funny on the floor, not numb or tingly, just a little funny. I thought I was imagining it. Later that day I realized that I couldn't feel my bottom properly when I sat down (saddle anaesthesia).

This worried me a lot as I work as a physiotherapist and new this was a red flag and could have serious implications, that is; that there may be some sort of pathology occurring which could potentially reduce bladder and bowel function.

Later that evening, these symptoms had not subsided and so I decided to go to Accident and Emergency to make sure there was nothing sinister going on.

I waited 3 hours in A&E... until 4am to be seen and told there was nothing wrong with me and I may have a virus but it would clear up and I would be fine. I went home.

At this point I couldn't feel any of my feet properly. The numbress was worsening and spreading. I managed to get an urgent appointment with a consultant physiotherapist where I worked the following day.

By the time I saw the physiotherapist, the numbness was spreading up my legs as far as my knees and parts of my thighs, symmetrically. He was unsure what was causing it since it did not fit anything he knew. MS came to mind, but symptoms for this are not usually symmetrical. He felt I required an urgent MRI scan of my lower back and wrote a letter to my GP requesting this.

The following day I saw my GP with the letter from the physio, he felt I needed to see a neurologist urgently as I may have a condition called Transverse Myelitis (TM). I was referred to my local hospital where the urgent waiting list was 9 weeks long. My numbress at this point was still progressing and I had a gripping sensation around my calves and thighs. The proprioception in my toes was gone, i.e., they felt like they were all twisted and contorted but they were obviously in the correct position.

I read up on Transverse Myelitis and realised how serious this could be. The cause is not really known but it is felt to be caused by a virus, which in turn triggers inflammation and demyelination of a section of your spinal cord. All function is then lost below this level to some degree. This can mean in many cases complete loss of all feeling and strength and even the requirement of going on a ventilator to support breathing. I was so scared. It was like living a nightmare.

Each day the numbness would progress and I didn't know when it would stop. Would I become incontinent, would I be in a wheelchair and never walk again, would I still be able to breathe. I tried to book a neurology appointment online with the NHS's online booking facility, only to be told the system had locked me out just as I tried to book it online, as you are supposed to. I then had to wait until the following day for the system to unlock itself, but apparently, this particular appointment couldn't be booked online, and I was told I would have to ring up to do this, which I did.

I was so stressed and angry. I decided to book a private appointment and lost faith in the NHS there and then, and to be honest... this faith has never returned.

I managed to get an appointment at a local private hospital 2 days later. I attended this and had a thorough examination. I was given a probable diagnosis of Transverse Myelitis and told to rest as much as I could to get the best possible outcome. An MRI scan was arranged which I also had to pay for since the NHS waiting time was another month minimum, and that was if he pushed it. By this time it would have been too late for any treatment.

Possible treatment consists of IV steroids, but generally these are only beneficial when used within the first month. I organized the scan myself at a private hospital I used to work in. I had this within 3 days. I then had the results 2 days after this. These were inconclusive. They showed a lesion on my lumbar spine, a large one in my neck and a few in my brain stem, indicative of Multiple Sclerosis (MS).

By this time my thoughts had moved from 'please, I don't want transverse myelitis' to 'please let it be TM and not MS'. I didn't have sufficient lesions on my brain to confirm as MS, but on the other hand, TM spares the brain - you get no brain lesions. Therefore, a lumbar puncture was arranged. I had this the following week with a barrage of blood tests.

During this time my numbness had progressed to chest level. I had a very tight girdle like sensation around my waist that moved up to chest level. At times this was so tight I felt like I couldn't breathe properly. I had strange muscle spasms all around my rib cage that felt likes big worms wriggling around my back. I had muscle spasms on my chest muscles. These often woke me and made me catch my breath. I had constant vibrating down my spine.

Whenever I woke in the morning I never wanted to move, as just for a few seconds, I felt normal. I had no sensations, then as soon as I moved just a little, just once, all the sensations returned. I felt like I had constant water being flushed around my legs. Although my legs were numb, if anything sharp touched them, they were so hypersensitive it felt like someone had pushed pins into me.

One day I realized I wasn't aware any more if I needed the toilet - I just had no sensation at all, so I took medication to make me go to the toilet.

I had so much fatigue and constant exhaustion that sometimes I didn't have the energy to speak. Going downstairs once a day exhausted me for that day and the next. I had to sleep for the majority of every day. I couldn't look after my daughter at all, not even get her dressed, so she had to stay with her grandparents in Essex at the other end of

the country. This was truly terrible. I couldn't move properly, feel anything, keep awake more that a few hours, be a proper wife and I couldn't be a mother at all.

My brain had become like a fog, my memory was impaired, concentration had gone - I felt like I was thinking through a cloud. How could I ever work again?

I used to put a really tight belt around my waist so I could feel the crushing sensation less and enable me to forget about it enough to get some sleep at night.

When I rested I would get little flickers of muscle spasms all over my body, like little twitches and aching and strong jumping in my left thigh.

My legs felt like I was walking on planks of wood that did not belong to me and when I lay in bed I felt like I was floating in space as I couldn't feel the pressure of the bed on my body.

I returned for the results of all my tests. My neurologist at that time was very lovely and read me very well. I knew for this to be MS they were looking for something called Oligoclonal bands in my lumbar puncture. Right in front of where I sat was a bright yellow post it note with positive for oligoclonal bands written on it. The consultant kept flicking this up so I could read it. I guess he was preparing me.

All the other tests were negative. But, this still wasn't a conclusive diagnosis. For a proper diagnosis of MS you have to have a second relapse. All he could tell me was it was probably MS. So there was no treatment they could offer me at this point. I just had to wait and see what happened.

I discussed with him some research I had read on the internet. This was about people in my situation with probable MS, and that if they receive the Disease Modifying drugs for MS at this point, they had much less chance of going on to get clinically definite MS. I asked him if I could have this treatment so I wasn't left in this limbo situation. He agreed to refer me, but said I probably wouldn't get accepted for this as I didn't fit the criteria, but he would try.

I was accepted to see the MS neurologist at my local University NHS Hospital, and I was sent an appointment to see him within 2 months.

Whilst resting as home and awaiting for this appointment, I spent a lot of time on the internet, determined to do all I could to help myself get the best outcome possible. I joined the MS Society forum and started reading about supplements that can help, eg vitamin D and Omega 3's etc. I asked for advice on the MS society Forum. A very kind man suggested I read the information on LDN research; which I did. This was when I discovered LDN.

I had already read about the usual NHS treatments for MS that require sometimes daily injections. These drugs only at best reduce relapses by 30%. They mostly suppress your immune system which obviously isn't good and have many bad side effects such as flu like symptoms, infections at the injection sites in very large numbers of people, and they do not help address the chronic fatigue that I was experiencing. I have a 3 year old daughter, a busy job as a physiotherapist and have only been married for 3 years. I just had to get better from this and find something to help me.

I asked a lot of people a lot of questions on the internet regarding LDN and their experiences, not to mention the Dr who prescribes me my LDN who gave me a huge amount of information. I even asked a friend that worked for a big pharmaceutical company about what she thought, and if she'd got any inside information on the drug side of things. I was scared and very hesitant to take LDN as it hasn't been clinically trailed for MS. Also, I didn't have a confirmed diagnosis, and my neurologist wouldn't prescribe it for me.

During this time, I started to have new symptoms; tingling in my face and lower jaw and occasionally around the top of my head. I knew this meant it was likely to be MS. Transverse Myelitis does not give facial symptoms unless you have a very high lesion on your neck, which I didn't.

I then started to get numbness above my chest and down my arms. I was now afraid I was going to lose feeling in my hands as well. This would have made functioning at all very difficult. At this point I decided to take the plunge. My husband was so supportive, that for my first dose, he took it first!

That was 6 months ago now, and I haven't looked back since.

Within a few weeks of taking the LDN my energy levels gradually returned. I had to very slowly increase my dosage as I am very sensitive to medication and so I started on an extremely low dose. Every time I increased the dose I felt better. My brain fog, concentration and memory all cleared within 2 weeks. I actually feel like my concentration is better than before my illness.

My energy levels are fantastic and I'm living my life normally again. Yes I have to be a little careful not to overdo it, but to be honest I have more energy than my husband!

As for my symptoms, they initially worsened but only for a few days. I was told to expect this. Then, they all very gradually disappeared. The Girdle like sensation went first. Then my sensation began to return in the same order it had first developed.

I now have just a tiny bit of numbress in one finger, slightly reduced sensation on both big toes and a bit of tingling in my face but only when I'm tired or stressed. I get the occasional tingling on my thighs when I have done some exercise.

I attended my NHS consultant appointment and I discussed LDN with him. He completely dismissed it, would not look at me, or talk about it at all. He arranged some repeat MRI scans to look for any new lesions that would give me a definite diagnosis. There was a 3 month wait for this.

I had the results to these only a few days ago. I have no new lesions, and in fact one of the brain lesions has gone, which is great. I was told by my neurologist that I wouldn't go a long time without a relapse given what my lesions were like.

But it is not plain sailing from here. The large lesion in my neck, which resulted in my numbness, still has some inflammation around it. This hasn't properly settled down yet. There is a risk this can all happen again, if this lesion reactivates.

I take many supplements alongside my LDN to help me, and I will never stop taking the LDN. All my lesions indicate MS, and I believe LDN has helped my lesions.

Well, touch wood, I haven't had any relapses so far. My energy levels are fantastic. I even rode the Tissington trail the other week! My thinking, memory and concentration are better than ever and I feel great in myself. These are all certainly down to the LDN.

This drug needs trialling so that it can be available to all those people that need it so much.

#### UPDATE March 2010

I still take my LDN and have settled at a dose of 3.5ml per day.

A year since starting LDN and I am still improving. The vibrations I had in my left leg have gradually disappeared and I just have a little tingling in my middle toes on both legs after I have exercised. This recovery may have happened without the LDN, but I'm just glad it's happened!

I have only had one small relapse in the past twelve, and that was directly following a set of holiday immunisations I had, and they were entirely to blame. I made a full and quick recovery from this. Other than that I feel great. No relapses and no progression. Yeh! So I shall keep on my LDN.

# 110

#### LS, UK 2007 - Relapsing Remitting Multiple Sclerosis (RRMS) October 2008 - LDN

I'm a 50 year old female with Relapsing Remitting Multiple Sclerosis, and I was diagnosed some 2 years ago.

The diagnosis itself was a big shock and was not helped by poor communication and lack of support from a variety of health professionals.

The original diagnosis did not include or recommend any treatment as 'it was not necessary and I would not want to inject myself and have to cope with awful side effects'.

However, I am a confident person, literate and totally supported by a lovely husband. I am also a full-time Director in a College of Further and Higher Education, which include specific responsibilities for people with learning difficulties and disabilities.

This position also gives me full access to all possible literature and a search of all unbiased European research quickly made me realise that I should be prescribed medication, and as soon as possible. As a result I have been on Copaxone for more than a year now and, despite the assertions of my consultant, get on with this very well.

I keep up to date with news from the MS world, and my husband found an article in the Daily Mail about the Welsh GP who has MS and takes LDN. Further research into LDN

convinced me that this had been well-tried and tested, was relatively cheap, and could help to address my energy levels and my stiff limbs in the mornings.

I got the address of an LDN prescribing consultant from the LDN Research Trust, made a private appointment, and have been taking LDN for more than 10 months

Since taking LDN, I've had no stiffness in the morning, higher levels of energy, improved circulation, and have been feeling good all-round! I've had no side effects at all, and I continue to work full-time in my role.

The response from my consultant is that I am wasting my money on "quack medication". Despite this assertion, I continue taking LDN and have recommended it to others. A colleague of mine has been taking it for more than 4 months now. She also has Relapsing Remitting MS, and she reports that the biggest change is that her feeling of depression has been lifted and she feels positive about life again - worth every penny as far as I am concerned.

I would like to conclude with a plea that GPs take LDN on board and prescribe it and that other health professionals at least respect the LDN choice their patients make.

#### UPDATE April 2010

I am still taking LDN and benefiting from it.

I will add, that at my latest visit my consultant did not comment on LDN as being 'quack' medication but enquired as to the identity and qualifications of the prescribing physician... and my condition has not deteriorated.

#### Lynne M, Scotland 1982 – Multiple Sclerosis November 2009 - LDN

111

I was diagnosed with Multiple Sclerosis in November 1982, in my early thirties, when I totally collapsed after trying to put out a fire in my home, and get my babies out safely before the fire brigade came. It was a dramatic onset of MS, the hospital said, and I was diagnosed straight after a lumbar puncture.

At the time, I had a 7 year old, a 4 year old, and a 1 year old baby still being breastfed. Thankfully, I had a wonderful NHS doctor. They gave me all the books on diet, eg; Judy Graham, Roger McDougal, Swank, etc; and all the vitamins on prescription.

It was she who raised funds for me to have HBO in Dundee, and organised a childminder till I could walk again. I did very well for years and even had a fourth baby which I breastfed fully for a year as recommended. I even had the immense personal satisfaction of returning to teaching after 25 years, though I kept my illness a secret from them for years, until my M.S. nurse advised me against coping with the strain of that secrecy. My illness very slowly progressed though, until my right hip became very stiff and spasm-y and I couldn't stand long without low back pain. I began to lean on a stick when I was out, especially at airports.

Then in 2008, I needed Baclophen for a very stiff neck, lower back and legs. It came on after an ecoli infection I had while abroad. As you can imagine, the high fever and dehydration literally 'floored' me. It also affected my blood and liver enzymes for a year as well as my balance. I began to need a stick for walking outside again after 25 years. I was also getting very fatigued, and falling asleep as soon as I got in from work or shopping.

I heard about LDN online and thankfully, I went on it in November 2009. My doc says my illness is now inactive, and he believes it will stay that way! I so hope he is right!

### 112

#### Maija H, Finland December 2005 - Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (M.E.) March 2007 - LDN

Maija Haavisto is a 26-year old CFS/ME patient and medical writer from Helsinki, Finland. Her CFS/ME, the symptoms of which first developed in August 2000, was unrelenting and progressively debilitating from onset.

As CFS/ME is not recognized as a real illness in Finland, it took her years to get an official diagnosis, let alone any kind of treatment. Her sick leaves and disability applications were all rejected - the public insurance provider pronounced her perfectly healthy, as in their eyes her illness did not exist.

By 2007 Maija's condition was rapidly declining. She was plagued by severe cognitive difficulties, many troublesome symptoms like chronic fever and chronic urticaria and was barely able to walk enough to get from the entrance of a small grocery store to the checkout. Even the smallest exertion would make her bed-bound, and she was getting desperate. She had already heard of LDN several years before, but her doctors refused to even consider it.

Luckily Maija was able to find an open-minded doctor, who had never heard of LDN, but agreed to prescribe it. She already felt better after the very first capsule. Her walking ability began to return, and her fever and urticaria greatly diminished. Thanks to LDN, and some other medications and supplements, she is now about 70-80% better.

Maija still experiences good days and bad days, but she no longer experiences the awful 'crashes' so characteristic of CFS/ME. While in Scotland to share her experiences at the LDN conference she walked up to 10 kilometres on one day!

Maijas's comprehensive book 'Reviving the Broken Marionette: Treatments for CFS/ME and Fibromyalgia' (ISBN 978-1409203353 www.brokenmarionettebook.com) features over 250

medications for the treatment of CFS/ME and fibromyalgia. It has received good reviews on Amazon and elsewhere. A new, revised Finnish version will be out in May 2010 from the academic publisher Finn Lectura. In it LDN has an even bigger role, as Maija's doctor, a prominent sleep researcher who has adopted LDN as his main weapon against CFS/ME and Fibromyalgia, agreed to write the foreword.

Maija maintains the only Finnish website and forum about CFS/ME (cfs.gehennom.org). She has websites about LDN in both Finnish (ldn.gehennom.org) and English (fiikus.net/?ldn), which contain a large collection of scientific references related to LDN and its mode of action. She also wrote a report on the LDN conference:

(http://autoimmunedisease.suite101.com/article.cfm/report-from-the-2nd-european-Idn-conference-glasgow-april-2010)

## 113

### Malcolm W, USA 1995 – Relapsing Remitting Multiple Sclerosis (RRMS) March 2009 – LDN

In 1991, shortly after the birth of my son, I began losing my balance and stumbling into things. I was 34, in good health, a competitive squash and soccer player. What was going on with me? Was it the stress of our first child? Was it the stress of my job? I called my doctor who sent me to an ear, nose and throat specialist who performed many tests, but found nothing. Was it a brain tumor?

Next, I was referred to a top neurologist at Georgetown University Hospital. He did more tests but unfortunately, still no answers. I was put on a drug called Tegritol for the control of seizures.

After a month or so, my condition got a little better, except for an annoying tingling and numbness in my feet, weakness in my left arm and tightness around my rib cage. I hoped that these symptoms would go away and I just tried to ignore them.

Two years later: My symptoms increased to having double vision and difficulty with focusing. When I turned to the left, my right eye wouldn't follow my left eye. I went back to the doctor, and to another neurologist. Again, more tests. This neurologist thought it was probably Multiple Sclerosis (MS). I knew nothing about MS.

In about two weeks, after a five-day home infusion of steroids, my vision returned to normal, but the strange symptoms persisted, coming and going, some old, some new.

Then I had another attack of optic neuritis, and was again prescribed home steroids. My balance got worse, and because I wasn't able to lift my left foot properly, I started tripping. My squash and soccer days were over. Besides, now we had a new baby girl and there was no time for games anyway.

At about this time a new drug was approved for MS, a beta-interferon called Avonex made by Biogen Corporation. I had to wait a year until enough of it became available, but finally I was able to get it. Avonex requires a weekly intramuscular injection with a two-inch needle. The side effects made me feel like I was coming down with the flu

during the 12 hours following each injection. Another side effect was ongoing depression. And because of Avonex's toxicity, I had to get blood tests every three months to make sure it wasn't damaging my liver.

For the next five years, my wife and I faithfully injected this drug into my arms or legs every Saturday night. The intramuscular shot was difficult for me to do by myself so my wife helped, which she hated. Sometimes we would hit a vein, or a bone. When we hit a vein, the drug went directly into my bloodstream and soon caused uncontrollable shaking. Every Sunday, I felt sick. Even with these weekly injections, my MS symptoms continued to slowly progress.

My limp was now becoming more apparent to everyone. I tired easily and couldn't walk long distances without the help of a cane. People at work started asking me what was wrong and I could no longer brush them off with an excuse. I started to confide in some of my closest co-workers about my MS. Many of them didn't know how to respond, since they had only heard scary things about MS, about crippled, unfortunate people confined to wheelchairs, even bedridden.

My new neurologist decided that Avonex was no longer working and switched me over to a new, more powerful interferon drug, Rebif. Rebif involved three injections per week. But Rebif didn't help, either. The flu-like side effects persisted, and after two years, the depression became unbearable.

My neurologist suggested adding an anti-depressant drug or trying another new MS drug, Copaxone, a once-a-day shot. While the Copaxone involved a smaller needle and the shots often bruised or left welts on my body, I was no longer feeling sick and depressed. I continued with Copaxone for two more years. But still, my MS continued to progress. Soon I could no longer walk more than 10 feet without a walker. I bought a wheelchair and an electric scooter.

My neurologist now decided that the Copaxone was no longer working, either. I asked him about a drug I had recently read about on the Internet, called Low Dose Naltrexone (LDN). He quickly dismissed me, saying there was no clinical data on LDN. It was, he said, an "Internet cult drug." I asked him questions about how LDN works, but it was obvious that he knew nothing about it; nor was he willing to learn about it, or talk about it with me.

Instead, he recommended that, since the drugs I had tried so far weren't working, I begin chemotherapy treatment. (Note: In a further effort to suppress the immune system, chemotherapy is sometimes given to MS patients when the more often prescribed drugs haven't worked. The primary function of all of these standard-of-care MS drugs and treatments is to suppress the immune system.)

For the next year, every three months, I went to an infusion center where they injected a dark, inky blue chemo into my veins. I began losing my hair, was nauseous for several days, constipated and urinated blue. It was obvious this drug was especially toxic because before each session, I had to get an \$1800 test at the hospital to make sure the chemo was not permanently damaging my heart function. They injected radioactive dye into my bloodstream. The technicians wore gloves to protect themselves from any exposure. My blood was also tested before every infusion for the possibility of developing leukemia from the chemo.

In 2004, another new MS drug was approved: Tysabri, a monoclonal antibody, is a drug

that prevents T-cells from crossing the blood brain barrier and attacking the myelin nerve coating. Tysabri involved an infusion every four weeks at a cost of over \$4000 each time. I was referred to a new neurologist for a second opinion. He authorized the drug and my health insurance approved it.

With Tysabri, I would have to have a \$2,000 MRI scan every six months because the drug can cause Progressive Multifocal Leukoencephalitis (PML), a rare and usually fatal viral disease characterized by progressive damage to the white matter in your brain. People with compromised immune systems get PML, so people with MS are particularly susceptible. Interferons, chemotherapy and Tysabri all suppress the immune system. Biogen, the company that makes Tysabri, originally conducted trials on Tysabri, in combination with their interferon drug, Avonex, hoping for better results and profit potential.

The combination proved too much for several MS patients who developed PML and died: Several others sustained permanent brain damage. Biogen briefly withdrew Tysabri from the market but reintroduced it in late 2005 as a monotherapy with an FDA 'black box' warning.

Even though I wasn't getting any better, and even though I was wary of taking this drug, I was grateful to have good health insurance because my MS treatments, which were always expensive, were now costing well over \$40,000 a year.

Every four weeks my wife drove me to the infusion center where I shared the room with approximately twelve other patients, most of whom were receiving chemotherapy for some type of cancer. I felt strangely fortunate that I 'only' had MS. On the other hand, I felt unfortunate to be the only one who usually arrived in a wheelchair. At the infusion center, when people completed their chemo treatments they rang a bell on the wall and the nurses all cheered and wished them good luck. There was always a cake and lots of food and snacks available, supplied free by a constant stream of attractive pharmaceutical sales representatives. As time passed, my wife and I become very disappointed with Tysabri, since it turned out not to be the miracle drug some people reported. There seemed no end to this treatment and I never got to ring the bell.

Because I could no longer walk and travel on company business, I lost my job in the beginning of 2008. The human resources manager told me they were simply downsizing as a result of the weak economy, and unfortunately there were no other positions appropriate for me, and that the company was struggling. But we both knew I was let go because I was now in a wheelchair. Discrimination can be hard to prove in a recession.

No job meant that soon there would be no more health insurance for my family. I contacted my health insurance provider to inquire how much the new monthly premium would cost after COBRA expired. I was told the premium would double from \$1486 to approximately \$3000 a month. While under the law, this health insurance company had to accept me regardless of MS as a pre-existing condition, other insurance providers would not have the same obligation. My wife and I decided to drop health insurance coverage for ourselves after COBRA expired, and just buy HMO policies for the children.

At this point, I decided to start my own business, working from home creating websites for meetings and events, even though it was not the best time to start such a business: The Great Recession was tough on everyone. After 18 infusions of Tysabri I decided it was time to stop. Now that COBRA had expired, we could not afford the \$4000 monthly

cost of treatment on our own, and Tysabri didn't seem to be working anyway. Besides, I knew that the longer you take it the greater your risk for developing PML. One out of every 1000 Tysabri users developed PML and, as of October 2009, 23 people had developed the brain infection (<u>http://www.xconomy.com/boston/2009/10/23/biogen-shares-drop-as-tysabri-pml-cases-climb-to-23-europe-may-seek-drug-holiday/</u>).

Two years after the release of Tysabri, there was still no safety data on this drug and it appeared the chances of getting PML increased the longer one was on the drug. 46,200 people worldwide were on Tysabri, with that number to increase to over 100,000 in 2010. Many of those people will now have been on the drug well over two years. Biogen still recommends MRIs every six months to check for PML infection.

While all MS drug costs have increased dramatically over the past five years, Tysabri only increased 5.8% in 2009. And while Avonex increased 9% in 2009, it had actually increased in price 53% since 2007. On July 17, 2009, an article in The Wall Street Journal noted that Biogen had been able to raise prices in the middle of a recession, and that the company had embarked on a new effort to persuade doctors and patients that Tysabri's potential PML side effect were minimal.

(http://online.wsj.com/article/SB124774457299150965.html)

Now with no health insurance, I turned my attention back to Low Dose Naltrexone (LDN), which I knew was inexpensive. Besides LDN, I really had no options for treating my MS other than begging for financial assistance from Biogen, or from one of the other MS drug companies. However, in order to qualify for assistance, we would first have to drain our savings and our children's college fund.

To this day, we continue to receive the glossy direct mailers from Biogen touting the many benefits of Tysabri therapy. They show attractive, happy MS patients leading active lives, thanks to Tysabri. In these brochures, no one is using a cane, a walker, an electric scooter or wheelchair. There are no disabled people in any MS drug advertisements, only attractive healthy people smiling, laughing, walking, running, climbing and biking. Having MS almost looks like fun. And just about every MS drug company has a celebrity spokesperson who clams their drug contributes to their active, productive life.

Soon after I stopped taking Tysabri, a woman from Biogen called me to ask why I had stopped. Was there a problem? How could she help?

At this point, I again asked my neurologist to write me a prescription for LDN, and again he declined. Instead, he recommended I undergo plasmapherisis, a process where they admit you to the hospital and your blood is removed. The plasma is then separated from the blood cells, and the blood cells are returned with a saline solution, evidently free of the cells that were attacking your myelin. My doctor told me that, although he couldn't guarantee that it would stop my MS progression, he thought it was worth trying. I told him I'd "consider it" (I had no idea how I would pay for it). I left his office, never to return.

Thank Goodness for the Internet.

The Internet is a gift for people with MS. Up to about five to six years ago, the only way you could share information with other multiple sclerosis patients was by going to a monthly National Multiple Sclerosis Society meeting or attending a drug company sponsored seminar.

There, a neurologist would give a talk about new MS drug treatments, while you'd be served a hotel chicken dinner. You'd leave with a new tote bag bearing the drug company's logo, and brochures and pens handed out by attractive drug company sales representatives. Of course, they'd get your name and address and soon you'd begin receiving direct mailers with pictures of happy people enjoying an active MS lifestyle while taking their company's drug. The neurologist would leave with new patient referrals and a speaking fee from the drug company sponsor.

Now, MS patients can communicate worldwide through many websites and discussion forums. Soon, I found out more about Low Dose Naltrexone and was referred to a doctor who agreed to prescribe it with only a phone appointment. He didn't accept health insurance, which was fine since I didn't have any. His charge was very affordable at US\$135. When I called this doctor and asked him what he thought of LDN, his words were direct; "LDN stops MS in its tracks." He wrote me a prescription for a three-month supply and I filled it by mail order at a compounding pharmacy in Florida for \$55. The doctor would have to renew my prescription every three months, at a cost to me of \$35 a month.

Excited, I took my first 1.5mg LDN capsule and went to bed. A night of interrupted sleep and 'vivid' dreams followed, but the next day I awoke with a smile on my face. The resulting 200% to 300% increase in endorphin production from LDN caused me to feel pretty good. After a few more nights the disturbed sleep patterns started to dissipate, though my dreams continued to be vivid and entertaining.

After two weeks I doubled my dosage of LDN to 3.0mg, as instructed. In another two weeks, I increased it to 4.5mg, the recommended dose for multiple sclerosis and other autoimmune diseases. While I experienced some stiffness in my legs, I soon found that the drug caused no other side effects besides deep dreams and perhaps the most restful sleep I had experienced in decades.

My multiple sclerosis fatigue lifted almost immediately. Prior to taking LDN, it was not uncommon for me to have to take a nap two, or three times a day. People who have MS often complain that fatigue is the most difficult symptom they struggle with, and many take additional drugs to help them stay awake. My balance also improved and I found myself not falling as much as I made my way through the house with my cane or walker. My vision, which often suffered from optic neuritis, the result of MS plaque on my optic nerve, returned to normal.

One problem almost all people with multiple sclerosis have is the urinary urgency or incontinence, and I was no exception. Since starting LDN, rushed visits to the bathroom have diminished greatly. Finally, my general mood became more elevated. I felt great. No more depression side effects like those I had experienced while on the interferon treatments. And it was a cheap little pill! No shots. No infusions. No blood tests. No heart scans. No neurologists. My MS drug therapy was now costing me less than \$500 a year.

Yet, most important – and most exciting – is that after taking Low Dose Naltrexone now for over a year, my MS does not seem to be getting any worse. At best, the FDA-approved multiple sclerosis drugs have only been found in clinical trials to slow progression between 30 and 40%.

The most toxic and invasive treatment, Tysabri, has been shown to be 66% effective in slowing progression with multiple sclerosis patients who have the relapsing remitting

form of the disease. People usually start by taking an interferon treatment first, and if that fails to slow progression a neurologist will recommend Tysabri.

All these treatments are very expensive, costing between \$2000 and \$4000 per month. The accompanying tests - such as MRIs and blood tests – and the doctors' visits are extra. All have significant toxic side effects and severely compromise the body's immune system. All multiple sclerosis drug treatments are based on the assumption that the way to treat the disease is to suppress the immune system.

The common belief is that rogue T-cells are for some reason attacking the myelin coating of nerves in the brain and spinal cord. Preventing these T-cells from attacking the myelin is the primary function of all MS drugs. Likewise, other autoimmune disease treatments for conditions such as rheumatoid arthritis, fibromyalgia, lupus and Crohn's Disease are based on the same assumption; suppress the immune system.

Running contrary to this assumption, LDN boosts the body's endorphin production the day after you take it and these increased endorphins better regulate the immune system. Other substances like vitamin D and Omega fatty acids also help regulate the immune system. As the human body ages, its capacity to effectively produce endorphins declines. As a result the immune system weakens and becomes less capable of protecting us from illness, chronic diseases, and cancer.

It is well known that multiple sclerosis is largely a Western disease. People usually come down with MS in adulthood and most often, these people live in regions of the world that receive less sunlight. Or they may pursue a lifestyle that limits their exposure to sunlight. Or they eat a fatty diet that is not rich in Omega fatty acids. Or they may have been exposed to some type of environmental toxicity.

These lifestyle issues, coupled with possible genetic factors, appear to make some individuals more prone to developing multiple sclerosis, as well as other similar autoimmune diseases. People with MS are almost always found to have low vitamin D levels and accordingly, low endorphin levels.

Further supporting these findings would be the evidence that many people with multiple sclerosis report success limiting disease progression by regular exercise and following a low-fat diet rich in omega nutrients. These people are increasing endorphin production and maintaining a well-regulated immune system. LDN basically does the same thing.

The limited dose of Naltrexone, taken at bedtime, blocks opioid receptors and tricks the pituitary gland into over-producing endorphins. In the next 16 hours the pituitary gland pumps out 200-300% of the normal amount of endorphins. Taking LDN is essentially like going for a run every day without your muscles participating. For people with a chronic disease like MS, which limits mobility, LDN may be the only way to consistently generate sufficient endorphins to regulate the immune system.

The implications of maintaining high endorphin production as the body ages are profound. We already know that older people who incorporate exercise into their daily routine usually lead healthier, longer lives. Could LDN help prevent age-related disease, deterioration and extend the human life span? I think it is quite possible.

It's also interesting to note that Tysabri, said to be the most effective MS treatment available today, is now being used successfully to treat the inflammatory bowel

condition, Crohn's Disease. LDN, too, has been found an effective treatment for Crohn's.

The April 2007 issue of the Journal of Gastroenterology published the results of a study carried out by Dr. Jill Smith and Ian Zagon at Penn State. The study titled 'Low-dose naltrexone therapy improves active Crohn's disease', concludes that 67% of patients experienced complete remission and 89% experienced symptom improvement with LDN. The study concluded that LDN is safe and effective for patients with Crohn's disease, and that further studies on LDN for patients with Crohn's disease are warranted.

(http://www.ncbi.nlm.nih.gov/pubmed/17222320 and (http://www.suite101.com/blog/daisyelaine/crohns\_disease)

Multiple Sclerosis and Crohn's Disease seem linked, and Tysabri is said to effectively treat both. So apparently can LDN, but LDN costs less than a dollar a day and there is no risk of PML, as opposed to Tysabri costing over \$130 a day and carrying a high risk of PML.

Immune suppressant multiple sclerosis drug treatments, while somewhat effective, carry the risks of compromising the immune system, as well as possibly damaging the liver. People with MS may therefore be exposing themselves to significant dangers the longer they remain on these drugs. This was the case with the PML brain infections and resulting deaths that occurred from Tysabri. By compromising the body's immune system, the latent PML virus, present in everyone, was released.

The concept that you can treat a wide variety of debilitating autoimmune diseases with this generic drug that costs less than a dollar a day would be catastrophic to the for-profit US healthcare industry. Multiple sclerosis drugs alone represent an approximately \$9 billion a year marketplace, not including the countless tests and doctors' visits involved. It is estimated that immune/inflammatory drug treatments in the US exceed over \$68 billion a year, supporting approximately 375 drugs from 250 companies. (http://www.news-medical.net/news/20100105/Report-on-the-lucrative-immuneinflammatory-disease-marketplace.aspx)

These maintenance drugs are continuing revenue streams. No one gets cured. Besides large drug companies, hospitals, doctors, and medical technicians, autoimmune disease supports countless researchers, foundations and charitable organizations. LDN has the potential to turn this status quo on its head.

For multiple sclerosis, all it would take would be a relatively small clinical study to prove whether LDN is a superior first-line treatment for those newly diagnosed with the disease. Every day approximately 200 people are diagnosed with MS in the United States. Take 200 of these people and give 100 of them a standard beta-interferon treatment and the other 100, Low Dose Naltrexone. Conduct an MRI scan at the beginning of a two-year study and an MRI scan at the end and measure plaque formation in the brain and spinal cord.

All LDN needs is to be equal to or more effective than 40% in slowing disease progression and it becomes the preferable treatment in terms of administration, cost, and toxicity. If LDN were shown to be more effective than beta-interferon treatment, it would validate the tens of thousands of user reports that LDN either completely halts disease progression or is 80% effective at slowing disease progression.

The lucrative US \$9 billion multiple sclerosis drug marketplace would soon collapse.

Despite several large user surveys that consistently demonstrate that LDN is between

80 to 85% effective in preventing MS exacerbations (<u>http://www.ldners.org/surveys.htm</u>), there has been a strong reluctance from the medical establishment to investigate the drug.

Even the National Multiple Sclerosis Society (NMSS) is highly resistant to supporting any meaningful LDN research. To date, NMSS has only directed \$40,000 for a small study conducted in mice by Ian Zagon, PhD to determine whether LDN is safe. In that study done at Penn State, not only did no mice die, but those injected with the MS-like disease saw no progression while taking LDN. And those already taking LDN never came down with the MS-like disease

(<u>http://autoimmunedisease.suite101.com/article.cfm/low\_dose\_naltrexone\_in\_experimental\_model\_of\_ms</u>).

Despite these published results, the NMSS maintains the position that 'further studies are needed to determine if LDN is safe for people with MS'. NMSS has turned down all further LDN research study grant proposals from Penn State without comment.

It is estimated that well over 10,000 people worldwide currently take LDN for MS, and no one has died or reported life-threatening side effects. People who take LDN rarely stop taking it. Unfortunately, the four major multiple sclerosis drug manufacturers are major contributors to NMSS. One only needs to pick up a copy of the monthly edition of MS Momentum and see the full-page advertisements to understand their power and influence.

Every day 200 people walk into a neurologist's office and are given the devastating, lifechanging news that they have MS. And every day 200 people do not hear about LDN. Instead, they are encouraged to take a drug treatment that is only 30 to 40% effective in slowing disease progression, requires weekly if not daily injections, carries unpleasant and often very toxic side effects, and costs over \$2500 a month - not including required tests and doctors visits.

They never hear about a drug that cost less than a dollar a day, is a nightly pill, is nontoxic, makes you feel better and may halt the disease in its tracks. They will only hear about LDN if they aggressively search out alternative treatments for multiple sclerosis, or if they hear about LDN from a concerned friend. Most likely, they will only learn about LDN after their disease has progressed, after they have already experienced permanent damage to their myelin, and after they've lost their ability to walk. In other words, after the other drugs have failed.

They will not hear about LDN from their neurologist. No neurologist will suggest taking LDN first because no pharmaceutical sales rep visits their office with free samples. There are no all expenses-paid LDN conferences at golf resorts. No fancy dinners. No consulting fees. What is going on is a modern medical tragedy and this is why I have joined well-known UK LDN advocate Linda Elsegood, and several others to start www.LDNaware.org.

The mission of LDNaware.org is to raise public awareness of LDN. Our slogan is: 'The more people who know about LDN, the more people will benefit from LDN'. While a clinical trial proving the efficacy of LDN would indeed be valuable, it is unlikely that it will overcome the many obstacles the healthcare status quo will intentionally, and unintentionally, put in its path.

The greatest resistance to LDN will always be found in the US where a for-profit healthcare system prevents many lower cost, or generic treatments from being explored. In other countries, such as the UK, Germany, France, Australia, Canada and

Japan, where health insurance does not distort market supply and demand forces, LDN is already gaining fast acceptance.

People and governments simply cannot afford multiple sclerosis and other autoimmune therapies that cost in excess of \$40-50,000 per person, per year. In the UK, many MS-related organizations and charities have already embraced LDN, while in the US their counterparts have not. If the NMSS were to seriously consider supporting LDN research, they would risk angering their four drug company sponsors, and accordingly, their careers and lucrative salaries. (Joyce Nelson CEO of NMSS makes a \$475,000 a year salary (Source: NMSS)

As a grassroots movement, LDNaware.org is a means of organizing the world community to effect change across many countries and cultures without the interference of for-profit interests.

LDN has changed my life. My MS-related symptoms have improved and my disease does not seem to be progressing. However, I still walk with a cane or walker and require use of a wheelchair or scooter. I did not learn about LDN soon enough, so I have permanent damage to my cervical spine. It does not have to be this way for others - if they learn about LDN when their disease is first diagnosed.

I envision the day when a neurologist will sit down with a terrified, newly diagnosed MS patient, and will recommend LDN as a first treatment, before the costly, toxic, injected drugs. The phrase as related to the common interpretation of the Hippocratic Oath, 'First Do No Harm', would seem to apply to LDN.

I continue to tell everyone I know about LDN. My wife now takes LDN for her mild Crohn's Disease that is now in remission. My 83-year-old father takes LDN for a Parkinson's-like disease that has now not progressed any further. His neurologist just shakes her head and keeps renewing the prescription. She has even started prescribing LDN for her MS patients who request it, and they keep reporting positive results.

My mother takes LDN for depression and has since stopped her Zoloft. The increased endorphins resulting from nightly LDN make her just "feel better." Could LDN be a preferable treatment to the multi-billion dollar antidepressant drug marketplace? I certainly think it is worth trying LDN first.

In business, a cash cow is 'a product or a business unit that generates unusually high profit margins: so high that it is responsible for a large amount of a company's operating profit. This profit far exceeds the amount necessary to maintain the cash cow business, and the excess is used by the business for other purposes'.

Every company wants a cash cow to milk. Multiple sclerosis and other autoimmune disease patients are the cash cows of pharmaceutical companies, specialists, hospitals and testing facilities. As long as these patients have good health insurance, they will be fed a never-ending supply of expensive drugs that require expensive visits to doctors who, in turn, prescribe more expensive tests. It is a never-ending cycle in which the patient never gets any better, but only 'manages' his or her condition while waiting for the next drug to arrive.

Perhaps it will be a drug that no longer requires painful injections, perhaps it will not harm your liver, or perhaps it will not make you feel sick after taking it. One thing is

certain: If a pharmaceutical company makes it, you will have to take it forever and it will cost a fortune.

Autoimmune disease treatment is a multi-billion dollar marketplace that is only getting bigger. Better medical diagnostic equipment identifies MS earlier than ever before, and drug company sponsored doctors recommend DMDs (Disease Modifying Drugs) as soon as possible.

(Source:<u>http://www.nationalmssociety.org/search-</u> results/index.aspx?pageindex=0&pagesize=20&keywords=Disease+Modifying+Drugs&x=10&y=3

Drug companies battle to show which drug is more effective with slick marketing of confusing clinical trial data to participants whose disease is characterized as 'relapsing and remitting' – disease that comes and goes. The FDA is pressured by patients, doctors and drug companies to approve something for MS patients, even though, in clinical trials, all first-line MS drug treatments have been found to be really no more than 15% as effective as a placebo. The armies of attractive drug salespeople swarm doctors' offices bearing food and trinkets with sales targets of increasing prescription volumes.

Paid celebrities make TV and conference appearances. Database marketing professionals collect user data, do telemarketing and direct mail, conduct customer satisfaction surveys and entertain their favored doctors – i.e., the ones who prescribe their drug the most. The NMSS holds endless walk and bike-athons across the country to raise money for research, and most of that money goes to fund studies on drugs that are manufactured by pharmaceutical companies. Multiple Sclerosis is a business and autoimmune disease is an industry.

Once acquired, an MS patient is worth between \$30-50,000 a year for a pharmaceutical company, \$2 million over a lifetime - a cash cow to be carefully milked until they can develop a new, improved, and more expensive MS drug.

While I still have MS, I am no longer a cash cow. I take LDN. The more people who know about LDN, the more people benefit from LDN. Spread the word.

### 114

Margaret S, France April 2009 – Rheumatoid Arthritis Aug 2009 - Small Carcinoid Tumour August 2009 - LDN

I was married for 10 years, but it ended by 2005. My husband (French) turned out to have mental problems and drank. In the late 1990s he began to be stalked by a deranged local woman who claimed he belonged to her and was the father of her son. She stalked me and my house, telephone, and letterbox too.

As a result he lost his job and would filch my money. He had two spells in psychiatric hospital, angina, smashed elbow and hip, and hospital emergencies after her physical

violence. Even though our marriage was over, he stayed with here for a couple more years, when I at last got him into social housing. A friend reckons this was when my autoimmune disease showed itself due to years of inescapable stress. I've lived in rural France since the early 90s. What family I have are all in the UK.

I had no idea what was happening when in autumn 2008 I started getting pains - first in my right wrist, then my left - shooting up to the knuckles. I was told it was 'rheumatics' which to me meant that aged in my mid sixties; old age was coming down on me fast. Loss of strength had already been depressing me and reducing my quality of life for two or three years. Without thinking about it too hard, I just accepted loss of strength, aches and pains were a normal part of getting old. Not accepting this was somehow a bit silly. Now I know better.

Osteo-arthritis in my neck had been identified in 2002 and I was prescribed Piascledine 300. It worked well. My GP at the time (since retired) said he didn't know how it worked but that everyone who was taking it found it helped a lot.

Around the same time I had two cataracts replaced, the first in 2002 and the next in 2004. During a post-operative check, the ophthalmologist found I had druse (a cluster of small crystals) on both retinas and diagnosed age-related macular degeneration. That was in 2004 but I still had excellent sight until 2008 when it began to distort at the same time as the pains started in my hands. The distortions became steadily more numerous and pointed.

I now realise that the leaden-like exhaustion was one of the first symptoms of my autoimmune disease. In about 2006 I realised I was facing physical work, even movement, with dread and despair. I heat my house with wood and used to order 1 metre logs that I'd chainsaw in two before stacking. Now I had to order the more expensive pre-sawn 50cm logs.

I couldn't start the lawnmower any more, so had to pay someone else to do it. It was clear I ought to think seriously about moving into a more convenient home, but just couldn't get my head around the idea of all that upheaval and stress. I felt I was about to collapse most of the time, and found myself using chairs and tables for support, as I moved from one part of the room to the other. It wasn't till the evening that I could even think about making the bed and washing up.

After a couple of minutes vacuuming I had to stop and rest. Dusting was the same. Every movement hurt, but even trying to relax didn't work as pains would shoot throughout my body. Brushing my teeth, getting in and out of the bath, squeezing the washing up sponge, and the countless ordinary everyday activities became painful and difficult. I dreaded going to bed as there was no rest, just more pain. The future seemed very bleak. I was becoming reclusive. I loathed the thought of going out and being with healthy people who expected me to be healthy too, so I stopped going out.

I was ashamed of the state I was in, the state my home was in, and my inability to do anything about it - so I stopped inviting people around. I sensed that other people thought I could snap out of it. Someone told me I should flex my fingers when I woke up to get the blood moving. I didn't even try to explain that my joints were being destroyed. I couldn't resent the advice - apart from the fact there was nothing anyone could do to help me, I'd been as ignorant as they were just a few weeks earlier. I used to wonder how much longer I'd be able to live independently. How would I cope with being bossed about by the social services whose duty it would be to protect and help me? I consulted the large arthritis research organisations for help and advice and found them thoroughly demoralising. They seem to advocate a 'mind over matter' approach. Sufferers must be brave, soldier on, make the best of it, buy gadgets to help around the house and in the garden, use arms to open doors instead of hands, and not let the pain get them down. They must listen to their doctors and take the medicine, even if the side-effects can be as devastating as the disease. One site I was looking at the other day warned readers not to read research articles if they thought they might be upset by them.

The kind of information they had was concerning, with an estimated average of 6-10 years shorter life span for RA people as the body will start to attack and destroy vital organs as well as joints. The British Arthritis Research Campaign has published a complementary medicine survey but LDN isn't included.

In December 2008 I had finally presented my hot, swollen and painful joints to the GP and she said it was Rheumatoid Arthritis but also said it wasn't age-related. Looking it up on the internet, I learned that it could attack people of all ages and for the first time, I began reading about autoimmune diseases.

A short course of prednisone helped the pain a bit, but not for long. I had another course in January. Neither helped the mental and physical exhaustion and the pain, stiffness and swelling was reaching the whole body - my elbows hurt, so did my shoulders, knees, ankles and toes. No day was like another: Sometimes the exhaustion was worse, sometimes not so bad, and the intensity of pain would shift about.

A third, longer course of prednisone from mid-February to mid-March 2009 helped a lot more. For about ten days or so I even had a wonderful burst of energy before it faded, leaving me as washed out as ever. I spent most of that time pruning one of my apple trees. That burst of energy intrigued me - what had happened? Where had it come from? It seemed it must mean I still had energy within me that could be unlocked. The trouble was, of course, if I relied on prednisone, I'd soon have additional health issues like osteoporosis, etc, etc.

By this time an appointment with a rheumatologist had been arranged. This was a gruesome experience: He seemed bored, impatient with his job or his patients, or both – whatever. I felt like a nuisance, especially when my blood tests came back negative and the x-rays showed only moderate joint damage. I got the impression mine wasn't the kind of inflammatory arthritis he was interested in. He dismissed me with a prescription for Celebrex - I looked this up on the internet when I got home and chucked it into the fire.

I mentioned to the rheumatologist that I'd replaced painkillers and cortisone with Vit E 400 and large doses of omega 3 for the pain and inflammation, and that I'd felt some relief, but he wasn't interested. Nor was he interested in the fact that I'd gone gluten and casein-free which also seemed to help. I offered him a print-out of information about LDN, but he pushed it back at me after a cursory glance.

Mind you, it was in English and he was French, but I think it's fair to say that French doctors and scientists can all read documents in English, even if they find speaking English difficult. All in all, I felt he just wanted to deal with me as quickly as possible and what I had to say was a waste of time.

Awareness of LDN in France is virtually non-existent. An internet forum I joined is dormant - my message of introduction received no reply. It's thanks to the English speaking internet, of course, that I learned about LDN. A friend spotted an article on Dr Mercola's website describing LDN as a treatment for RA.

At first I thought it was just another flaky idea purporting to be a miracle cure, but I soon changed my mind. I spent about six weeks learning as much as I could about it. I learned a lot about MS and Crohn's, but information on Rheumatoid Arthritis and LDN was relatively thin on the ground. Still, I figured, if RA was an autoimmune disease, it should respond to LDN, so I wanted to try it.

Without really understanding why, it was internet advice I'd followed to go gluten and casein free and start using Vit E 400 and fish oil. A lack of funds, however; stopped me taking all the recommended supplements. On this regimen I felt so much better. I had begun to wonder if I needed LDN. I decided I had to go ahead though, because without LDN, as I understood it, my immune system would keep attacking my body - it wasn't enough just to make the consequences of RA bearable.

I began LDN on 22 April 2009. For the first couple of weeks I had some reactions - headachy, agitated, and the first hours in bed were unpleasant, with quivery and restless legs. My hips itched and burned, there was a peculiar tingling sensation in my hands and feet, and I had to keep getting up to go to the toilet. Then, usually around 2 or 3am in the morning I'd drop off.

During the day after, I'd feel groggy, fed up, and very tetchy. I began to hanker after bread and cheese. My feet got worse and I started limping. Any physical effort brought about trembling muscles, and I had no stamina whatever. Sometimes after a midday nap I'd feel better and more positive. I was disappointed that I had none of the vivid dreams others had talked about.

During this same time though, there were some positive changes too. There was still fatigue, but it felt somehow less profound, especially if I paced myself. I had been feeling breathless when walking up hills, and that stopped. I began to be able to relax again, to feel comfortable and cosy. I slept well once I'd fallen asleep, and I began to contemplate chores without a sinking heart. Getting up in the morning got easier - a lot less pain, just a bit stiff.

A most memorable moment was 4 days after starting LDN: I got up and picked up the kettle without thinking about it first AND with just one hand. According to the journal I keep, 30th April (8 days after starting) was the first time I got up and actually felt well. The next day I noticed my fingers felt a bit stronger, even if they still wouldn't bend much. My feet, which had seemed to be going numb as well as painful, began slowly to come back to life. My sense of balance came back and I could stand on one leg to put shoes on.

About this time I ran out of the Vit E and omega 3. New supplies arrived 10 days later but improvements still steadily continued, and there were other changes. As I mention above ... last autumn, around Sep 2008 when the RA was setting in, my vision began to distort. The ophthalmologist had told me to come back in 18 months when it might be bad enough to do a laser treatment. He was as dismissive of what I had to say as the rheumatologist - they both seemed to be telling me I was going more or less blind and crippled, and that's all there was to it.

Well, on 9 May I wrote in my journal that my earlier feeling that my vision seemed more stable on taking LDN was confirmed. It is now mid July 2009, 3 months since I started LDN, and I hardly notice any distortion at all except when I'm tired or have overdone it. I hadn't expected this symptom improvement. Nor had I realised how puffy and itchy my eyelids had been till I suddenly realised they felt normal again.

An accumulation of something in my right eyelid has been diminishing. My skin feels smoother. Two patches of red, dry, flaky skin under my eyes is very, very slowly going away - so slowly that sometimes I think it's just wishful thinking, but no, today I can feel hardly anything. So far these types of improvements have been subtle, but consistent.

I'm stuck with deformed joints in my hands, and both my wrist bones are still too big; but ... as the muscles get stronger... this telltale RA deformity seems less and less noticeable. Without the internet I don't see how I would ever have heard about LDN.

And, what is also wonderful is the time and effort given freely by LDN old-timers, to help others understand it. I send my heartfelt thanks to them all. LDN itself does not fight any disease - it boosts and regulates a malfunctioning, disordered immune system, which then starts to perform the way it is meant to. This is why LDN can help with so many different problems.

For most people, it's while their body is readjusting to functioning 'normally' that strange things can happen. For most of us, if we just sit this out, and don't get scared away, it passes - although once the immune system starts working properly it can sometimes, I've heard, stir up pathogens that have been lurking in the body maybe for years. It can be scary, especially as most of us are on our own with this.

So many doctors know nothing about LDN, or they're not interested and can even be hostile. To my surprise, my GP aid 'yes' when I first asked for a naltrexone prescription that I could dilute and take in small 3ml or 4.5 ml doses. In April 2009 she couldn't see any problem. She even seemed pleased to let me try something I wanted to try, and said I should let her know how I got on. Since then, however; a friend of mine who was very impressed with my obvious improvement, asked my GP's colleague if she could try it too. That caused quite a ruckus, and when I next saw my GP she told me she couldn't prescribe it for me again.

I showed her my hands, and asked her if I didn't look so much better. She had to agree I did, but didn't want to discuss it. The laws about off-label in France are very strict, she told me, and she could be liable if anything went wrong. I still have a few months' supply, but then I'll have to pay for it - such a small sum for the health service, such a big sum for me.

Last Friday, 17th July, I saw my GP about another problem. Although LDN has transformed my life, my health and my future, I had this problem that suddenly began at the beginning of April - 2 weeks after the last course of prednisone and 3 weeks before starting LDN. It was diarrhoea.

Against everyone's advice I had doggedly refused to accept it wouldn't get better soon, which was stupid of me. Anyway, stool analysis showed no infection apart from candida - probably the result of antibiotics I'd taken for an inflamed colon 2 weeks earlier.

As far as I know the candida was the result of the antibiotics I'd taken for the inflamed colon, which presumably was the result of the diarrhoea. The diarrhoea started 3 months ago, early April and I still have it – as far as I know I didn't have candida when it started.

More surprisingly the TSH reading of my blood test was abnormal - 7.27 - whereas the normal range is 0.35 to 4.97. This, my GP said, was a thyroid problem, and prescribed Levothyron to correct it. There was no improvement following Leothyron. In fact, it got worse, so after speaking with my doctor I ceased Levothyron after only 2 days.

I spent some hours trying to relate my GP's advice to internet thyroid information, but couldn't make head nor tail of it. As the diarrhoea started well before I began on LDN, it's unlikely to be related to that - though it could, I suppose, be related to my autoimmune disorder.

The diarrhoea and thyroid episode went beyond my understanding level, and the diarrhoea got worse after starting the Levothyron. When I phoned the doctor, she said to stop Levothyron, but gave me no further advice except to continue the SMECTA and eat yoghurt (I can't, I'm casein free), but I do take probiotics.

I took Imodium for 2 days and felt a bit better. I'm really surprised at how complicated these accounts become, so many seemingly disparate events, attitudes, and decisions all coming into play and quickly moving on.

Sadly, I sensed my GP's attitude towards me had changed since the LDN prescription episode - not so friendly and seemed to have stopped listening. She was probably overworked and tired, but I was seriously thinking of changing to another GP.

I was due to have an echograph on 30th July to check the condition of my thyroid. However I was feeling quite ill that morning so I rang my GP who said I should go to Emergency. This is what I did and it was they who decided to keep me in saying they wanted to investigate the weight loss. In the meantime they took me to have the echograph - the thyroid was pronounced 'small' but without nodules.

Because I hadn't expected to be hospitalised I had nothing (e.g. LDN) with me but a friend organised everything for me by the next day - and looked after my cat. I had been trying a homeopathic remedy, which matched my symptoms. The main improvement after 4 days of Jatropha curcas was less flatulence and less watery stools, less volume and urgency, but no stool formation, but it was to be only wishful thinking.

I had a colonoscopy on 4th August. There was no cancer, but there was an ulcer. As I understand it the gastro found nothing to explain the diarrhoea or the ulcer. He biopsied the ulcer and ordered tests, and I'm to see him again on 27 August. I had a chat with the junior doctor, and she speculated that such ulcers can be caused by anti-inflammatories (I had taken prednisone Feb-March).

They discharged me from hospital on 5th August, with a prescription for Pentasa granules 2 mg in the morning and at night. I told them, of course, about the low dose naltrexone and it struck me that no one batted an eyelid. The gastro made careful note of all the dates and remarked on the fact that as I'd started the LDN 3 weeks after the diarrhoea began, it wasn't that then!'

In view of the anaesthetic I stopped the LDN 3 days before, starting again the evening of 4 August. I was well cared for at our local hospital - everyone was so kind, everything was clean - a comforting environment at the same time as being an awful place to be, and I'm looking forward to some home rest.

#### Update 19 August 2009

There's nothing particularly positive to report regarding the diarrhoea. It's the same, with no sign of improvement yet. I'm drinking more water - 2 glasses on getting up before my one coffee/day, 2 during the afternoon, 2 before going to bed or when I feel discomfort or slight pain, which usually amounts to another 2.

It's possible there's a bit more flesh in my cheeks - slightly less sunken. So far the nighttime diarrhoea seems less, but there's more in the morning. I'm on Mesalazine now (2mg granules twice a day am/pm). Tried stopping it last Wednesday, but started it again Sunday as I started feeling queasy. I see it's a 'topical' anti-inflammatory, and hope it's not blocking the LDN. I'm having some very slight cramping above the ankles in the morning and slight restless legs before I get to sleep.

I'm doing gentle 'blood pumping' exercises to aim for a mild 'runner's high'. It was something Dr Zagon said in his interview with Mary Bradley that gave me the idea. It did get rid of the headache/neck-ache I was getting - either from being a bit dehydrated or from too long hours at the computer or a bit of both. But today I don't feel so good - very bad diarrhoea during the last 24 hours (though I did sleep OK).

I lost a lot of fluid and feel quite unhappy and anxious. So far there's never been any blood, which is a relief. The good news is that the RA is not giving me any trouble. My eyes are still good and I'm still free of that crushing fatigue - which to me means the LDN is still working - so I assume it will eventually do the job for the ulcer.

Since some time in April I've been taking fish oil and Vit E 400 – sometimes 3 times a day, sometimes less, sometimes I forget? I'm running out of them but will re-order today as I'm convinced they help against inflammation.

Update 9 September 2009

I ended up in hospital for a couple of weeks - just a couple of days before my appointment with the gastro! I learned how he'd found a small carcinoid tumour (a benign, non-cancerous tumour with malignant potential). He felt it could be the cause of the diarrhoea but that any operation or treatment would have to wait till they get the results of the scintigraph octreoscan and that can't happen till November - all results are otherwise normal.

Another scan they did at the local hospital showed nothing abnormal. Potassium levels are a problem at the moment - they were too low – so now I'm taking potassium tablets am and pm and having blood tests here at home twice a week to keep control of them. I'd lost another 5 kilos, so I'm down to 45kg now.

Also my blood pressure is only about 9 over 6 - usually 12 over 6. I'm also on Immodium, which does help and I'm trying to find the right level - which seems to be between 2/3 a day. The dietician gave me a low fibre diet to follow which isn't too bad at all.

I was so well looked after - a lovely room to myself with a small balcony but it was still gruelling. I'm such a light sleeper I'd rear up each time the nurses checked on me every couple of hours but the worst was having to separate my waste matter for inspection night and day. Gawd, it was horrible!

So, it's a long wait and I hope I make it without having to go back to hospital, but my friend Sue (who, fortunately for me, dragged me there against my will) is keeping a beady eye on me and we've been told not to hesitate, better make a fuss than allow things to get worse.

The octreoscan concerns the abdomen. The doctor said this type of tumour can secrete a hormone that provokes diarrhoea. He said an operation may be necessary - he would take it out plus a bit of the colon but I wouldn't need an 'artificial anus'. And/or it may just need medication to stop the action of the hormone.

He insisted the tumour he found is very small - the size of a semolina grain - and isn't cancerous. I got the impression he was surprised it could cause me such problems. The scan I had of the abdomen a couple of days after this last hospitalisation showed up nothing. I don't know whether he just wants to be sure or suspects there's more to it.

I'm not taking any probiotic, milk based or otherwise, since about 20 Aug, I think. On the other hand, the gastro says I have no celiac or other IBD, apart from colitis (so I ate what the hospital gave me - no gluten/casein free – because it all got too difficult to insist). As what I eat seems to make no difference whatever, I'm just going along with it for the moment - and buckwheat is on the 'not advisable' list in the diet I was given. Anyway I figured everything's going through me so fast it hopefully doesn't matter.

My potassium is low again (2.5 instead of minimum 3) so I'm now on 2 Diflu-K every meal-time – six per day in all instead of 4 per day - plus 85% black chocolate and bananas. I was on a k-enhanced dehydration drip most of the time I was in hospital, but I could only hold the needle a couple of days before it started leaking and had to be put somewhere else. The 9/6 equates to Blood Pressure of 90/60 - it's the way they read the twice-daily blood pressure readings in hospital.

#### Update 25 January 2010

Just to recap the last six months... In late June 2009 I was hospitalised for 4 days due to severe weight loss. They did a colonoscopy and told me they'd found colitis and an ulcer that was being biopsied, but that the gastro thought was benign. He prescribed Pentasa granules 2mg x 2 times per day which I took till about mid September with one short break.

About 21 August I was hospitalised again, this time for 10 days, during which time I was on drips and everything that went in and out was monitored. The gastro told me he thought the diarrhoea may be caused by a hormone expressed by a benign carcinoid tumour: That's what the 'ulcer' was. He said he needed to know if there were more tumours, and if not, he could remove the one he'd found.

If there were others he would give me medication to control them. Two octreoscan sessions were arranged but not before November as my vital organs were functioning normally and it was not urgent.

I came home still plagued by diarrhoea. The dietician told me to eat a low residue diet. A nurse came twice weekly for 3 weeks to check my potassium (I was taking potassium tablets to get the levels up).

Before these 3 weeks were up I noticed some lessening of the diarrhoea - then for a while everything was normal - confirmed by continued blood tests once a week for another 3 weeks. However, some weeks later, things began to get worse again - though not nearly as bad as it had been. I had started eating more vegetables, but no matter what I ate it didn't seem to make any difference.

On 14 January 2010 the gastroenterologist told me the octreascans (taken over 2 days on 24 & 25 November), showed no trace of any tumour in my body. He said he'd like to do another colonoscopy in a year's time. He reminded me of the colitis which I'd forgotten about and asked me to start the Pentasa again. I agreed and, at the time meant it, but when I got home I knew I really didn't want to.

All this time I was convinced that LDN would help my immune system deal with the carcinoid and the colitis, however: the diarrhoea continued and I learned that my guts were probably damaged. Others seemed to have benefited from the Specific Carbohydrate Diet and when I looked into it, I found it was much more straightforward and easy to follow than people had said, so I started on it.

I can eat most foods, including most vegetables with just cereals, sugar, potatoes not allowed. So I started it last Monday, 18 January 2010. There were signs of improvement the very next day, and within 5 days, the following Friday, everything was normal again.

I'm probably luckier than some - I don't have a sweet tooth, am used to doing my own basic cooking from fresh, local ingredients, preferably organic, and the almond flour 'bread' instead of ordinary bread and potatoes suits me fine. There are plenty of recipes available on the web thanks to generous SCDers. In fact, I'm enjoying the SCD and don't understand why it has such a difficult reputation.

I stopped taking the 160 mg aspirin last autumn (for proliferation of platelets). I wanted to see if LDN will keep my blood levels within normal - so far, so good, but I wonder if the haematologist will appreciate this. Another possible very significant change: Being unable to get a prescription for low dose Naltrexone, I instead diluted one 50mg tablet in 50ml of distilled water.

I was advised to shake the bottle before I draw my dose, but recently someone on the main LDN group (who said they were a chemist) suggested we shouldn't do this because it means we ingest the iron oxides in the tablet, which in turn can cause digestive issues for some.

He said the Naltrexone dissolves like sugar and doesn't sink and there's no need to shake the bottle. So now after the initial shaking to dissolve the tablet, I let it settle, then pour off the dilution and throw away the deposit. I put the strained solution back in the bottle and don't shake it again. Not taking the iron oxides may also be contributing to my improvement.

I feel great, and I'm very surprised and very pleased... not least because I can still eat my vegetables as usual. I'm looking much better, less gaunt in the face, skin is clearer, though I still have to get a bit more weight on. Still I have what must be normal energy levels, and often sleep 8 hours straight through, though sometimes my sleep is a bit disturbed.

The RA is still improved and not giving me any trouble. I'm gaining strength in my hands and throughout my body. I can garden, and household chores are no problem now. I'm still pain free, but do my Chinese stretching exercises to keep that way. My eyes are still good.

During the past month I've stopped all medication apart from the LDN. I was only taking Piascledine 300 for osteoarthritis and Nutrof for the AMD.

# 115

### Marie D, Australia July 1987 - Multiple Sclerosis 13th May 2010 - LDN

It's only been 10 days and I'm already seeing benefits!!!

I had read so much about LDN on the internet over the past few months that I decided I wanted to try it.

I've had MS for the past 30 odd years but it wasn't diagnosed until 1987. I've never had any of the accepted drugs; partly because I was considered too old (past my use-by date!), and partly because I was otherwise very healthy. I've never caught colds or flu. I've only had a couple of Urinary Tract Infections (UTIs) over the years, for which I take daily cranberry tablets.

I had told myself that if there was something that could do good things for MS that I would be prepared to try it. After all the reading about LDN I then had to find a doctor who would prescribe it. The neurologists are not interested, or so it seems.

I asked my General Practitioner, a lovely man whose father in South Africa also has MS. He said, "Why not?" and wrote me a script for 3mg LDN capsules.

As you know it has to be compounded so we then had to find a pharmacist who does compounding, and we found one... Yippee! So on 13th May 2010 I took my first dose of 3mg LDN between the hours of 9.00pm and 3.00am (not sure why, but I obeyed the rules).

That was 10 days ago, and I am so excited!

I first noticed getting out of bed more easily, i.e.; not having to hold on to anything, and each day I see more improvement. Friends are saying 'Wow' when they see me walking. I'm not quite at the point of walking alone yet, but I'm very close to it.

I am now a total convert to LDN!

## 116

### Marjorie S, USA Feb 2009 - Frontotemporal Dementia & Parkinson's Disease November 2009 - LDN

My 63-year old husband was diagnosed with Frontotemporal Dementia and Parkinson's Disease in February 2009.

He was getting so bad that he had sprained his wrist when trying to get up and was falling almost every day.

He has not fallen once since he started LDN approximately six months ago.

His Parkinson's Disease is still progressing, but very slowly, and I do believe that if he hadn't started on LDN, he would be in very bad shape today.

It took a lot of persuading on my part, but his neurologist finally relented after I sent my husband's primary care doctor the info on LDN, and the primary care doctor then called his neurologist to recommend he prescribe it. My husband's neurologist was somewhat amazed at his last appointment and said that he had learned something new!

I hope this testimony helps someone else.

# 117

### Mark J, UK February 1999 – Multiple Sclerosis early 2005 – LDN

I was diagnosed with MS in 1999, having had symptoms for about 10 years previously.

I asked my GP to prescribe LDN on the NHS in early 2005.

Hee took a look at the info I brought along and agreed to write a prescription. I have since changed GP, as the first one retired, and the new GP has agreed to continue prescribing.

My initial dose was 3mg. I experienced some sleep disturbance, really vivid dreams and some leg stiffness, however; all these side effects passed within a few weeks. I was comfortable at that dose so I waited for a year before moving up to 4.5mg, and have continued on that dosage since.

Over the time I've been taking LDN I've noticed a marked decline in the muscle spasms I was experiencing, and a much improved standard of sleep: I need to sleep less, but I sleep more deeply. All in all, my LDN experience has been very positive.

It has not improved my poor mobility (not that I was expecting it to), but I don't think it has got significantly worse.

My own experience of getting LDN has been good, but I know of others who have been frustrated by the refusal of doctors to prescribe.

# 118

Mark S, UK February 2009 - Multiple Sclerosis May 2009 - LDN

I'm still under 40 years old. Before taking LDN, Multiple Sclerosis was causing many problems for me, and I'd had to stop working. Tiredness, numbness, incontinence, double vision and spasticity were all getting worse and making life very difficult.

I was deteriorating pretty quickly, and frightened of needing a stick or a wheelchair in the near future. I couldn't walk very far at all. If I could manage a day's walk, it would meaning spending the next day in bed. My active life was gone, life was closing in on me, and I was very upset.

The LDN Research Trust helped me find a doctor willing to prescribe Low Dose Naltrexone, and after only two months my symptoms are improving so much that last week I climbed Ben Nevis, and next week I'm going back to work!

I believe LDN is giving me back what Multiple Sclerosis was taking away, and I'm not as worried about the future now. I can't thank the LDN Research trust enough for helping me.

## 119

Mark W, UK early 2006 - Multiple Sclerosis January 2007 - LDN

The first time I noticed something was wrong was one evening when I got in the bath. The water felt warmer on one foot that the other and when drying myself I found a numb patch around my right shoulder. I thought it was a bit odd and made an appointment with my GP but he was not too worried. He said it was probably a trapped nerve but to come back if anything got worse.

Things did get worse over the following months with a whole array of symptoms such as losing my sense of taste, more numbness, pins and needles in my hands, feet and tongue and the final straw was losing strength in my right leg until it became practically useless.

Although my GP did not mention MS to me, he had sussed it out and said I needed to see a neurologist. The wait for that on the NHS was around three months, which was unacceptable. Even going private would see me having to wait a month but I needed help ASAP.

Being the good man he is, my GP at the time (he's now retired) recommended I get myself checked into hospital and I would be seen by a neuro in a matter of days. It was 'off the record' advice but the best thing he could have done in my eyes.

After a battery of tests I was told it was suspected Multiple Sclerosis. A bit of a bombshell, but at least now I knew what it was and could try and deal with it. I'm fortunate enough to have a wonderful, supportive wife who was/is with me all the way, for which I'm eternally grateful. I also had other family and friends around which all helped.

The steroids I was given slowly brought the strength back into my leg and other symptoms subsided. Within a couple of months I was back at work, but that was far from the end of it. Sensory symptoms seemed to come and go as they pleased so I looked forward to my neuro appointment for some answers and treatment. I got neither!

I left the appointment feeling let down, and with another appointment made for a years time, I was not happy. It was a couple of months after that when I had another major relapse with the whole left side going numb and the leg was getting weak again. This MS thing was now pissing me off, and I needed to know all I could about it and what could be done so I embarked on a mission to learn all I could.

The internet is a great tool and if you can avoid all the rubbish on there, then there are some very helpful sites.

I was looking into what drugs were available and reading patients own first hand opinions on them when I came across something called LDN (Low Dose Naltrexone). The reviews this drug was receiving were too good to be true, so at first I was sceptical, but I read on. The more I read into LDN, the clearer the picture became, and I felt a relief that there was something that worked, and a degree of anger about the situation surrounding the drug which prevents many GPs from prescribing it. Red tape and profit should never come before health, but it does!

I contacted Dr Lawrence and made more progress in that first phone conversation than I had since I was first diagnosed. Pretty soon, my first batch of LDN arrived and the affects were immediate. I took my first capsule that evening and felt like a new man come the morning. Some of the numbness was still there but it was definitely going.

Over the following few weeks, along with support from Dr Lawrence, I moved from 3mg of LDN to 4.5mg and I reached a point where, for the first time in a year, I was

symptom-free. That was two and a half years ago now, and apart from a couple of hiccups that I can put down to personal stresses, I'm symptom free to this day.

To say that LDN is the best thing to happen for MS is a gross understatement, but more needs to be done to get this drug available to everyone on the NHS. It's thanks to wonderful people like Dr Lawrence who first brought LDN to the UK and Linda Elsegood who runs the LDN Research Trust that LDN has got where it is now and both deserve a big 'Thank You' for the work they are doing. With support, I'm sure LDN will get to where it needs to be.

## 120

### Marna M, USA 1996 – Ulcerative Colitis (UC) 1 March 1998 - Primary Sclerosing Cholangitis (PSC) October 2008 – IV Glutathione, 15 March 2009 - LDN

My son was diagnosed with Ulcerative Colitis (UC) in 1996.

He was only a baby.

Then in 1998 following a liver biopsy, at the tender age of 3, he was diagnosed with a rare and devastating condition, Primary Sclerosing Cholangitis (PSC), confirmed again later via follow-up ERCP when he reached school age.

At the time of diagnosis his liver enzymes were in the range 900 to 1100.

When he was first diagnosed, he was put on 5 different medications. One of those was Flagyl/metronidazole, which he took for 6 weeks.

I believe he suffered neurological damage as a result: He began to fall all the time and it was particularly noticeable when he played soccer. After walking in the woods with his uncle, my sister's husband, he reported, "He falls too much. Something is not right.". I knew he had no balance because his brother, 2 years younger, could balance on things at the playground and at home while he could not.

His eyes became extremely sensitive, and his vision impaired. I told the doctors. All they asked him to do was walk across a three-foot area in their office. They would then look at me like I was a paranoid mother and say that they'd assess his vitamin levels.

Unfortunately I didn't make the connection with Flagyl until October 1, 2007: I went to the doctor with a bout of diarrhea (which I think I picked up in Mexico) and was prescribed Flagyl for 7 days. My vision became impaired and I began to lose balance. I fell all over the house when trying to stand. I had to hold a grocery cart to keep from falling if I ventured out. I got to the point of needing a wheelchair, but managed to avoid that by praying to God, "Please just don't let me fall!" My speech was messed up

for over a year! I stuttered. I would say 'red' when I meant 'blue'. I still say the wrong words occasionally, though my comprehension is intact.

I suffered extreme short-term memory loss. Once a top speller, I now have to double check what I write and use spell-check. My muscles began to waste, and I suffered hearing damage. I was diagnosed with Diabetes Insipidus. Every organ, gland, muscle and nerve in my body lost blood supply due to vascular damage. I thought back to my son's experience, added that to my own, and put two and two together; Flagyl.

So 9 years after my child suffered vision, balance, and speech issues necessitating speech therapy for the next 4 years, I suffered similar impairment for 3 years following administration of the same antibiotic commonly prescribed for Crohn's, UC, and diarrhea.

Back to our early years...

During those early years I lost my husband to a heart attack, and four years later, my darling brother who'd helped fill the role of father figure for my boys. He was taken in a tragic trucking accident.

There is something about the tragic loss of loved ones that galvanizes. I would not lose my son too.

If not for the Ulcerative Colitis diagnosis, it's unlikely my son would have been diagnosed with PSC as young as he was. The test confirming his diagnosis followed an extreme Ulcerative Colitis exacerbation that saw me carrying my naked toddler to the bath tub while large amounts of bloody, bloody diarrhea gushed from him. It was quite traumatic, and I was a skeleton within a very short time. My weight plummeted to 102 pounds and I could not gain weight due to constant worry over my little blonde, blue-eyed precious baby boy.

My son is a one in 300,000 case. The Hepatologist I last saw in New York, the eminent Dr Steven Lobritto, said that his case should have been nationally recognized as he's the rarest PSC patient known (due to his age at diagnosis). Most PSC patients are diagnosed in their 50s.

No effective medical therapies are recognized for Primary Sclerosing Cholangitis (PSC). It is a slow but serious disease that can lead to liver failure and the need for a liver transplant.

He had a rash almost from the day he was born and was prescribed many different medications over ensuing years, such as cortisone cream. Basically the rash was ignored, considered only as a symptom of his Ulcerative Colitis.

I asked his first dermatologist what the rash was when he was a baby on my lap... (It was an Ulcerative Colitis rash)... doctor after doctor after doctor could not treat it. My son was embarrassed to be seen without clothes on.

A special diet was not advised. The physicians said to give him Flintstone vitamins and let him eat whatever he wanted.

I always consulted the best doctors I could for him, even hopping a plane for an appointment with a 'top' researcher and specialist in the field. He said he'd seen

thousands of PSC cases and that none of them looked as good as my son. He scoffed in disbelief that he even had PSC, saying, "Your son may not even have it.". I then listed the high profile doctors that had diagnosed him, and he then admitted they were good doctors.

My son was not taking any drugs at the time, but the doctor did not at any time ask me what it was that I was doing for my son that may have been making a difference.

He called Ursodiol worthless, and said Infliximab was only used as a last resort, for those who were extremely ill. He drew my son's blood but would not prescribe either of the drugs I thought might help.

That same doctor, almost as soon as my plane hit the ground back home, was calling me on my cell. He said my son's test results had come back, that his liver enzymes were elevated, and that he now wanted an urgent liver biopsy based on his March 2006 test results:

Aspartate Transaminase (AST)	604
Alanine Transaminase (ALT)	598
Alkaline Phosphatase (Alk Phos)	755

I said how soon? He said in two weeks at the latest, but... we had no insurance and were not poor enough to get it done for free. That doctor ended up having to wait 6 months for his biopsy.

My son had been prescribed Ursodiol in the past and had taken it in spurts prior to 2004 because it was all they had. Doctors would actually get mad if he wasn't on it. Even so, he ended up taking it only for a few months due to all the conflicting advice we were given: One would prescribe, another would say not to take it, then yet another doctor would say to take it. Then a higher up doctor would say not to take it... back and forth it went. Which gastroenterologist was I to believe? Finally in 2004, I took him off it for good and it became another prescription in the drawer.

That was our life, a seemingly endless round of doctor appointments and tests, none of which brought the improved health my son and I both dearly wanted for him, and for which I prayed regularly.

In 2006 my son's MRCP (Magnetic Resonance Cholangiopancreatography) came back worse than ever. For the first time he had an enlarged spleen. His liver biopsy was stage 3 of 4, yet no treatment was advised other than the controversial Ursodiol/UDCA.

I did not give it to him. Many gastroenterologists had already told me it would not delay transplant, and as mentioned earlier, there was conflicting advice around it.

(NB Now I'm glad I didn't continue with it because my son is better off! In 2009 a study showed Ursodiol caused twice as many liver transplants, three times as many esophageal varices, and twice as many deaths, and study participants were only stage 1-2 patients. They ended the study due to patient deaths. In the January 2010 Hepatology Journal: The American Association for the Study of Liver Diseases advised against the use of Ursodiol/UDCA, validating the choice I made on behalf of my son back in 2004.)

In October 2008 I found out about the importance of glutathione (an antioxidant), and my son began IV glutathione treatments from Dr. Gurney Pearsall, a 6-hour drive away. The glutathione relieved ALL of his symptoms, so we continued with it. For a child that has never known life without fatigue, his words to me, "I feel like Superman!" were music to my ears. He was now asymptomatic, as in; NO itching, strength he had

NEVER known, and NO fatigue. You can only imagine how his mother, me, felt... tears of joy!

Then early in 2009 I found out about Low Dose Naltrexone (LDN) from the internet.

We decided we wanted to try it, but I thought, 'If we're going to do this, we should do it properly and see a gastroenterologist for an assessment, so we can track if there's any document-able change. I travelled by car 2000 miles to John's Hopkins for his endoscopy, colonoscopy and liver biopsy. Their reputation is known worldwide and it's why I went there. (The Johns Hopkins Hospital, for the 19th consecutive time, earned the top spot in the U.S. News & World Report's annual rankings of more than 4,800 American hospitals.)

The 9 March 2009 colonoscopy and biopsy pathology report came in: It stated that 'colonic mucosa' from the 'Cecum, Ascending, Transverse, and Descending biopsies all had 'active chronic inflammatory disease, cryptitis, crypt distortion, and basal plasmacytosis', and the colonic mucosa of the Sigmoid and Rectum biopsies had 'prominent chronic inflammation'.

The notation read 'the changes are those of inflammatory bowel disease. There is relative distal sparing, although the overall distribution is more consistent with Ulcerative Colitis.

There was also measurable improvement in his liver enzymes, reflected in his 9 March 2009 results:

Aspartate Transaminase (AST)	54
Alanine Transaminase (ALT)	67
Alkaline Phosphatase (Alk Phos)	504

The endoscopy was clear of inflammation, H. Pylori bacteria, and best of all no esophageal varices were found... one of the greatest fears with chronic liver disease.

The liver diagnosis read '... Overall the histologic changes in the biopsy would support an early stage (2 of 4) of primary sclerosing cholangitis. However, given the bridge of fibrosis, careful follow up is necessary.' The physicians were startled to find no inflammation in areas and barely stage 1-2 in others. Knowing this is a progressive disease without a cure and that three years ago he was stage 3, they mentioned possible sampling error. They didn't ask, and I never told them about the IV glutathione, nor did I ask for LDN. They did not seem receptive.

Personally, I was ecstatic and thrilled with the test results. They delivered real, hard evidence of the improvement we'd hoped and prayed for, and had validated the IV Glutathione treatment choice I'd gone out on a limb to make.

Like every other mother who's ever been in a similar situation, I struggled with every decision and every choice I made on behalf of my son. My quest to indefinitely defer the need for a liver transplant had seen me consult the best of the best, only to hear differing expert opinions and recommendations that typically, provided no clear path forward.

I was often forced into a position of having to weigh up all the pros and cons and make, hopefully, the right choice for my son. You can't imagine how frightening and stressful it

is to feel the burden of that responsibility as you await the outcome. So to say the test results were a welcome validation for me that I'd made the right choice at the right time is an understatement: A huge weight was removed from my shoulders.

My son's health was finally improving and we could not have been more elated.

We still had some way to go though. His hemoglobin had dropped to 8.0. According to Johns Hopkins, this was due to blood loss from chronic and acute inflammation of the colon, however; he was asymptomatic and had not been losing blood in his bowel movements each day – so this result in combination with low Red and White Blood Cells set off a light bulb warning in my head which resulted in my finding out his bones weren't growing at the rate they should, AND that he had developed adolescent onset mild scoliosis.

He has laxity in his joints (double jointed), which incidentally is likely linked to his liver being unable to process the growth hormone (GH) generated by the pituitary gland in the brain, and him not having enough healthy GH receptor sites. I researched it and found that 50% of liver children do not produce enough GH or IGF-1 (which is made by the liver in response to the pituitary gland producing GH). Suffice to say that at this point I determined I needed to do further research into GH and GF-1.

The Johns Hopkins doctors prescribed Mesalamine - 5-aminosalicylic acid (brand names - Pentasa, Rowasa, Asacol, Lialda, Canasa) for the colon inflammation, and three iron pills a day. They also prescribed the controversial UDCA/Ursodiol, but I put the script away in a drawer. I gave my son a reduced dose of the iron - one iron pill per week (because supplemental iron can be damaging to the liver).

But having learned of LDN, I now wanted to see if adding LDN could spur further improvement, so whilst still at Johns Hopkins, I phoned for a consultation with a knowledgeable LDN doctor, Dr John Sullivan; simultaneously forwarding all of my son's records for his review and documentation.

Being the persistent mother I am, I then went further and arranged an appointment with Dr Steven Lobritto, a top pediatric gastroenterologist in New York who specializes in liver disease, so he could review everything. I also wanted to draw his attention to the results of my son's liver biopsy, because they inferred a reversal in progression of his PSC; from stage 3 to barely 1-2 of 4 stages.

He ordered a Doppler ultrasound with color-flow imaging of the liver, more lab-work and compared the past three years of tests. I informed him that I was not giving my son the Ursodiol and he said, "Your son has such good flow that he does not even need it." I told him about the IV glutathione.

He wrote on the hepatology orders for my son to continue with the IV Glutathione. No Ursodiol was prescribed. As my son did have chronic and acute inflammation of the colon, he prescribed Asacol. Again I was afraid he would not know about LDN and therefore would not prescribe it. And once again I put the Mesalamine/Asacol prescription in the drawer, on hold. The research and patient testimonies about LDN were just too compelling.

My son's lab work, biopsies, Doppler ultrasound, and now a leading New York children's hepatologist all backed up the way my son felt!

I filled Dr Sullivan's LDN prescription, and on 15 March 2009 my son and I both started on LDN. I had decided to take LDN at the same time so I could better understand what he was experiencing. I started my teenage son on 3mg and then moved him up to the highest dose of 4.5mg after only two weeks.

We experienced sleep disturbance on the first night only: We were up at midnight, walked around a bit, raided the fridge, then went to bed and slept heavily. The next evening we adjusted the time. My son took his LDN right before bed. He took his LDN, went straight to bed, and slept heavily. So neither of us experienced any lasting sleep issues and it has actually helped him sleep better.

There was a significant change in my son's health within two weeks: My son had suffered a 'rash' his entire life. I say 'rash', but that doesn't give the full picture: He'd get painful sores on his inner thighs and buttocks and the scars left behind looked like a teenager's acne scars. As a young man he thought of his future and how embarrassed he'd be with a girlfriend.

All the cortisone in the world would not take his rash away. Within two weeks of starting LDN, the rash he'd had his entire life cleared completely. It went away and has not returned! He was all smiles and, without any prompting, took his LDN faithfully!

In April 2009, after one month on LDN plus one iron pill per week, his hemoglobin rose to 12.5. I saw this as a positive sign that the problem was fixed.

My son has also had a severe peanut allergy his whole life. If someone even ate a peanut in the same room as him he'd start coughing. But after only two weeks on LDN, his mother, me, ate peanut M&M's in the car with him. He didn't cough. He and I were both shocked. The only thing that had changed in his life-threatening allergy to peanuts was 4.5mg of LDN nightly!

After he'd been taking LDN for three months, and seeing it helping, not hurting, I stopped taking it myself.

And as time went on there were other indicators that LDN was benefiting him:

Soon after beginning grade school, my son had a strong and immediate adverse reaction to a flu vaccination. The nurse was forced to stop the vaccination mid stream, delivering only half a flu shot. During the vaccination my son suffered immediate bloody diarrhoea and we ended up in the Emergency Room soon after... so no more vaccinations for him per gastroenterologist orders.

This is why he was not able to get the recommended H1N1 flu vaccine in 2009. My other son and I also did not get the H1N1 vaccination. Well, I had mild flu with fever for 8 days, and my other son had it for 3. We didn't get a bad case, and I attribute that to all of us taking Primal Defense Ultra Probiotics and Vitamin D3 daily.

You'd be forgiven for thinking someone suffering from both UC and PSC would be more susceptible to seasonal flu than other members within the same family, but my son, the only one in the family taking LDN for the prior 9 months, did NOT get the flu - and as members of the same family, we're together and in close quarters all the time.

Meanwhile I was still concerned with my son's low GH and IGF-1 levels, particularly as he was now around 14.5 years, a critical developmental window during which most young teenage men experience a growth spurt (he hadn't), and during which he'd developed scoliosis. Over the previous 9 months I'd raised this concern with 4 specialists who'd remained unconcerned and unmoved, so I'd gone back over previous test results with a different perspective, and for the first time noticed my son's 'Bone Isoenzyme' was around 31% of 'normal'.

All these factors fuelled my determination, so to demonstrate my point, I took my younger (taller) son along to an endocrinologist appointment to convince them to address it, and finally, my son was prescribed injectable human growth hormone (HGH). But in between, nine precious 'growth' months had been missed, nine months in which a young man could develop a strong young back.

Back home again, I needed a local doctor. I booked an appointment with the top paediatric gastroenterologist in my area. This time I told him about LDN and IV glutathione, even emailing him documentation and information ahead of the appointment, and asked if he would prescribe LDN or IV Glutathione. At the appointment he walked in shaking his head exasperated at me. He crossed his arms angrily. He would not do what I wanted him to do for my son. I left crying to God!

Soo... I needed a new gastroenterologist: I found one, but I lied: I said my son was taking Asacol. I told the truth about his IV Glutathione, but from the response, felt that was enough for her to accept at the time and did not mention him taking 4.5mg LDN nightly.

During the first office visit the doctor asked where I was taking my son for his transplant. This startled me but I said I hadn't decided yet, probably Minnesota because they do the most liver transplants for PSC children... but I added that my goal was to avoid the need for a transplant for as long as we possibly could.

The doctor prescribed 800mg Asacol twice a day, three iron pills to take each day, and ordered a full work up: Labs, abdominal ultrasound, KUB, MRCP, colonoscopy, endoscopy, biopsies, and pathology reports. Later would come Upper GI with Barium and small bowel follow through. She was already aware of the results of the 2009 Ursodiol study, read everything I gave her about IV glutathione, and was willing to work with me on my son's many serious health issues.

On 21 December 2009, my son underwent the MRI/MRCP of his Abdomen that she had ordered. At that time, he'd been on IV Glutathione for around twelve months, and LDN for nine months:

It stated; 'Again demonstrated is splenomegaly. On the MRCP there appears to be stricturing of the proximal common bile duct as well as mild stricturing of the common hepatic and distal portion of the left common duct. There is NO intrahepatic biliary dilatation (good thing) identified. There is homogeneous enhancement of the liver parenchyma and the portal vein and hepatic veins grossly patent. (very good things) Pancreas appears unremarkable. (great) Kidneys are within normal limits. There are no identified varices (miraculous/wondrous).'

But another problem re-emerged: My son's hemoglobin had dropped between April and December from 12.5 to 10.6, even though he still remained asymptomatic. Instead of one iron pill per week, I increased his dose to one every other day, but that was to last

one week due to receiving news my father had died January 4, 2010. With the exception of LDN, everything was forgotten during this period of upheaval – iron pills, and even IV Glutathione.

#### Back to LDN

Twelve months ago, in March 2009, the surgical pathology report on the biopsy taken during his colonoscopy showed 'active chronic inflammatory disease, cryptitis, crypt distortion, and basal plasmacytosis', and 'prominent chronic inflammation', and his blood pathology report showed his hemoglobin was 8.0.

Now his 3 March 2010 endoscopy and colonoscopy showed a healthy colon: The exact words from his 3 March 2010 colonoscopy and biopsy pathology report were; '... No crypt abscesses are seen. There are no granulomas. Glandular distortion is not appreciated or foreshortening of the glands off of the basement membrane zone. Lymphoid tissue, when present, appears appropriate for site and age. There is no surface ulceration.' The additional comment read '... The increased number of eosinophils may reflect a process of food allergy. There are NO findings for either chronic or ulcerative colitis, active or quiescent and no granulomas for Crohn's disease.'

Also on 3 March 2010, my son's blood pathology report stated all his levels had returned to normal, and his hemoglobin was back up to 13, though I attribute some of this improvement to the injectable Human Growth Hormone he started on November 16, 2009, because it would be expected to benefit bone, muscle, cartilage, and blood.

The doctors kept telling me the drop in hemoglobin was due to blood loss, but I couldn't accept that. During all his years of illness my son's hemoglobin had always hovered around 14, even during his worst exacerbations and blood loss - so I'd been truly puzzled by the drop, especially because it occurred during a period of improving health and at a time when he had no inflammation or blood loss.

I also felt the supplemental iron could be 'masking' an underlying cellular problem that needed to be addressed in a better way, perhaps with the addition of IGF-1 to the HGH (to address the lack of receptors). I have another appointment on May 7, 10 hours from my house, to see an endocrinologist knowledgeable in this area, and I hope to learn a lot more about whether IGF-1 could help.

Needless to say, whilst the blood-work results were received with relief, I was and remain curious about this particular conundrum and am still on a quest to understand 'why'.

Going back to the test results... I was sitting in the gastroenterologist's office to discuss the 3 March 2010 test results when she gave me the beautiful color photos of my son's healthy colon! I started crying and hugging her! Can you imagine the relief I felt?!

I then told his doctor he had never taken a single Asacol, and that he'd been taking LDN for the past twelve months. I told her after and not before, for obvious reasons, but more importantly, I wanted her to see for herself what LDN had done for my son so she'd consider it as a treatment for her other UC and Crohn's patients.

I was scared of what might happen. Would she refuse to treat my son? But instead she asked if my son was in a study. I said there was a study, but that I didn't live close enough. She said she'd never heard of it and to my relief, indicated she wanted to know

more about it. I sent her 150 documents! Amongst them, I emphasized the Penn. State Univ Crohn's Trial results by Dr. Jill Smith, Professor of Gastroenterology.

My son and I wish every Crohn's and UC patient knew about LDN and would give it a try. I'm thrilled because LDN has worked better than ANY Dipentum, Asacol, or Sulfasalazine ever did for him. And, where Ursodiol never relieved his itching or fatigue, IV glutathione did.

I know there are hundreds, if not thousands of doctors who've seen improvement in patients taking LDN, yet who still refuse to research it further as a potential treatment option for other patients. And I also know there are doctors who've refused to treat patients when they find out they're taking LDN.

Looks like my son and I are among the lucky ones to have found this doctor with an enquiring, open mind. Yes, the truth of this dramatic improvement was there in the test results for anyone to see, but other doctors have also seen similar results and reacted very differently.

Dr Mihaela Ringheanu is very intelligent, compassionate, and speaks three languages. Perhaps she approaches things differently due to her life in Romania, a country with cultural integrity, or maybe it's because she has greater capacity for common sense intelligence. I don't know. But personally, my son and I think she's one of those rare doctors who's more concerned with what is best for her patient than she is about following strict plans of care that may NOT be working so well.

I do know as a mother who would do anything for her son, I have a renewed respect for this doctor whose professionalism and skills are now partnering me in the best interest of my child. My prayers have been answered! Wesley and I have tremendous admiration for Dr Ringheanu, the only doctor who took the time to listen, believe, research, and do a thorough work-up involving biopsies, labs, MRCP, KUB, and ultrasounds to confirm the improvement she was witnessing.

She treats us with respect and greets us with a genuine warmth and kindness. She is now focussing on LDN, and I know she will educate herself on the clinical trials and huge success rates being achieved through Dr Jill Smith's trials. Now that her focus is on LDN, I know she will make an educated decision for the sake of her patients.

And my now teenage son is a walking LDN and IV glutathione poster child.

We have seen them all - dermatologists, gastroenterologists, hepatologists - none of them ever helped my son as LDN and IV glutathione have! The dermatologists need to know about this! The gastroenterologists, the hepatologists, and the allergy doctors - all of them need to know now! If any doctor from any country is interested in my son's healing journey, with a view to helping their other patients, they need only ask and I will provide copies of all my son's test results.

One more thing... during all of this my son suffered, from his very earliest year through the following 12+ years, where his consistently elevated liver enzymes fluctuated in the range 400 to 800. But my son never complained about his lot in life, because it was all he had ever known... repeated periods of illness and exacerbation, repeated tests, carousels of different drugs and their side effects, and multiple medical tests and procedures; many of which were invasive and painful. Yet he went in for biopsies

smiling... never flinched when an IV was started... and has even started his own glutathione IV's one-handed.

LDN is becoming better known. There are physicians and gastroenterologists involved in MS and Crohn's clinical trials, lab researchers and scientists, and now; my son's new personal gastroenterologist who's also aware, as are his New York hepatologist, pediatrician, and 'intelligent medicine' doctor. All now know of LDN and have seen it works. The work of all those involved in scientific research and trials and the publication of their scientific research and trial data has contributed to the expanding scientific knowledge-base for LDN.

Patients who've benefited from LDN understand how important it is to diligently record their experiences, submit their testimonies, and grow the volume of testimonial evidence. They've responded to the urgent need to raise awareness through their testimonies, and their hope of decreasing unnecessary suffering around the world is united.

This is our contribution to that worthy worldwide effort, and to helping others discover the benefits of IV Glutathione and LDN, as we have.

# 121

### Martin P, Germany 1997 – Multiple Sclerosis November 2009 - LDN

I'm in my mid forties and I had my first serious MS symptoms 12 years ago in 1997, presenting in form of optic neuritis that left me almost blind for a few weeks. The doctors at the hospital in San Francisco (where I lived at that time) couldn't find an explanation and sent me home with the advice of coming back, 'if it didn't improve (??)'.

A Homeopath, of all people, 6 months later sent me back to the hospital for an MRI after listening to my story. I got a diagnosis of "Probable MS" with along with other great advice to "not worry too much", but at the same time to keep looking for another type of work (I'm a musician). My trust in doctors started to become somewhat affected by the whole experience.

I ignored the thought of having MS over the next five years as I felt symptom-free. (My eyes were ok.). In 2002, after having moved back to Germany from the USA after over a decade there, I made a run through every doctor's office, because my whole physical situation seemed to seriously disintegrate. I had no energy and was always extremely tired and felt totally burned out. I perceived this to correlate with our difficult situation of starting our lives again from scratch here in Germany.

The MDs weren't able to diagnose anything. At the end of 2002 I had another serious bout of optic neuritis, rendering me almost blind. This time (after having an MRI and

Lumbar Puncture) I got the clear and swift diagnosis of having serious MS, with all the consequences and all the recommended drugs - Copaxone, Cortisone etc. I also found out that I'd had a lot of other MS symptoms, which I'd never recognised as such: My extreme tiredness had been diagnosed as fatigue-syndrome. I was often very testy, had Trigeminal Neuralgia, Restless-Leg-Syndrome, and Lhermitte's Sign. I had balance problems, little blackouts during concerts, spastics, light depressions, and what not.

I took Copaxone for 18 months but then stopped taking it because my condition did not improve much. I actually never knew if I felt so bad because of my MS or because of the drug. Well, I felt better after I stopped taking the drug.

My therapy for the next year was to live and eat really healthy and to schedule my days to be able to take sufficient breaks. With this method I managed to at least establish a way to get somehow through my daily life. (I take care of my two kids, age 10 and 12, the household, and I work half time as a private music teacher. My wife is doing the 9 to 5 part.)

But even when I felt really good, I always had only 25% of normal energy. I sometimes had to ask my kids to get me the coffee cup because I could not move 5 feet, let alone going up the stairs.

Then in 2009 I had 2 serious MS attacks within 3 months (again with my eyes) which left me pretty shaken and with a lot of follow-up symptoms, such as not being able to walk longer distances without the help of a cane.

At this point I finally conceded, after 12 years, that I was seriously ill and could see no real light at the end of the tunnel. (It seems laughable but I could never identify myself as being an MS-club member, and some members do seem to have a much bigger load to carry.)

The worst thing in my life was the impossibility of prediction. Every scheduled rehearsal with the band, every dinner plan with friends was a challenge and a fight. Usually, I was too exhausted to do it, but I couldn't always cancel so I'd do it anyway. Playing music – the easiest thing in my life - turned into a huge mental and energetic challenge. I had quit an additional band 2 years earlier and in September 2009 I announced I was giving my last concert because I didn't have the strength and balance to hold the guitar on stage. (Yes, I had to sit!)

So I decided to do anything that would help me function for the next 10 years to be at least able to take care of my kids, and my neurologist talked me into Avonex.

One thing I would like to say about my personal conclusions, and something I learned over the years – there is NOBODY who will take you by your hand to lead you and tell you what's best for you to do. With a disease like MS, the doctors seem clueless and use only the tools the pharmaceutical companies hand them, without even really understanding the mechanisms of how they work.

So you have to listen very carefully to your own body to decide what is good or bad for you. And if you're lucky, you have a caring partner or friends to discuss things with. For example I hate any medicine that alters my personality in any way and sometimes I felt like a guinea pig when they gave me antidepressants for fatigue. (That was a disaster.)

That brings me finally to LDN...

A good friend, a nurse we used to house with us in San Francisco, continued to tell me about LDN over a period of 2 years. I looked at all the web sites and didn't want to believe that something so complicated like MS could be held at bay with a 'low dose something' that would supposedly work also for every other curse and have no side effects.

In November, with all the side-effects of Avonex and no real objective measurable positive effect, I decided to finally trust my friend's advice (which I usually did), and give it a try. Very lucky for me one of my guitar students is an anaesthesiologist and my friend. He wrote a prescription for Naltrexone - no questions asked. I had no other feedback with any of my doctors. I just wanted to try it without the arguments of anxious doctors, as it was my decision in the end anyway.

I dissolved the 50mg Naltrexone in 50ml of water and started with 2ml (equivalent 2mg). After 2–3 days I was totally fatigue-free. After a week, I stopped using an aid to walk, and since then I haven't needed an aid at all.

If I couldn't believe myself what happened, I was convinced by everyone else. My wife, my kids, my friends, my family, my band members were all in awe about the new person they saw. My balance came back, I could walk, the fine motor skills I lost came back, and the mental blocks disappeared.

It has only been two months, but my energy level is back to normal. I saw my homeopathist after 4 weeks and she was so surprised about my condition, she squeezed every bit of information about LDN out of me. My neurologist has a positive attitude and tells me to keep using LDN if it's helping so much. (I ditched the Avonex).

We're going to monitor the development of my MS with regular MRIs. Of course, I've taken LDN for only 2 months now. Who knows if the changes will last? I don't try to convince other people or convert anybody. But then, I only say that to give the impression of composure and serenity. Truth is, I feel like I won the lottery and I'm jumping up and down on the inside. Better still – in the last 2 months I actually FORGOT most of the time that I have MS - something I had in my face every day since 2002.

There is a side effect though, I have sleep problems sometimes - but I experimented with the dose and time of day and established a working pattern -2.5ml before 10 pm works fine for me. Another positive side effect is that my intake of painkillers has stopped after getting out of hand.

I had often hoped to wake out of this cursed dream I lived in. Now my life's got a very positive spin and I feel hope again for the future.

Thank you all for spreading the word!

### 122

### Mary B, UK August 2005 - Multiple Sclerosis 2004 - LDN

Since starting LDN five years ago I haven't looked back.

Within two days of taking 4.5mg LDN, my fatigue vanished and my energy levels improved steadily.

Despite numerous knee surgeries and treatment for breast cancer, I haven't had any relapses or any noticeable deterioration in symptoms. I no longer see the Neurologist, and the MS nurse is very impressed with the stability of my condition over the past few years.

At times the LDN capsules have been difficult to access but the chemist, Dickson's, has been brilliant.

I would recommend anyone with MS to give LDN a try, because if it works for you it gives you most of you life back.

### 123

### Mary L, UK 1967 - Multiple Sclerosis July 2004 - LDN

LDN and Multiple Sclerosis (MS) - Our Experience

My wife has had MS for at least 42 years and it progressed steadily over that period.

She was initially diagnosed as having Epilepsy a year after our marriage in the early 60s (quite traumatic in itself). Then she was diagnosed as having MS as well! About 10 years ago they said the initial diagnosis was wrong (there were no MRI scans in those days!)

She lost the use of her legs and has been in a wheelchair for the last 25 years, since 1984. She'd been in constant pain for about 30 years and had been using a TENS to alleviate the pain. Ages ago she lost the use of her left hand (she was originally left handed) and had progressed to the stage that she could no longer feed herself. She was incontinent and had various other problems.

Throughout, my wife has remained cheerful and chatty. She was in the process of losing the use of her right hand and would then have been unable to even hold a drink

in her hand. We were rather worried to say the least, and then some friends told us about LDN. They said it had worked for them, and my wife said, "I want some of that!"

I wouldn't let her rush into it until we had discussed it with our doctor. He was reluctant to give us a prescription at first but I was insistent, and after discussing it with two colleagues he agreed to give us a Private Prescription. That was in July 2004.

Our doctor's reluctance is easily explained by the fact that the NHS makes it quite clear that it is the doctor's total responsibility if he prescribes 'off-licence'. We started her on a 3mg dose because that was the recommended starting dose at the time.

We played around with the dose at first and ended up on a 2mg dose. We're still trying to get the dose right, and this appears to be the one factor that needs to be resolved with LDN!

My wife got slightly worse at first but within days the pain in her legs had gone completely, her fatigue was greatly reduced, and spasm had been decreased to almost nothing. She still suffers from stiffness in her legs and sleeplessness (both problems, but not life-threatening).

Importantly, she can now hold a mug again and drink by herself - that small bit of independence is important! We had hoped for more improvements but did not expect any. We mainly hoped that there would be no further progression.

In fact, my wife's condition has slowly deteriorated over the 5 years she has been on LDN, but she is still better than when she first started on LDN - and Dr Bihari only ever claimed LDN would stop the progression. It has been £1.00 per day very well spent!!

In fact, she has also tried AIMSPRO which claims to improve her condition. It did for a while, but any infection stops it working, so that is on hold for a while as she keeps having bladder infections, and she is back on the LDN.

All along we have been determined not to allow MS to rule our lives! It does of course, but my wife has been brilliant at keeping going. We have flown to South Africa (last time in 2007), Turkey, have travelled by ferry to France where a friend has a place we're able to cope with and which we hope they won't sell, have flown by helicopter to the Isles of Scilly, and have driven to various places in Britain.

It gets more difficult each year, but our motto is 'you only live once and a long time dead!!'

## 124

Maurey G, USA July 2007 – Multiple Sclerosis August 2007 – LDN

I was diagnosed with MS in July '07. Looking back before my major episode, I had strong symptoms that I denied for 5 years or so. In July 2007 I couldn't climb steps, I

dragged my legs to get around, had no central vision in one eye, cried for no reason, had slurred speech and couldn't find the words for my thoughts, and I was so dizzy I walked into walls.

I started LDN in August '07, right after receiving my diagnosis. The first month I took 3mg, and I've been taking 4.5mg ever since. The greatest improvement in my symptoms occurred in the first 30 days. Improvement is slower now, so I keep a diary and check in with myself every 3 months. I haven't been disappointed yet. Once in a while if my legs feel stiff I drop back to 3 mg for a day.

I follow most diet and supplement recommendations related to my condition. I also have high cholesterol but my new diet has reduced my bad cholesterol by 20 points and increased my good by 7 – a nice side benefit.

I have 80% of my leg function back, no more dizzy spells, and no more speech problems. I have some loss of color vision in one eye, but I can see. My MS taps me on the shoulder every now and then, but I no longer think about it 24x7. I continue to work on my balance and leg strength with various activities.

At my 6-month check up with the same neurologist, he gave me a lecture on LDN not being FDA approved and strongly recommended Rebif to slow the progression. I asked him how he could possibly recommend expensive painful injections when I'm doing so well on LDN.

My LDN was prescribed by my GP who said "Why not? It makes perfect sense, won't hurt you, and the CRAB drugs are limited in their effectiveness."

My Neuro report came in the mail. He must have done some thinking after our visit. It reads, "The patient has done quite well since I saw her in July. She has had no attacks of multiple sclerosis. She takes low dose Naltrexone. She gets that medication through her primary care provider. She is aware that there is no evidence that this is helpful in multiple sclerosis. She is not interested in going on Interferon medication at this time and I do not think that it is necessary at this point either. It may turn out that she has benign multiple sclerosis."

I say, that if it is benign, it's only because of LDN, diet and exercise. I do believe attitude plays a big role. I'm putting a son through college and have 5 horses that must be fed and cared for. I cannot be disabled and will find the way.

That's my story and I'm sticking to it.

Update - July 2008: I'm still doing very well on LDN - no further progression or attacks, no medical information to report. Still following the same routine, LDN, supplements and exercise. No episodes, no progression, slow but steady improvement in leg strength and balance. Tolerating the heat of summer much better than last year.

Update - July 2009: 2yrs on LDN and I'm still firmly committed to LDN. No exacerbations - one very tired day after extreme exercise in high heat. In general, I'm able to handle heat much better than a year ago. Frustrated by a plateau in improvement, I've been seeing an acupuncturist/Chinese herbalist who is doing FCT testing and therapy for Lyme, Babesia and mercury poisoning. I believe it has sparked some improvement.

I'll see my neurologist on July 31 for my first repeat MRI.

#### **UPDATE February 2010**

I had my first repeat MRI in July. It showed all the same lesions as before, possibly one more in the brain, but the neurologist said that it was probably there before, just showed up in this 'slice'. No active lesions and no other new lesions.

No exacerbations since starting LDN - I would not go a day without it.

I wanted my diagnosis changed from MS to Lyme disease. The neurologist said, "That will never happen. You will always have the diagnosis of MS.".

My alternative Dr. says that the Lyme disease and heavy metal poisoning are no longer an issue, but are what caused my symptoms in the first place. He is now working on regenerating nerve impulse via a therapy called 'Field Control Therapy' (FCT). He uses bio-resonance testing and prescribes 'therapies' that involve dropper bottles of water infused with 'frequencies'. It is very cost effective. The therapy was introduced by Dr Yurkovsky.

It's working. I am skiing and horseback riding.

My remaining symptoms are leg weakness, loss of color vision and acuity in one eye and occasional, but manageable fatigue.

## 125

### Michael G, UK 1983 - Multiple Sclerosis 1st January 2009 - LDN

I have had MS since early 1983 but I was not aware of it until 1995 when I had a full medical in order to secure a mortgage.

Until four or five years ago it was relatively easy to live with and had very little effect on my quality of life. Then my balance went, I lost a lot of function in my fingers, I started to get spasms, and strange sensations in my legs (which I now know is called paraesthesia).

I continued coping reasonably well until 2008 when things went really downhill. I had to give up work in August 2008 due to losing function in my legs so much, that in November 2008 I got a wheelchair because I could no longer walk more than a few yards - and that was very slowly and carefully with the aid of a walking stick.

My legs felt like permanent lead weights. I was getting faecal urgency five or six times a week, and it was taking me ten minutes to get out of bed and stand up in the morning. My strength was failing fast, I was permanently tired and mostly in bed well before 9pm.

I stopped going out and I would not go on holiday because I got to the stage where everything was beyond me.

My GP arranged for a physiotherapist and an occupational therapist to visit me, but also told me that there was nothing that could be done about the particular type of MS that I had. However, when the occupational therapist came she told me of a patient of hers who had made a substantial recovery using Low Dose Naltrexone.

After researching LDN on the web I approached my GP (my original GP had just retired) and after she had done her own research she agreed to prescribe it for me despite the fact that it has not been approved by NICE.

I started taking LDN on January 1st this year, beginning at just 1.5ml each evening. After two months I, and my family, noticed very small improvements in lots of areas. I increased my daily dose to 2ml (which I am still on) and after another two or three months there were further small improvements, the most noticeable being that faecal urgencies are now only two or three times a month. My balance is better although still far from good, my strength has returned a little, I have more control of my digits and I'm told that my speech has improved.

My legs still feel like ton weights all the time, and walking and balancing is still very difficult and uncomfortable, and I still tire quickly - but having previously been told nothing could be done for me, I feel that LDN has helped me back towards a better quality of life.

It's now September 2009, and I've been taking LDN for 8 months, still at 2ml each night.

I have just received my first private prescription via online ordering - E-Med - and they were very efficient.

I've also been trying to obtain my LDN as an NHS prescription rather than a private prescription to get the cost down, so I submitted the required 14 page form, duly completed by my consultant physician.

My case went before the PCT, who suddenly decided they could not make the decision! It then went before the Drugs and Therapeutic Committee at the N & N Hospital who said they could do nothing as my consultant was not the person who should have filled in the form! The form is now with my GP, who I will be contacting shortly.

My condition has been a little erratic of late - I put it down to this stress - is this possible?

If, once my case is heard, I am still not allowed an NHS prescription I intend to write to our local MP.

## 126

### Michelle X, UK April 2004 – Multiple Sclerosis Sept 2006 - LDN

I had my first MS attack just before I turned 20.

I went into Oldchurch Neurology Unit for 6 days for tests.

I recovered completely, and MS wasn't diagnosed at the time. All they said was that the results from the lumbar puncture showed a trace of a virus in the spinal fluid.

My life then went on as normal. I had 2 children and it wasn't until my early thirties that I started to have problems, which I now know was leading to the Multiple Sclerosis diagnosis. I slipped on a cliff path abroad and tore a ligament in my ankle... this led to various operations and complications, but they still never mentioned possible MS, even though I was experiencing classic symptoms such as walking quite badly. My walking had deteriorated, and I couldn't walk long without pain.

I booked a routine optician appointment in April 2004 because I'd started having problems reading small print. From there things moved really fast downhill, and I was offered an MRI scan, which showed undoubtedly that I had MS.

It was shortly after this that I began using a crutch to assist my walking, and joined a local MS therapy group to make sure I was doing the right exercises, etc.

They offered me Rebif as a treatment. I was on Rebif for a year before I started getting warning signs that it wasn't helping me but making me feel worse.

Then one day, after what had become a regular high dose injection of steroids to help me recover from the Rebif, I was walking upstairs 1 day (comfortably) when I was hit by the most awful pain. It turned out I HAD BROKEN MY LEG IN TWO PLACES JUST WALKING UP THE STAIRS!!!!!

Having never broken a bone before, I started to question why... and I found out that brittle bones was a by-product of repeated use of steroids. I resolved there and then to seek another treatment.

I went to my Neurologist to ask his advice, but he was totally unhelpful and told me I was lucky to be on Rebif... and I just had to accept that my MS was progressing...

I'd heard a bit about LDN from various MS sources, so I asked him what he thought about it. He said, "Try it if you want, but you won't get it prescribed round here." He then told me of the dangers of unlicensed treatments... all of this though, he said in a sneering 'I know best' way. I was mortified at his lack of support. I then tried my GP... same story there!

So with no help from my Neurologist, I decided to ask anyone I could find with MS if they were using LDN. I got lots of emails back - with lots of really positive effects. I then made what was the hardest decision of my life, and that was to ditch the Rebif (against my specialists and GP's advice), and pay privately for an online prescription and liquid LDN from Dickson's Pharmacy in Glasgow. The Rebif had started having such bad effects I felt I had to.

I began LDN in September 2006, and within a few weeks felt better than I had for ages ... I had more energy and I just felt more alive. People commented on how much better I looked.

I was still working full time, but it became less of a struggle on LDN.

Then one day, quite suddenly, I realised I hadn't been having to have a 2 hour sleep as soon as I got home from work!!! I had hoped it would reverse the damage to my right foot... but that was probably too much to ask. I really do believe that if I'd been diagnosed sooner and found LDN sooner, I'd have been a whole lot better off.

I've been on LDN now for nearly 3 years and I'm really happy with what it's done for me. I wouldn't even like to imagine where I'd be now if I'd stayed on Rebif. For the last 3 years I've been relapse free and I've continued to work full time more easily than before. I've even been able to redecorate my house, completely redesign my garden and do all the physical work in it.

I couldn't have done this the way I felt on Rebif, and most importantly, I've noticed no more progression!!!

I'm so glad I made the decision to try LDN.

It was a really difficult and frightening decision at the time, but it turned out to be the best thing I ever did. My MS nurse mentioned Tysabri last year ...... but there was no way I was leaving the LDN to take a huge risk with that, when I'd been stable and happy for 3 years!

## 127

Mike M, UK 1999 - Multiple Sclerosis November 2004 - LDN

I started taking 4.5mg LDN back in November 2004. I'd had Mitoxanthrone treatment earlier that year due to the severity and frequency of my attacks. The proposed follow-up treatment was to be 'REBIF'.

When I was in rehabilitation in Queen Square, I met a considerable number of people who were less than complimentary about 'REBIF', so I decided not to go that route, but still... nobody in the medical profession would even talk to me about LDN.

I have not had the strange dreams or any other notable side effects while on LDN, and dare I say it, but I have not had any relapses since then either. I can't say positively that LDN is helping but it's certainly not harming me.

### UPDATE March 2010

Yes, I'm still taking LDN, and it's certainly not doing me any harm.

## 128

### Nathan K, USA 2004 – Multiple Sclerosis 2005 – LDN

In the 2004, after two low speed auto accidents one month apart destroyed two of my vehicles, I suspected the increasing numbness in my lower lip was a consequence of a pinched nerve. A physical therapist asserted that he could not help me but that I should see a neurologist. When I made that appointment I was told I should have an MRI before coming for the appointment.

I was given a copy of the images of my MRI and the reviewing doctor's assessment the day before my appointment. The assessment said that there were many lesions throughout my brain probably from Multiple Sclerosis. That night, I searched for information about MS for the first time and discovered that symptoms, which I had experienced over the past several years, could easily be explained if the diagnosis was MS. This discovery was an enormous relief.

Though I didn't recognize it as such, footdrop had been evident in the uneven wearing of the soles of my shoes, and; soon after noticing a loss of coordination and control over my legs, I'd stopped playing basketball regularly. So, the diagnosis made a lot of sense in consideration of these and other random symptoms I'd been experiencing intermittently over quite some time, such as; occasional balance irregularities, unexplained anomalies in bladder and bowel frequency and control, and occasional profound fatigue.

When I met with the neurologist for the second time a month later, he delivered a diagnosis of definite MS, as though it was a death sentence. I was already convinced this was the right diagnosis and was untroubled by it. Unfortunately, after taking his recommended drug, Copaxone for a year, another MRI showed an increase in both size and quantity of lesions. If it was working, I was not satisfied with the outcome.

When my wife asked me what I thought of LDN, I had no idea what it was, but I was interested to learn of anything which might be more effective for me. After researching for a month I became convinced that I had nothing to loose by trying LDN and may benefit. I obtained a prescription from the neurologist. He agreed that it would be better for me to get the drug with a prescription than from out of the country.

Within a week of starting LDN, I noticed a subtle return of the feeling of hope. Six months later, I accepted an invitation to attend law school, which I had postponed when

the diagnosis of MS had introduced such uncertainty about my future health. I withdrew from law school long before finishing and resumed the job I had before as an engineer.

It is now over four years since I first began taking LDN. Other than a continued sensitivity to heat, I hardly remember that I have MS.

Interestingly, when my son was diagnosed with ADHD I recognized some of the same symptoms in myself (ADHD and MS share some similar cognitive symptoms). Consequently I began taking an amphetamine salt, Adderall XR, and it has proven beneficial for my ADHD symptoms.

An MRI taken when I had been using LDN for four years confirmed what I had been feeling. There has been no increase of lesions in either size or quantity since I began taking LDN. In addition, previously active lesions have become inert.

I only recall my previous symptoms and experience with MS when I read my journal, and I can't recall when I last experienced recognizable symptoms of MS. No doubt this is why all the LDN groups recommend regular diary or journal notes.

I'm pretty sure taking LDN has up-regulated my immune system because I seldom get sick and when I do, I recover quickly. MS has become something of an afterthought. Though I continue to be sensitive to overheating, I've learned to avoid these situations through minor behavior modifications.

My experience with LDN might only be improved if more people chose to try LDN for themselves, journal, and report back that it helped them. Still, when LDN treatment becomes the standard of care and a first line treatment, I suppose that will be even better.

I continually share my experiences and hope some people and their families and friends find similar benefits as me.

### 129

### Nettie E, New Zealand

May 2008 - Peripheral Neuropathy, Hashimoto's Thyroiditis, Goitre July 2008 – LDN

For a time I kept a detailed diary, at least, up until I started to get well, because it was the only way for me to keep track of everything while traipsing from one doctor to another.

I have at least 5 foolscap, handwritten pages from less than a one-year period, and that was just dates and symptoms and treatments. I was misdiagnosed, mis-medicated, and eventually bumped from one specialist to another, which of course made everything worse.

I began taking LDN in July 2008 for Hashimoto's, then was diagnosed with Microscopic Colitis (MC). Initially, the LDN didn't seem to help at all, but as soon as I added probiotics, digestive enzymes and a raw, natural diet to the mix I very quickly improved.

I think the enzymes and diet helped my system absorb the LDN much better and I have gone from 8 or 10 painful, watery motions a day to just one regular motion. After only 3 months on LDN my health had gone from seemingly hopeless to miraculous.

My time on LDN has been short compared to the time spent searching for answers, which I guess is pretty much the same for everyone on LDN. We all have health issues throughout our lives that we encounter and deal with.

My two-year nightmare began in August 2006 when I woke up with severe cramping in my abdomen, vomiting and diarrhoea. A trip to the ER and lots of tests revealed nothing more than dehydration.

However, a month or so later I began intermittent bleeding from the bowel. My GP thought it was just internal haemorrhoids, but recommended a routine colonoscopy just to be sure because I was nearing the magic 50 plus years. The colonoscopy was performed a few days before Christmas.

The Gastroenterologist found a large polyp and informed me, while I was still lying on the table and as he took a biopsy, that there was a 50/50 chance it was malignant.

My early Christmas present was that it wasn't malignant, yet, but I had to have it removed surgically because it was high up, on the bend between my ascending and transverse colon, and impossible to remove by colonoscopy without the risk of perforating the bowel. By the way, a sigmoidoscopy would not have found this, so beware if you are ever in the same situation. Also, the bleeding did not recur once I had made the appointment, so I believe it was just God's way of getting my attention.

The surgery in February 2007 was straight forward, but while in hospital the nurses noted fluctuations in my B/P and suggested I see my GP once I was recovered. He wasn't concerned, but prescribed Temazepam as I was having problems getting a full night sleep (due mainly to my snoring husband). Taking Temazepam turned out to be a huge mistake on my part, but I was ignorant at the time and trusted the doctor. He wrote the Rx for numerous repeats and I blindly took it, happy to get a few more hours sleep a night.

Within a few weeks I was experiencing tremors in my hands and rapid weight loss. I finally went back to the GP and got a different medication. I asked if the sleeping pills could be causing my problems but she said, "No, no - keep taking it - you need your sleep". She diagnosed anxiety and prescribed Effexor. Only took it for two days as it made me 10 times worse.

Then she prescribed Lexapro, which I took for 3 weeks. It stopped the tremors but made my head buzz. She said that wasn't good so prescribed Paxil. The tremors didn't return, but I continued to lose weight. (25lbs over a few months, without trying - in fact - I often drank two bottles of beer after work as it was the only thing that helped slow the weight loss).

I felt progressively unwell and in September I developed electric shock symptoms and numbness in one foot. Saw yet another doctor who told me I was 'obviously anxious as

he could hear it in my voice' and told me to increase the Paxil and add Naproxen for the tarsal tunnel syndrome. This was despite the fact that my B/P had climbed to 170/110, but he ignored that and my protestations that there was 'something wrong'.

Two days later I called back into the clinic to have my B/P re-checked as I felt worse than ever. The nurse told me it was 170/120, that it shouldn't have gone up that much in two days and to see a doctor straight away. I saw doctor number 4, and at last I was viewed as someone who was sick.

He immediately reduced the Paxil and added B/P meds, referred me to a Neurologist, as well as ordering other tests. My blood pressure fell dramatically within a few days, but before I got to see the Neurologist I had one episode of extreme weakness in my legs, finding myself unable to stand for more than a few seconds at a time.

The Neurologist seemed concerned: I had stocking glove paresthesia in all four extremities and he told me I had Peripheral Neuropathy of which there could be a 100 causes, but he was most concerned about Myasthenia Gravis.

He ordered up a bunch of tests and said he would see me in a month for the results. I read up about PN and MG on the internet and found that the B/P meds that I had been given should not be given to patients with MG, and since my muscles were becoming weaker every day, I returned to my GP to have the Rx changed.

On October 30th while at work, my world turned upside-down when I developed shooting pains in my jaw while eating grapes, and then the whole left side of my face went numb. I felt it tingle and go progressively numb over just a few minutes.

I actually took a paperclip (working a desk job has its benefits) and stabbed both sides of my face to be sure. Panic ensued, co-workers gathered, husband was rung and he came immediately to take me to the ER. I found that my legs were very weak and would barely support me to stand, never mind walk without support.

A CT scan revealed nothing, but the Neurologist assured me, by phone, that the MRI he had ordered for next week was bound to tell him something. It was decided I couldn't return to work in the meantime as I had to drive half an hour each way and it was simply too risky. My symptoms came and went, but I never knew how I was going to feel one minute to the next.

With nothing else to do, I hit the internet, and a few days later, to my horror, I discovered that the drugs I had been given should never be taken together - not even within 14 days of each other!! The Temazepam should only have been Rx for a 10-14 day period and then re-evaluated. I was never told all the foods that I shouldn't take with it - and it turned out they were all my favorite foods. The only thing I was aware of when I began taking Temazepam was the warning that taking it with alcohol could make me drowsy. Duh! I was taking it to help me sleep, so what was wrong with that?

I went straight to my GP and asked that I be taken off Paxil and Temazepam.

He assured me there would be no withdrawal affects from the Paxil since I was on the lowest dose (wrong, but that's another story). He put me on a decreasing dose of Temazepam over a week to wean me off. If I thought I had had trouble sleeping before, this was something else, but I was determined to get through it. The withdrawal was awful, but the damage was done - and November 2007 was the worst month of my life.

Was it the drugs, did I have some yet to be diagnosed illness, was I going to get worse, or was I going to get better? All I could do was wait to see the Neurologist on the 19th.

What an anti-climax. Tests all revealed nothing, he said, and he recommended taking a wait and see approach. I was flabbergasted. He knew I was off work, he knew I had had a major collapse, yet he seemed not to care. So I laid into him with my findings about the drug reactions. He told me there was no way that the drugs could be causing my symptoms, so I left his office with an order for a Spinal Tap which was performed the following week. One of the new symptoms was electric shock sensations down both arms whenever I turned my head and I knew this could be an MS symptom, so I had to have the Spinal Tap to be sure. Results? Nada, but no surprise to me by this stage.

So where did all this leave me? I was convinced I'd been damaged by the drugs prescribed to me, but was without a doctor who would admit it, and without any help whatsoever to aid in my recovery. If I did have an underlying disease, it was either exacerbated or triggered by the drugs. But what did I have? Where would I turn? You guessed it - the internet.

To cut a very long story short (I know, too late) I basically dealt with each symptom separately, since looking at myself as a whole was too confusing. I wasted a lot of time waiting for appointments to see specialists (my GP tried to get me into Mayo, but they declined), and waiting for test results, most of which I asked my GP to run as I read more and more about my 'condition'.

I became convinced early on that I had developed a Thyroid condition, but which one? My symptoms continued to change on a daily and weekly basis, so my theories had to change too, but the Thyroid remained at the top of the list. Actually, the thyroid and drug withdrawal pretty much covered everything, but with no confirmation of my theories, it was impossible to just quit. I was also convinced that I was suffering from some sort of autoimmune disease or diseases and read books galore on the subject.

In January 2008, I found a wonderful Chiropractor who hit the internet too, researching everything I was telling him in an effort to understand and help me. He did reduce a lot of my pain but after a few months I had reached a plateau. When I lost my job and my health insurance and had to sell my car, I had no choice but to stop going to see him.

The third Neurologist I saw finally had a hit with a test for TPA (Thyroid Peroxidase Antibodies), which measured 170 instead of the norm of less than 30. He referred me to an Endocrinologist. More waiting.

Finally was seen by her at the end of May and she diagnosed a goitre, Hashimoto's Thyroiditis and low levels of Vitamin D. I was relieved, for about 5 minutes, until she told me that my symptoms could not be due to the goitre or the HT and that I should take Vitamin D to improve my muscle strength, try T4 (though she doubted it would help), and get more exercise.

Now I am not overweight, I have always eaten well, exercised regularly, and worked hard - 40 hours a week plus spent my weekends renovating my home - really hard physical work. Now I was simply not capable of exercising - muscle pain and weakness and fatigue made it impossible to do much more than care for myself.

I looked at the side-effects of the T4 and was horrified, once again, to read that it could cause all of the symptoms I was already suffering, and more. I told her I had chronic

diarrhoea, but she didn't appear concerned. In the last few months I had tested negative for Celiac and Whipples, so I think she decided I was simply lying about it. With no other options available to me I tried the T4, but it made me far worse. The diarrhoea worsened (and I didn't think that was even possible). I had the worst 3-day migraine I have ever had, and so I after a month I threw the T4 in the bin.

It was time to speak up and take charge of my own health for once and for all. I had been reading over the preceding months about LDN and how it had been doing wondrous things for all manner of people with autoimmune diseases. I had asked numerous doctors about it during my appointments, but they all scoffed at such an idea. With nothing left to lose I returned to my GP.

God bless this man because he believed in me all along and ordered up every test I asked of him. I told him I was done with specialists and tests and all I wanted was a Rx for LDN - that if he wouldn't write it for me I knew people and I would get it - it would just take me a bit longer. He simply said, 'Yes, I know you have done your research - just give me some information on LDN for your file'. If only all our doctors could be as open and caring as this man. I had my Rx for 1.5mg up to 3 times a day, the very next day.

I took my first dose of 1.5mg on July 18th and continued taking that for one week, suffered no sleep disturbances, so increased to 3mg. Almost immediately I felt an improvement in my energy, the pain and dysesthesia in my knee all but disappeared, and I felt an overwhelming sense of hope for the first time in more than a year. I tried increasing to 4.5mg after a few weeks as the diarrhoea would not settle down at all, but my leg muscles became stiffer so I dropped it back to 3mg.

Life was good, but I knew it could get even better. I had had an appointment arranged at one point, in early July, to see a Gastroenterologist, but had to postpone due to a clash with an interview with the INS. Anyone who has had dealings with this department knows you do not mess with the INS. I became a US citizen on August 6th, following that interview.

My new appointment was scheduled for late August and when I finally got there I was feeling so good, I didn't even bother telling him my whole history. I just said I wanted to be re-checked for any more pre-cancerous polyps, and while he was in there, to please take some biopsies to check for Microscopic Colitis. This was the only disease left that I could find that explained my unending diarrhoea. He felt that it was probably caused by bacterial overgrowth, due to half my bowel and the ileocecal valve being missing, but agreed to the biopsies. He did prescribe a course of antibiotics in the meantime, but to no avail.

The colonoscopy was set up for September and to everyone's surprise, not only did I have a couple more pre-cancerous polyps (small and easily removed), I also had Microscopic Colitis.

The Gastroenterologist wrote a prescription for Asacol. I had already studied the possible treatments and was far from happy with the prospect of taking yet another drug with horrible side-effects. This one even included possible hair loss, so I wasn't holding out much hope for a happy relationship with it. Four days!!! That was as long as I could tolerate it. I guess I can't complain - it stopped the diarrhoea. It stopped me up so darn well, I may as well have had a cork plugged in me. And the nausea!! Terrible!!

Took me a week to go again, and in the meantime I began a diet called 'Great Taste, No Pain' by Sherry Brescia.

Guess what? Once I got going again, no pain and no diarrhoea. It was like a miracle. Between the LDN and the diet, I was cured. I say cured because unless I stray from my diet (and it isn't a difficult diet, just avoiding certain food combinations rather than eliminating any foods), I have no issues whatsoever!

I have cut my coffee consumption to one cup a day - I used to drink at least three - and I drink green tea instead. That is the biggest change I have made. To be honest, I don't miss the coffee, and often can't finish my one cup. Love the smell, but the taste just isn't the same anymore.

By the way, I have never before been contacted by a Pharmacy regarding a prescription I had been taking, but I was contacted - not once, not twice, but three times by the Pharmacy who dispensed the Asacol!

I was encouraged to continue taking Asacol, that it was the only way I was going to get well, that I would never be able to cure the MC, just control it. Poppycock!! It just goes to show how much money the drug companies are making when they try so hard to keep patients on their drugs. And this crap was not cheap... the first month cost me \$45. (I should have taken back the 26 unused days worth of pills for a refund - lol).

This is my story ... It has changed forever the way I view the medical profession ... It has changed my whole perspective on life ... But most of all, it has given me the confidence to question, question, question and to demand what I believe is right, without exception.

No-one knows your body like you do, and no-one has the right to tell you how you feel or what is best for you. Fight on, my friends - we are not alone. LDN should be the first line of defence, not the final, last-ditch attempt. I will never quit taking it.

Update March 2009

No real changes for me except that I am now living in New Zealand and I've found a doctor who's just 20 minutes from my home and prescribes LDN. Could not believe my luck!! I continue to take 3mg of LDN each morning.

I'm working 6 days a week full time in two very physical jobs with no adverse effects to my health. I hope to eventually get a job as a support worker for the intellectually handicapped and the physically disabled.

### Update February 2010

Good health continues for me on 3mg of LDN and 65mg Whole Thyroid (compounded) per day. I am taking no other meds or supplements at all now.

I am now holding down a full-time job and two part time jobs, all in the Care Industry. Watching my diet (not eating any wheat) is the only other thing I am doing to keep myself fit and well. My diet is concentrated on NO wheat since I am intolerant, and it has made a big difference to my overall health.

Hiking with my husband in New Zealand's beautiful bush is a pastime I can enjoy with no restrictions, except that of a lack of hours in the day.

I actually have come across another whole theory on autoimmune disease, and it has to do with cows milk and the difference between A1 cows and A2 cows and the milk proteins they produce. If you search for info on 'The Devil in the Milk', you will find what I am speaking of. A university lecturer here in NZ wrote the book a few years ago and has been battling Fonterra (dairy producers), politicians and others regarding the research on this 'bad' protein in A1 milk. (A2 milk is available in most supermarkets but at twice the price.)

The really interesting thing in the book was that mice they were using in one of the experiments were being given naltrexone to block the proteins from getting to the brain. It was on reading this that the penny dropped and the whole theory came full circle for me as to why and how LDN may benefit.

The theory is controversial in the science world: Kinda like the whole thing of lack of Vitamin D causing MS, except the A1 milk theory holds way more water than the Vit D one. I would be interested in hearing what others think.

I hope this helps someone.

# 130

### Nikolaos P, UK March 2007 - Multiple Sclerosis November 2007 - LDN

Before I was diagnosed in March 2007, I was leading a happy, stress free life. I was working as a background artiste and music composer.

After I went to hospital, the whole world collapsed around me. While in hospital, my Neurologist (who, incidentally, I saw only while in hospital), had the clever idea to give me a course of strong steroid treatment, without knowing, or telling me, what I was suffering from!

His team said that the steroid treatment would bring the inflammation down, but he failed to tell me what he thought my illness was, or ask if I wanted to have the treatment! After I was dismissed, I developed my main symptom; HEAT intolerance; which I believe was caused by the steroid treatment.

When I was told about the NHS approved drugs for MS I was horrified. My Neurologist in Queen's square advised me to start treatment immediately. When I asked her for LDN, she agreed but stressed that this was not an NHS recognised treatment.

After 1 year of taking LDN, I requested from her an MRI scan to monitor disease progression. She refused to order a scan on the grounds that MRIs are used for diagnosis purposes only, BUT, she said she was willing to authorise a scan IF I agreed to start treatment with interferon.

I argued that I was on alternative treatments and managing my MS via diet and LDN, but she still refused.

After LDN, I regained hope and optimism. I've had no side effects from LDN, and best of all, there are no painful needles. I'm happy to take LDN until I fully recover, which I believe strongly will happen.

# 131

### Noreen M, USA 18 Dec 2003 – HIV January 2006 - LDN

First, I wish to state that there is much hope out there for those who suffer with immune diseases, as I have had a life-time of them, literally everything from A to Z; AIDS, ADHD, anemia, asthma, bronchitis, cancer, chronic fatigue, cystitis, Epstein Barr, Fibromyalgia, GERD, Hepatitis, herpes I, herniated disc, hiatus hernia, Hypoglycaemia, lymphadenopathy, Lymphedema, mono, low platelets, osteoporosis, progressive multifocal leukoencephalopathy (PML), quicksilver (mercury poisoning), radiation damage, scoliosis, stenosis, tachycardia, tinnitus, urticaria, vertigo, etc... and I am still here to tell my story.

As someone who has certainly experienced what many of you are going through, I wish to help others. Knowing that sometimes dealing with the mainstream can be frustrating, many of us have to search for answers elsewhere. My health issues first started in the mid 1970's and since that time, off and on, I have searched for answers.

I have completed a nutritional consulting course under a naturopath and I am currently enrolled in a BS program for holistic nutrition and am enrolled in a naturopath degree. I am the author of 'Perfect Immunity Against Disease'. My philosophy is to use what works, being it alternative or mainstream. I do not believe that one should be forced to choose one over the other.

Over the years many have contacted me about HIV and I try to help them as best I can. I do not sell any product, although I am happy to recommend any product that I feel is worthy.

I do highly recommend LDN to others because I have seen what it has done in my life, and for my friends and family. This is surely one drug that the world needs to know about.

My advice to all is to keep on searching for answers and never give up. There is light at the end of the tunnel.

### Update April 2010

I've had back problems for the past 8 years or so; herniated disc, pinched nerve, stenosis, osteoporosis, and curved spine. Due to back problems, in late 2007 and in 2008, I had numerous steroid injections where the anaesthesiologist weaved long

needles into my back approximately every 4 months. I also had several shot type injections (steroids) for bursitis in right hip in 2008. During this period, the arthritis doctor had me on prednisone in varying doses from 5mg to 20mg, but then I was slowly weaned off the steroids.

In 2008, I received a formal diagnosis of ADHD and was prescribed the generic of Adderal, which seemed to help. I have since stopped the med (in the fall of last year) due to other health issues, however; have found since starting Atripla in late 2009 that I don't seem to need it. My philosophy has always been, if it works then use it!

Then in late 2008 and all of most of 2009, my fibromyalgia and chronic fatigue symptoms came back. My arthritis doctor placed me on steroids, various amounts, which helped with both diseases. I felt great but did gain over 20 pounds.

Nevertheless, steroids are not a viable, long-term solution, so I was slowly weaned off them. However, all my painful symptoms returned and I found myself back on the couch and unable to function in life.

During this time, late fall of 2009, I developed new symptoms in my right leg and foot. They were reddish purple, swollen, and very painful. This lasted 4 months and I saw numerous physicians, who were clueless. My infectious doctor finally admitted me to the hospital and numerous tests were undertaken. It was finally determined that I had lymphedema, which was probably related to past damage from radiation treatments and to the loss of lymph nodes for biopsy on that side of my body.

During all of this, I was extremely tired and again my doctor prescribed an antiretroviral: HIV drugs are collectively called 'Highly Active Antiretroviral Therapy (HAART)', and there are numerous drugs within that category. I was prescribed a combination drug called Atripla. Within a very short time, all my symptoms from chronic fatigue and fibromyalgia ceased. I was perplexed to say the least, but it was working for me, and currently; I am symptom free from chronic fatigue and fibromyalgia.

I could not take normal estrogens, so I was prescribed Biestrogen on 24 Feb 2010, and it works great, and I was prescribed Progesterine at the same time.

I've done a lot of research over the years, and read of a connection between AIDS and the HHV6 virus, so I tested for it and was negative for it. I also read about an enzyme in the body called RNase-L and research indicated that when this enzyme is depleted (has half the proper molecular weight), that the body is more susceptible to developing viral illnesses.

Following on from that, I read that a new retrovirus had been identified in Chronic Fatigue patients, XMRV, and that this recently identified retrovirus was believed to be associated with numerous immune system diseases such as Fibromyalgia. The treatment for retroviruses is antiretrovirals so it makes sense to me why my chronic fatigue and fibromyalgia symptoms go away when I go back on the HAART medications.

So now I am in the process of being tested for XMRV, RNase-L Dysfunction, and for mycoplasma by a lab in Reno, Nevada. I will have to come off my medications for 3 weeks but to me it is certainly worth it to maybe, finally, get some answers to a life-time of immune problems, so on 8 April I stopped taking Atripla, estrogen, progesterine, and LDN and will recommence in 3 weeks on 29 April 2010.

I'm seeing a chiropractor for my back issues and that's helping tremendously, thus avoiding long-term use of medicines such as Advil and also the steroid injections way up in my back by the anaesthesiologist.

I would like to add that LDN has kept other immune diseases away from me and it would be highly unlikely that it can cure everything. Nevertheless, I would never stop taking it. I have seen what it has done in my life, my family, and for others! In my opinion, Dr. Zagon should be nominated for a Nobel Prize!

For me, at present, life is great! I continue taking LDN, as I believe that it is keeping opportunistic problems away!

### 132

### Pami, USA 18th March 2008 - Breast Cancer (BRCA 1) April 2008 – LDN

I was diagnosed with Breast Cancer (BRCA 1) on 18th March 2008. I had a bilateral on 15th April 2008. I refused chemotherapy, then started on LDN.

I take LDN most days and get it prescribed from Dr McCandless.

I am cancer free to-date.

I have always been a vegan and teach that to others. I feel that food is your most important defence.

I have no way of knowing whether it is the LDN or my lifestyle that is working, but I feel something is.

#### UPDATE March 2010

I'm still taking LDN most of the time but I'm not sure if it is making me better or not. I have continued to have sleep issues so I take the LDN in the morning.

## 133

Pat P, USA June 1993 – Multiple Sclerosis October 2006 – LDN

I am a woman in my mid 60s with MS. I had my first exacerbation at 15. I began taking LDN shortly after a disastrous attempt to take Rebif. It (the Rebif) resulted in one of the worst exacerbations I have ever had.

Although my life has been stressful, since I've been taking LDN, I have not had an exacerbation.

I am not symptom free, and I do feel there is some slow progression... but I no longer have those horrible exacerbations. For that I am very grateful.

I am on a low fixed income so I am grateful I can obtain LDN at a very low cost.

I have an MRI scheduled for early September, so I'm going to be very curious to see what it looks like.

#### UPDATE March 2010

I am indeed still taking LDN. I had my neurologist appointment last week. It was good. The things I am so grateful for are; I can wear regular shoes (not crocs or berkenstocks) and still keep my balance; I've had another year with no wretched exacerbations (I can even tolerate those huge base-type vibrations that used to send me looking for the nearest lead-lined room {haha}); every once in awhile I run into something else that isn't making my life tough anymore; and finally... I have MS, but MS does not have me.

# 134

### Patrick R, UK August 2000 - Secondary Progressive Multiple Sclerosis (SPMS) mid 2008 - LDN

The first symptoms developed in 1999, but I wasn't diagnosed until August 2000. I started taking LDN about 5 years ago at 3mg but I stopped taking it after a while due to badly disturbed sleep that affected my fatigue levels.

However, I was working for a stressful boss in a stressful industry full time.

I restarted taking LDN about a year ago because I was continually having to wear a prosthesis bag as my bladder was out of control and I remembered that the LDN helped first time around with this problem.

I can now go to work and wear just a pad and only wear my prosthesis bag when I am going out the house either for a long time or I am unsure were the toilets are. So the LDN has improved my bladder control.

Also, in the last month I've noticed my pins & needles in the base of my spine and legs has gone!

I am now taking 4.5mg and my sleep is less disturbed. I am working less hours for a less stressful company, so whether that has anything to do with my improved sleep, I do not know. I still wake up about 4.5 hours after taking LDN but I can get back to sleep a lot easier.

I have secondary progressive MS & can walk a small distance, however, LDN does not seem to have helped with the slowing down of the progression of the illness or my mobility problems but it has helped with my quality of life with regard my bladder issues.

## 135

Pat U, USA Feb 1995 – Multiple Sclerosis Sep 2003 – Crohn's Disease 3 March 2009 - LDN

In mid-February, 1995, over the course of 4 or 5 days, my body progressively went numb from my feet to my chest. My feet felt like they were in ice buckets and I couldn't tell when my socks bunched in my shoes.

I went to the emergency room, thinking this was related to back surgery I had several years prior. Unable to find anything, they sent me home. When the numbness continued to progress, I returned to the emergency room and was admitted. A spinal tap confirmed my MS diagnosis. I was given Solumedrol infusions and sent home with instructions to see a neurologist. Avonex and Amantadine were prescribed. From 1995 until 2009, I had only two small exacerbations. The tops of my feet are still numb, but thankfully that is my only neurological deficit.

In the fall of 2003, I began to experience bloody stools. After a colonoscopy, I was given the diagnosis of Crohn's Disease. I was hospitalised three times in 9 months, becoming malnourished and anemic with each bout. 6MP was prescribed but I was found to be part of the population that is unable to tolerate it. Prednisone was then prescribed, which had marginal benefits compared to the side effects. I had two infusions of Remicade but it potentiated my MS symptoms.

The next attempt was Budesonide, which was better tolerated than Prednisone and helped calm flares. I was put on a maintenance dose of Methotrexate. A week after being dismissed from the hospital the third time in 2003 for Crohn's, I fell off a horse while on vacation in a semi remote area of the mountains. I was airlifted by helicopter to a nearby city and in the hospital for three weeks recovering from a head injury. 2003 was a year from hell!

In the spring of 2005, I read an article in a wellness magazine about LDN and its success with MS. I had reached a level of stability with my Crohn's and head injury and wasn't ready to 'rock the boat' medicinally, but mentally filed the information away. In 2006, my sister was diagnosed with PPMS and my other sister was having suspicious events, causing her to wonder as well.

In November 2008, my daughter, in her late 20s, was diagnosed with MS. I then spent days on the internet reading everything I could about LDN. She did not want to take any of the CRAB drugs after reading about their side effects, and wanted to try LDN. Her neurologist was not in favor of her taking LDN. She sent her records to a physician out of state and had a phone consult. He prescribed LDN and the prescription arrived from

Skip's in just a few days. I also sent my records to the doctor, had a phone consult and received an Rx for LDN. I stopped taking Amantadine, Avonex, and Methotrexate and began taking LDN on March 3, 2009.

After my MS diagnosis, I altered my diet to a low saturated fat diet, following Dr Swank's advice in his MS Diet Book. I have no way of telling whether or not it has helped over the years, but it is regarded as a healthy diet for anyone and I wanted to give my body every chance at keeping the dreaded MS beast at bay.

After my Crohn's diagnosis, I didn't significantly alter my diet, other than reducing most dairy products except for yoghurt.

I also introduced supplements to my regimen, and I take the following daily: Iron 20mg, choleast 600mg twice daily, calcium/magnesium 500mg twice daily, vitamin D3 1000iu daily, vitamin B6 200mg daily, DHEA 20mg daily.

When I began taking LDN capsules with avicel filler, I started on a 1.5mg dose for three weeks, stepped up to 3.0mg for two weeks and then 4.5mg. I take it in the evening between 10.00 and 12.00pm. Prior to starting LDN, I had been on a downhill slide with Crohn's for a couple of months. Two weeks after stopping Methotrexate, I had a flare.

After talking to Dr Skip of Skip's Pharmacy about whether or not I could take LDN and Budesonide (which I knew my gastro would prescribe) at the same time, he said that Dr Jill Smith did not require her patients be off steroids while taking LDN during her Penn State trials.

I went armed with LDN info to my appointment with my gastro. At least he was willing to listen and read the info and not usher me out the door! So I took Budesonide along with LDN for a time, and the two seemed to work together to keep me out of the hospital.

I titrated the Budesonide dose down to 3mg in early May, but again found myself dealing with bloody stools. Following my gastroenterologist's instructions, I went back up to 6mg for four weeks and am currently alternating between 3mg and 6mg, with the intent of tapering down to 3mg daily during the next week and then hopefully, zero, a few weeks after that!

During my telephone consult with my LDN physician on July 27, 2009, he prescribed not only a refill for the 4.5mg evening dose of LDN, but suggested I also take 1.5mg in the morning. Every body responds differently, he said.

It is now 27 July 2009. I've been off immunosuppressant drugs since 3 March 2009, and my only prescription meds are LDN and the temporary Budesonide! Hurray!

I try to go to the gym 3-4 times a week for cardio and strength workouts. In addition, my dog encourages me to go for a walk every day.

A delightful, and unexpected result of being off immunosuppressant drugs is that I have 'me' back. I now enjoy playing the piano, I have 'happy' thoughts, and I have rediscovered my creative side. I'm happy even though there are still struggles in life. I care about living again. It's been a long 14 years without feeling joy.

## 136

### Paul B, PA-C, Physician Assistant, USA 2004 - Crohn's Disease January 2008 - LDN

My son developed the first symptoms of Crohn's in 2003 at 9 years of age, and it proved to be severe, resulting in a 60 cm small bowel resection at the young age of 10.

After being on Imuran for almost 4 years, he had a flare from his gastric mucosa to his descending colon, and developed hypovolemic shock. None of the drugs he was prescribed helped him, nor did the surgery. When he got out of the hospital he was still not normal.

When I learned of low dose naltrexone as a treatment option, I researched it further and decided it was worth trying.

I started him on low dose naltrexone (LDN) in January 2008, and within 2 weeks his color had returned and his energy was back to normal. At his follow up examination 5 months later, his lab results were the best they'd been since diagnosis.

He's had NO flare ups since. He still has symptoms of cramping, but only when he does not follow his diet, and it's been 18 months now.

This is how our story started:

In October 2003, I took my ten year old son to the Pediatrician to investigate severe fatigue, and why he'd gained no weight in two years.

I have been a Physician Assistant (PA) for 27 years, so I strongly encouraged the Pediatrician to run some basic blood tests. Due to the blood tests revealing extremely low levels of iron, the Pediatrician recommended iron supplements.

We tried 6 different iron preparations, and my son vomited with each one, so we again consulted the Pediatrician. I suggested finding out why he was anemic, and to perform tests to rule out Celiac disease. The doctor agreed, and his TGG test was slightly high, suggestive of possible celiac.

In November 2003 we saw a Pediatric Gastroenterologist. He scheduled my son for upper and lower endoscopies performed over the following two months, resulting in a diagnosis of Crohn's disease in January 2004, and a prescription for Prednisone at the same appointment.

The same month we had to consult a surgeon due to my son developing an abdominal distention, and incapacity to eat. The surgeon recommended surgery to address my son's obstruction.

During surgery in February 2004, 60 cm of his small bowel was involved with the

disease as opposed to the predicted 10 cm on the CT scan. Therefore that segment was resected. The pathology report showed it was nearly perforated.

He was prescribed Prednisone for 6 weeks, and Imuran permanently. My son began to recover and gain weight. Blood tests revealed his Hgb went up to 11.8.

In May 2004 we started supplementing his diet with 300mg of fish oil per day.

Between May 2004 and November 2007, he did well on 150mg Imuran per day, but on 29th October 2007 he developed tremendous diarrhoea and lost 19 pounds, with his weight slipping from 116lbs to 97lbs in 5 days.

Hypovolemic shock followed, and we nearly lost our son.

Repeat CT scans were taken, and upper and lower endoscopies performed. They revealed active Crohn's from my son's stomach to his lower bowel, with abscesses in his stomach and throughout his whole intestinal tract, as well as granulomas.

He was treated with antibiotics, Azacol, and Flagyl, fed IV nutrition. He was still not doing well but was discharged. The Children's Hospital staff couldn't find a cause. Cultures for bacteria, viruses, and fungus were negative. His CRP was 20. He was discharged to go home. All medications, with the exception of Imuran, were discontinued. He seemed to stabilize but was still not doing great.

We increased his Fish oil from 300mg daily to 600mg per day after he was discharged.

In December 2007, his Hgb was still only 12.2. It had hovered around that level since he was 10, and since he'd begun taking Imuran medication nearly 4 years earlier.

In January 2008 we heard of a treatment called low dose naltrexone (LDN), and we consulted with Dr Grossman about the possibility of our son taking LDN.

In January 2008, our son started on 1.5mg naltrexone for 3 weeks, then 3.0mg for 3 weeks, then took 4.5mg every night thereafter.

Within 2 weeks of starting the 1.5mg and tapering down the Imuran, our son's color looked better, he became more active, and was off the Imuran completely by the time he was taking 4.5mg naltrexone.

In May 2008, he was active enough to return to BMX biking, but also due to that activity, ruptured his spleen.

The blood test taken for his Gastroenterologist follow-up was promising. His Hgb was up to 15.5, higher than it had ever been since he grew sick – and his CRP (inflammatory marker) was less than 0.5. When he'd been hospitalisation, his CRP had been 20.

His glutamine and magnesium were low on a spectra-cell blood test, and his B12 was slightly low also. We started him on 5 grams of Glutamine, 300mg of magnesium, and a multivitamin with Iron each day. We also started him on probiotics.

By June 2009 he hadn't had any flare ups since commencing LDN in January 2008, 17 months earlier. He was 15 years old, and had grown to 5'9" and 142 pounds. He looked healthy and was continuing to have normal bowel movements.

He still gets cramps if he doesn't maintain his dietary restrictions.

He does not eat sugar or milk products, and his bread intake is limited.

In June 2009, his CRP was 1.1 (less than .8 is considered normal), so it is up a little. Hgb was 14.1 (normal range 13.4-18.0). His ferritin was 26 (normal range 20-380), and his Iron was 37 (normal range 40-225).

I had started but stopped giving him a daily multivitamin with 18mg Iron per day due to him experiencing nausea in 2008, so I am now going to start him on a multivitamin with a lower iron component at 9mg. I'm also putting him on B12, and a combined B6/ Folate supplement.

I also have him on Vit D3 50,000iu once every 2 weeks because his Vitamin D test result was 29. Our goal is to get it into the 60-70 range.

We are increasing his D3 to 50,000iu every 10 days, and his fish oil to 900mg per day.

The fish oil was originally started for a different reason back in 2004, because he had symptoms of ADD. A Purdue University study had shown kids with mental disorders often had low Omega 3 Fatty Acids (FA), so I started him on it for that reason.

We're continuing the probiotics, and have added Sacchromyces, which might help minimize yeast, and has reduced his flatus substantially. The probiotics are from Prothera/Klaire as suggested my Dr Jaquelyn McCandless who has treated many autistic children with LDN and probiotics.

The time he takes his naltrexone varies with his teenage lifestyle, but in general he takes it at about 10 pm each night. I asked Belmar pharmacy what filler they use in his capsules, but the pharmacy will not tell me. They said it is proprietary. I think I will have to challenge them on that.

I also have a friend with MS who started on LDN, and 4 months later had more energy than they'd had in the previous 5 years - and they were able to go off Rebif.

### UPDATE February 2010

The update on Danny is he is doing well.

We just had the Crohn's researcher call us for an update so the summary is; he is now 5' 10" tall and 156 pounds, so he's gained about 60 pounds since his hospitalisation in November 2007.

He has normal bowel movements, color and consistency, and no cramps unless he overeats on junk food.

He has no milk in his diet, but does eat cheese. He eats some sugar candy, but very little and only very occasionally.

He continues to take a Saccharomyces Probiotic, fish oil, glutamine 2 grams per day when he does not take his glutamine his rash breaks out on his arms, Magnesium 250

mg per day, LDN 4.5mg per day, daily teen vitamin with 9mg of iron, vitamin D 50,000iu every 10 days to 12 days.

He is playing hockey regularly, no exacerbations other than when he had a lot of breadrolls on a cruise ship and got bad cramps for several hours.

# 137

Paul C, UK 2004 - Multiple Sclerosis 3 October 2008 - LDN

My name is Paul and I've been taking LDN since October 2008.

I have had MS since 1996 (diagnosed in 2004) and was on Avonex for about 4 years but couldn't bear the flu symptoms, although I did persevere with it until I came across LDN quite by accident.

I stopped using Avonex, and took my first LDN capsule on 3rd October. I noticed an immediate improvement the following day, which was a Saturday and shopping was on the cards - something I never looked forward to because I live on my own and am forced to do everything for myself or not at all.

Other, noticeable, improvements were lack of fatigue, vastly improved bladder control and a 'can do' feeling even though I know I can't - like the days before I got sick when I was firing on all four cylinders, only now it's 24/7. Oh, and there's no depression now either. LDN has given me my life back.

# 138

### Paul S, Australia 2004 - Primary Progressive Multiple Sclerosis (PPMS) February 2009 - LDN

I have been using LDN for Multiple Sclerosis now for over 7 months.

I have found it is helping me with fatigue, as well as my speech. This is not in my mind, as I have been told this by other MS people who have been keeping a close eye on me since I started using this drug, and so have doctors.

At this stage I'm very, very, very impressed with LDN, and I thank you so much for giving me another chance in dealing with these MS problems.

I have Primary Progressive Multiple Sclerosis. I was diagnosed in December 2004 - a great Christmas present !!

I was told I would only go downhill, and there were no drugs out there to help with this medical problem.

I was very determined to try LDN, but, no-one here would prescribe it, so I showed your information to a heroin doctor as was told that I was the first MS person to ever come to him about this drug, and that he would only give it to me if I wrote a daily diary, which I did, and so far he is also impressed.

## 139

### Paul W, UK 2005 - Kidney Cancer July 2007 - LDN

I lost a kidney to cancer back in late 2005.

A year after surgery, in late 2006, I was told my cancer had returned and my prognosis for survival was from 2 to  $2\frac{1}{2}$  years.

I heard about LDN in July 2007 and I've been taking it ever since. My two and a half years has just ended, and I defy anyone to find a fitter 55 year old (well, almost anyone)!

## 140

### Paul W, USA (by wife, Aletha W) 2004 - Multiple Sclerosis December 2004 – LDN

When nearing the end of my husband's 48th year we had decided to purchase a rental property in a rapidly growing community in Florida. We worked for months doing research and finding a good property manager. Then there was the hard work of finding the right property and securing a loan. The most difficult part of our venture was doing this all from California and not being able to see the home in person.

Once we found a house that met our criteria and had the loan papers underway we booked a vacation for the family and flew to Cancun. From the resort we checked our email and the house had closed escrow one morning. The next morning the internet reported that Hurricane Charlie had hit the coast of Florida.

When back home in California, my husband worried for the entire month of September while the Sunshine State was ravaged by four consecutive hurricanes. He worked at a weather center where the days were filled with the topic of the hurricanes. Then he would come home and check the internet and spend the evening watching CNN. At the end of the month our new house was fine, but my husband was not.

Paul went to his doctor complaining of neck pain and, within a few weeks of extensive testing and a series of different specialists, we were told he had what appeared to be Multiple Sclerosis. The news was completely devastating to my husband as he pictured his life in a wheelchair and being unable to surf, play basketball, and play tennis.

Paul's symptoms began appearing in rapid succession. He experienced a strong depression and lacked the feeling of well being; he found that he could not coordinate a cordless screw driver to put up our new curtains; he had bladder frequency and could not stray far from restrooms; and one day he came home in tears because he could no longer shoot and make a basket.

Paul's depression grew despite going to a psychologist, learning to meditate, going through hypnosis and trying a selection of antidepressants. Every morning I would sit with him in bed and give him a pep talk. I would point out all of the people that do just fine with MS and how it can be very slow in progressing for some people.

Although he would try everything suggested to him to get beyond the empty spiral of extreme depression he was not getting out. The worst of Paul's symptoms was extreme fatigue. Everyday for two and a half months Paul would go to work for half a day and come home after lunch break. He was too tired to stay at work and too depressed to concentrate on getting anything done while he was there. Paul began thinking of how to end it all.

After going through a series of neurologists, our family doctor got us an appointment with a young neurologist in the area. She was very kind and caring. She took the time to explain everything to us. We felt like we were finally getting somewhere. She explained the four C.R.A.B. drugs to us and told us that Paul had a little time before deciding which one would be best for him. That evening I went on a quest to find out everything I could about these four drugs. Most of the sites that I found were from the drug companies themselves and from other organizations that advocated using them.

Over the next few days I spent countless hours trying to find out what people who were actually using these drugs had experienced. I finally happened upon a site called Remedyfind.com, which lists many ailments and their treatments. People themselves rate the drugs they have tried and they are able to write a paragraph about their experiences.

The news was pretty bad for all of the CRAB pharmaceuticals. They required taking shots, having a lot of nasty side effects, were very costly (\$800 to \$1400 per month) and did not appear to help very many people. When I looked at the overall rating of these drugs I was stunned to find them at the bottom of the list with a rating of 4 to 5.5 on a scale of 10.

I looked up to see what was in the number one place and it was a drug I had not heard of. It was called LDN and it was rating at 9.1. I quickly read that this drug was taken in a pill form, it had very minor side effects that typically disappear within the first month, and the drug only cost approximately \$20/month. The most amazing thing however, were the stories of how people were getting their lives back. An added bonus is that a majority of people were experiencing a lack of progression. Their MRI's were coming

back with no new lesions and their symptoms were disappearing. I spent the better part of an evening crying as I read through more than 60 stories from LDN users.

I printed out all of the stories so that I could give them to our new neurologist. I was sure this was a no-brainer and she would write Paul a prescription and we would be on our way. But she did not seem interested in looking them over or doing further research on this miracle medicine. I could not understand because it was FDA approved at a much higher dosage of 50mg, while you only took 3 to 4.5mg for MS. Certainly there was no danger in trying it.

While I concede that I am not a scientist, I could not understand how this many people could be wrong. I decided we needed to take my husband's health into our own hands. The following week I made an appointment with the doctor in New York who originally thought through the idea of administering this drug in a low dosage for people with autoimmune disorders. From what I understand, many neurologists are concerned about giving LDN a try because it most likely strengthens the patient's immune system, which they are concerned might then result in its further hurting and attacking the body.

Three out of the four CRAB drugs are described as immune modulators (or some say immunosuppressants). But as it turns out, once the immune system is up-regulated it appears to get into gear and remembers how to behave so as not to attach one's own body tissues.

The day after my husband took his first dosage he went to work and did not come home until 5pm. His feeling of well being returned and within a week his bladder frequency was gone. Within a month Paul could use the cordless screwdriver and he was back to 2 sports a day in the next few months.

5 years later, and my husband has never come home due to fatigue and his MRI's show no new progression. The only symptom that Paul has is minor numbness and tingling in his hands.

What I have learned from being on the Yahoo LDN chat site is that about 85% of people with various autoimmune diseases have lack of progression and/or some form of symptom relief. Not everyone reacts as quickly as my husband and not everyone has miraculous recoveries. But once in a while I hear of people that get out of wheel chairs, get their vision restored, gain their cognitive skills back or feel like they no longer have the dreaded Monster. I believe that neurologists that truly care about the health and well being of their MS patients should first try LDN and move onto the CRAB drugs only if LDN is not effective for them.

### Update April 2010

The day after my husband took his first dosage he went to work and did not come home until 5pm. His feeling of well being returned and within a week his bladder frequency was gone. Within a month Paul could use the cordless screwdriver and he was back to 2 sports a day in the next few months.

Paul commenced LDN in December 2004, nearly 5 and half years ago now. My husband has never come home due to fatigue and his MRI's show no new progression. The only symptom that Paul has is minor numbness and tingling in his hands.

## 141

### Peta S, UK 1990 – Secondary Progressive Multiple Sclerosis (SPMS) 23 March 2009 – LDN

I was diagnosed with MS in 1990, based on symptoms going back as far as 1981. I've been Secondary Progressive since 1997, and by 2009 I'd moved to a bungalow because I couldn't do stairs at all, was unable to drive any more, needed home and garden help and some help with washing and dressing.

Outside the house I was using a rollator to walk for short distances of maybe 20/30 yards, but was very slow indeed and needed a wheelchair when I went anywhere that needed more walking. Indoors I levered myself around on crutches, having great difficulty lifting my feet, especially the right foot. Just getting over the front doorstep with a grab rail was hard. I needed a special shower for washing and had grab rails everywhere in the wet room, which my bathroom has become. So I'm fairly disabled!

I'd gone on with my full-time occupation for as long as I could and for many years I had just worked around the attacks, which I could do as I was a writer of novels and short stories (under a pen name which I won't plug here!) In the end, a combination of the MS problems, which severely limited my working hours, together with government introduction of new rules about working while claiming an Incapacity Benefit, just about scuppered my career.

...But, I'm ferociously independent, live alone, and formerly was very active indeed. Now I'm an Old Age Pensioner of 62 life has really closed down, but I'm still trying to manage by myself as much as humanly possible. So, the hope of some medicine that might stave off the nightmare scenario of needing full-time care was very, very interesting to me when an American e-mail contact alerted me to LDN. I looked it up on the Internet, read it up in detail, then followed the links to the Research Trust. That was at the beginning of 2009.

I was very keen to try LDN. It represented my first, last and only hope, as there was nothing available for people whose MS was as advanced as mine. I'd had a spell of 12 days in hospital over Christmas 2008 and the New Year, because for only the second time in my life I hadn't been able to walk at all as a result of an attack. (I still have them about every three months, a further step downhill every time.)

As a result of the hospital admission I had that rare experience, an appointment with a neurologist. I waited for this in the hope of getting him to prescribe LDN. Some hopes! When I saw him in February 2009, he sighed heavily and said he didn't know how many times he'd been asked about it, but it was a bad idea as there were awful side effects. I asked where he'd learned about those as to my knowledge there weren't any. He said there was a mass of info about it on the internet and when he told patients that, they didn't want it any more. I said, "But I do."

I nagged the neurologist into admitting that any doctor could prescribe LDN off licence. I reminded him that Amitriptylene is patented for depression, but it is recognised as effective for neural pain and prescribed to MS patients off licence as a palliative for pain. At my insistence he agreed reluctantly to write to my own doctor to say that any doctor could prescribe LDN, but he took his time to do it and when the letter finally arrived at my GP surgery, he made it clear that he didn't approve.

As a result, my very nice doctor said apologetically that she didn't dare to risk her career by going against his wishes. It became clear that my only hope was to follow Linda Elsegood's instructions of how to get LDN by registering with the e-med doctor to get prescriptions and getting it supplied by Dickson's Pharmacy in Glasgow.

I started taking LDN on 23rd March 2009. The e-med doctor said that I should start at 2ml per day because my symptoms included spasms. I should increase the dose by .5 ml every fortnight up to a maximum of 4.5ml. He said it wasn't a case of the highest dose being the best but of finding the one that suited me best. I did try them all but the one at which I had the most noticeable benefit was 2.5ml, so I went back to that and have continued on it happily ever since. I found it gave me a great lifting of the spirits and increased energy.

I used to have a lot of falls and had to call out the emergency services using my Aid-Call button, because I can't get up from the floor by myself, but now my balance and strength are better and I haven't had a fall since I started on LDN. With my stronger legs I am a lot more confident about picking up dropped items from the floor, which used to feel very risky.

For several years I've had obscenely swollen ankles and frozen, bruised-looking feet due to poor circulation caused by my limited mobility, but since I started taking the LDN I've had the strength and determination to stand on tiptoe 400 times a day in batches of 100 and that has got rid of most of the swelling, to the point where I can wear my narrow (AA) shoes again. I can lift my feet better and make proper steps instead of shuffling. I can do household tasks a lot more easily and I can even begin to contemplate getting to the next Glasgow LDN conference via taxi and plane, something I'd have thought quite impossible before.

I saw my unhelpful neurologist once more, in August 2009, and I had the impression that he is only looking at Naltrexone in its high dose (50-150 gm for drug addicts) and refuses to recognise that Low Dose Naltrexone is quite a different matter. I did point out to him that I take 2.5 ml of LDN per night, and that the lowest dose for drug addicts' taking Naltrexone is 20 times as high. If I was drinking 40 litres of water per day and taking 60 Tizanadine (anti-spasm pills) and 20 Amitriptylene each night I would be having side effects! On LDN I don't get any side effects. He muttered that it did depend on the dose, but that was all.

What are his reasons? Is he influenced by an article I've seen criticised on the web as either sloppy or deliberately misleading? I know that the drug companies would lose a lot of money if LDN use replaced their drugs like the Interferons or Copaxone. I wonder how much pressure they are bringing to bear on neurologists to protect their interests.

I know that in MS the immune system goes mad and attacks what it shouldn't, but as far as I know, the research teams have never explained why. It seems very reasonable to me to suggest that perhaps the triggering virus has damaged the immune system and in its weakened state it thrashes about attacking anything that might be a threat, so maybe boosting the immune system as LDN does instead of suppressing it could help it to recover its normal activity. I accept that LDN can't reverse existing nerve damage, so there is a limit to what it can achieve for a Secondary Progressive like me, but what it has achieved has been very worth having.

## 142

### Peter S, UK May 1996 – Relapsing Remitting Multiple Sclerosis (RRMS) 2009 – Primary Progressive Multiple Sclerosis (PPMS) April 2009 – LDN

I was diagnosed with Relapsing Remitting Multiple Sclerosis in May 1996, and I was started on Beta Feron in Nov 1996.

I injected myself for 3 years with Beta Feron before my Consultant said my MS had progressed to Secondary Progressive, and took me off the Beta Feron. This change coincided with the NICE report on the effectiveness of the drug (and of course the costs)!

The only drug then available to me was a particularly aggressive drug, which can cause hardening of the heart and can only be taken for three years, so no good news there!

A pal of my fathers sent a national newspaper cutting about LDN to him so he could pass it on to me.

I immediately made contact with Dr Bob Lawrence and received sheets of information about LDN, recommended supplements, and advice.

My condition prior to starting on LDN was good, and the fact is... a drug that has possibility of improving my lot is of great psychological benefit.

I started taking liquid LDN at 3ml, and it was only when this was increased to 4ml that I went through a short period of discomfort. I'm due to start on the compounded capsule form very shortly.

I hope a trial of LDN for MS is started, so that others can see the worthiness of the drug and so it can be made available to sufferers of MS who, like myself, will grasp at any chance to improve their lives.

I hope one day a drug to halt MS will be found, but in the meantime, give this a shot. I have only been taking LDN since April, but have already got a feeling of well-being, and friends and family have told me that I look 'good'. The cost of this treatment is not outrageous, and for me that's a huge plus.

### 143

#### Philip M, Australia 2002 - Sjogren's Syndrome 1 July 2009 - LDN

My story is a bit lean on LDN information. I've only been taking LDN for about 8 months. It will, nevertheless, be clinical and hopefully of interest and help to some.

In the early 1960s, just short of 30 years old, a very sharp continuous pain in my left shoulder caused a doctor to tell me I had Rheumatoid Arthritis. It was sudden and without any sign or warning. Within a month or so I had the classic swelled up fingers and the symptoms progressed to other joints over ensuing weeks.

It was treated with aspirin at first, as much as 16 x 300mg per day, then Indocid. At that time I followed doctors' instructions, though they acknowledged no cure existed. I had to be managed. The most useful control drug (but most dangerous, as will be noted later) was the 5mg of prednisone daily. And I managed with copious amounts of beer regularly most days for years. Don't get me wrong. I did not become a drunk.

It wasn't long before I began to look to alternative medicine. I took Cod liver oil (yuk!), and ingested boiled leaves of all sorts. I gave everything a good months trial. I tried Chiropractic and even the historical '30-day fast' consisting of nothing but water. During this early period the doctor treated my knees by 'expiration', a draining of the fluid, and injecting cortisone direct into the cavity. As will be seen later, this had serious consequences...

Somebody in North Queensland was offering to let people with Arthritis be stung by their bees. I should have rushed up there but I was a coward. By 1970 the knees had deteriorated to beyond use, damaged (I later learned) by the cortisone. I had to stop work. I was hooked on prednisone to the extent that I would go comatose trying to give it up.

We were only now beginning to equate the immune system as a factor in arthritis, as well as many other diseases. They did try chloroquine as an immuno-suppressant, without any result, but I ended up rejecting it on the grounds of the alleged threat to my eyes. I might add that I had by this time become more knowledgeable in medicine than most medical students.

By 1973, two medical miracles happened. First up, a Dr Cilento offered to try bee venom injections. The method was essentially the same treatment used to get people non allergic to bee stings. Using a small needle, and starting with 10% venom in water, artificial stings were injected (three inside of each forearm). Over a month this was repeated every few days till full strength was used. Before it was over, I had gone cold turkey on the prednisone, and the arthritis was in full remission. Even the knees let me walk, with crutches.

Then my doctor introduced me to someone who I consider to be among the real heroes

of medicine; the orthopaedic specialist, Dr. Peter Milroy. Within 18 months I had received two total knee replacements, and those two knees are still working perfectly for me today, in 2010. That's over 35 years now, and he only gave me a 10-year warrantee.

So why am I still here writing to you? The Rheumatoid factor took a new turn over the years. Years ago it had already begun depleting my tear production and serious eye dryness had occurred. I managed this with artificial teardrops, but when the salivary glands began to dry up, I began to take notice: It was bad, and I admit for the first time I nearly panicked. There was no suitable artificial saliva. After innumerable internet searches I found information on a stimulant that could work... Salagen tablets. They are not, however; recognised or allowed in Australia. When I tried to do something about that, the drug administration threatened consequences if I tried to import them. Fancy being considered a criminal for such a big and terrible crime!

Anyway, a New Zealand doctor who publishes on the web described a method to make a liquid form from a common eye drop containing pilocarpine, an ingredient of Salagen. Whilst this certainly has worked for me, it is not a cure, and it has some mild undesirable side effects.

Hence, I am now trialling LDN, which is working on the real cause of most of these problems, a faulty immune system. Nothing dramatic for me to report, other than to say it's not getting worse, and yes, it has improved enough to cancel any panic attacks.

I would like to conclude by saying something that goes against my nature as a beer loving, beer drinking person who loves meat: To be fair, I must be honest and say it.

Among all the alternatives I have ever tried over the years, I have to admit that a healthy nutritious diet of fresh fruit and vegetables, raw and never over-cooked, with little or no meat, has vastly improved my condition... and especially so if I conscientiously give up all alcohol for a week or more.

I know that alcohol by its nature contributes to dry mouth. It dehydrates the whole body. I guess it's all a matter of balance, moderation and control.

### 144

### Pierre, Belgium 2007 - Ankylosing Spondylitis (AS) November 2009 – LDN

The first sign that something was wrong occurred in the winter of 2002, while skiing, and as a result, I had to stop skiing many years ago.

Suddenly, I developed pain in my lower back. I felt the pain with every bump in the sloop. It had never occurred before so after getting home I started seeing doctors - only to be diagnosed with a very severe case of osteoporosis - cause unknown.

On closer inspection one of the medical images did show a strange link between some of my vertebra in my lower back, though it wasn't obvious. I was the only person that

noticed it. The doctors did not. I also noticed that the ability to move my lower back, my flexibility, wasn't good at all - but once again nobody besides myself seemed worried about it. I was only in my mid forties at the time.

About 2 or 3 years later, I suddenly experienced extreme pain in my neck - sudden and very sharp - as well as a strange neck stiffness, a locking up (an inability to move my neck anymore) which was at first on the left side, then occurred on the right side.

My neck would stiffen every night while sleeping, and would be painful when I woke, or would wake me up during the night. During this period I was fatigued from interrupted sleep and trying to learn to live with pain every day. My spine also began to hurt constantly. After one month of constant pain I considered going to the doctor, but did not, because they were never able to diagnose the cause.

As the months passed I made adjustments, such as adding a pillow to sleep better. I had an artillery of natural remedies, but when they were not enough to control the pain I took Diclofenac. Whenever possible, I tried to catch 2 hours of sleep during the daytime.

In 2007; I broke a vertebra while trying to recover a 300 pound object that was falling from a wall. There were two of us guys trying to catch it, but for me it was too much. I had to see more than one doctor, but finally they arrived at an hypothesis that I had Ankylosing Spondylitis (AS).

I say 'hypothesis' because they wanted me to be scanned to be 100% certain, and I refused it. For me, it was clear on the Radiograph. The fusion of the spine was clear enough by then for everyone, except the specialist, who kept saying that to diagnose AS with 100% certainty, I had to have an Ilite (inflammation of the iliac bone), otherwise it was not AS. One thing is 100% certain. That was 100% stupid.

I remembered back to 2003 and 2004 when I told the doctor that I suspected AS and he kept telling me "no way" - that it was definitely not AS.

With my 'hypothetical' diagnosis, I was now able to actively begin my search for a treatment. I was already fighting pain with great success but it involved a lot of supplements - about 7 a day in big amounts, but they worked. When they did not, I would take some Diclofenac, which helped me manage the pain. But, I felt the AS was still progressing very quickly.

Over time my spine became less & less flexible, as did my neck. Reversing or parking my car was becoming increasingly difficult, and risky, because I couldn't turn my head. I learned to park my car looking only in the rear view mirror, but I was concerned that I wouldn't be able to drive safely within a few years.

Then the AS progression reached my Thorax, and the pain in my sternum was tremendous. Coughing became extremely painful, as did breathing. By 2007, trying to move the upper part of my thorax while still breathing was almost impossible.

The disease progression was so amazingly quick that I often wondered how many relatively comfortable years may still be ahead of me.

While I was able, I knew I would never stop searching for new products to fight the disease and the pain. I was only using two Diclofenac, and they worked fine against the pain, but they did not fight the unrelenting evolution of my AS.

Then in September 2009 I was asking a friend in the US if they knew of any new ways or ideas to fight pain, and they sent me an internet link to LDN information.

I started taking 0.5ml (equivalent 0.5mg) LDN daily in November 2009. In preparation, I'd stopped taking Diclofenac, but I did not stop the other natural remedy products I was using to help manage my pain.

I start feeling better the very next morning. I keep a diary and write in it whenever I try something new. Just two days later I wrote in my diary; 'Amazing, I feel like my ribcage is lighter and less tight/contracted. My mood is also better. The residual pain that I was not able to get rid of has gone away, except for the neck.'

The next day I wrote that I felt like my ribcage was more flexible and had moved a little.

So to make my long story short, apart from being unable to sleep well for 3 weeks, everything began to get better and better.

It is now two and a half months later. I increased my dose to 2.5ml each day, and I can now move my spine and neck a lot, lot, lot better.

I can look behind me while parking my car, and I can breath deeply again due to more flexibility in the upper part of my ribcage. BUT I have not regained complete motion of my spine, neck, and ribcage. Nonetheless, I feel like I've reversed the last 2 years of progression, and that's saying something. I'm also a lot more focussed and 'present' in everything I do.

I also feel a strong 'anti-depressant effect'. Of course, living with daily pain is linked to depression. So when pain is eased, it helps relieve the depression, but I feel there's more to it than that.

I'm so glad I had the chance to discover LDN. I feel I have a future once again.

### 145

#### PN, UK 2006 - Primary Progressive Multiple Sclerosis (PPMS) September 2008 - LDN

My Other Half has PPMS. It was diagnosed in 2006 after a year or so of tests that included a Lumbar Puncture, several MRI scans, and evoked response tests.

She was initially prescribed Baclofen, Gabepentin and finally Azathioprine. The high dose of Baclofen  $9 \times 10$  mg per day, achieved over a slow build up to that amount, resulted in unpleasant side effects. Fatigue was bad, but worse was the decline in her ability to concentrate. Gabepentin helped with her ocular neuritis.

After 9 months on Azathioprine, there was still no indication that progression had been reduced or become stable. Worse still was the effect azathioprine was having. Several months into this drug therapy her appetite was affected. She constantly complained of stomach pains and after 6 months experienced several asthma attacks (not something she had experienced since 2002).

After reading MS websites we became aware of LDN, and although our first thoughts on this were cynical we decided to give it a go. However, my partner's Neuro consultant would not prescribe and neither would her GP. We finally sourced LDN privately.

My partner had to come off Azathioprine before she could start on LDN. This she did over a period of about 1 month. We opted for liquid LDN because it would be easier to control the initial start-up dose, and gradually increase. Neither of us believed it would be beneficial.

Several weeks after reaching the 4mg dose, she started to experience improvement in balance and no longer needed my assistance to get her from kitchen to lounge. The spongy feeling in her feet started to improve, numbness in her hands slightly improved, and ocular neuritis disappeared completely. The incontinence problems have not improved though. From my own observations her mental alertness also improved, but I felt... could be all coincidence, could be all in the mind.

At the end of July this year my partner got a severe chest infection. Given her history of asthma, her GP prescribed a large dose of prednisolone, and that meant she had to come off LDN for 10 days.

The prednisolone worked and her chest and breathing ability returned to normal. She had no problems for about a week after stopping LDN, then ocular neuritis returned. After about 10 days, her feet started to feel fuzzy again and her balance was not as good. Again, could be all a coincidence, could be all in the mind.

She has now been back on LDN for about three weeks. Her ocular neuritis is gone, her balance is better, and she is generally feeling better.

We are now less cynical about LDN. After almost a year on this medication we know it has benefits, where the other prescribed alternatives she tried were disappointing. LDN is the only medication she is now taking for her PPMS.

## **146**

Rachel C, UK 2002 - Multiple Sclerosis March 2008 – LDN

I'm in my mid thirties now.

My MS symptoms started soon after my sister died tragically in 2002, 13 weeks after she was diagnosed with cancer.

I was working as a senior food technologist in York. I returned to work, got promoted, and was very stressed. The loss of my sister, being away from home and work stress brought on the first symptoms; tiredness, pins & needles, falling over, etc. I went to the doctor and he put me on Prozac!!!!!

I had a stressful life outside work too. I decided to put in a new kitchen and bathroom when my sister was ill (a way of coping with grief?). I also made the fatal mistake of moving in with my boyfriend who I hadn't been going out with for very long. I realised too late that we weren't suited, but I didn't want to be alone because of my recent loss.

A few months later I fell pregnant. I stopped taking the Prozac, but I still had a few MS symptoms; lack of field of vision, fatigue, pins & needles etc. This was all put down to my pregnancy. My Mum has MS but it's benign. I didn't even think about that though, because we thought MS was not inherited.

I gave birth to my son early in 2004. I was still losing my balance, and 4 weeks after giving birth I fell down the stairs. I was so frightened of going downstairs I called the NHS helpline. They sent for an ambulance to take me to York hospital.

I was put on a bed and x-rayed, but there were no fractures. The doctor asked if I could sit up. I used the cradled bar to pull myself up and he sent me home.

My partner drove me down south so my son and I could move in with my parents because of the lack of care and support in York.

We had an on-call doctor around to assess me. He gave me painkillers because he thought the nerves in my back weren't working after the fall. A week later we called the doctor again, and my mum's doctor came. She knew mum's history, had many other MS patients, and arranged for an ambulance to come immediately. I had my first CT scan in hospital on 13 Feb 2004, and was officially diagnosed with MS. I was paralysed at C3. It was the worst night of my life. I was scared, frightened and wanted my baby.

Luckily mum & dad are now retired and are able to look after my son. They brought him in to see me everyday in hospital, where I had white blood cells, immunoglobulin, and another course of steroids. Two months later I could move my arms better, but none of the treatments had a dramatic effect. I kept getting infections, which made me worse.

I celebrated my birthday in hospital, which was excellent as I had so many visitors! In April I was transferred to another hospital and was put on a course of plasma exchange. My arms grew stronger. I still had the MS hug but could stand better. I was transferred for rehabilitation and 6 months later was home at last, though in a wheelchair and paralysed at T5.

I bought a bungalow near mum & dad. It has now been totally adapted for me. My partner left because he couldn't cope with my MS. I now have a 24hr live-in carer, which is like having a flat mate when I find the right one!

I have been taking LDN since March 2008. I didn't initially have a dramatic response, so I went up to 4.5mg a day fairly quickly. My fatigue and standing improved, and I can't live without the LDN now!

On my last visit to my doctor he told me he is retiring soon. I approached my new GP armed with evidence and dad! I was told that naltrexone was so cheap it would never get licensed as a drug to help MS!

The practice doctors agreed my GP could prescribe naltrexone to me privately. Finally, no more trips to Bristol unless it's for shopping!!!

I'm still in the same state as when I left hospital, but I'm getting stronger and am standing everyday on an Encore hoist.

I am on copaxone & LDN now, and have had no relapses since 2004.

Over the past few years, I'd been on a mission to find Mr Right. Armed with a toddler and with a disability, it's not been easy. I've tried internet dating, been engaged to a man loaded with debt and 3 kids, met loads of people, and learnt to press delete on a lot of people! I was just about to give up when a great man came along... when I least expected it. He requested my friendship on facebook. We got chatting and now, 11 months later, we are madly in love and he is moving into my house next month.

My MS? Well, that has stabilised, no relapses at all since my first bout. I am on Copaxone and LDN still. I have adapted well to life in my wheelchair. I drive from my wheelchair (only short distances). My new man has taken me on many trips around the country to visit old friends in York and Preston and meet his parents. I have a portable hoist, and providing the room is large enough, we have managed so far in Travelodge accommodation.

My son is now at school full time and this has the benefit of giving me a rest during the day.

During holidays, he usually spends a day or two a week in clubs, a day with his grandparents, and the rest of the time with me. This doesn't tire me out too much.

At the age of 6, he is getting very independent and helps me when he can.

Generally he is a good boy! School has been most accommodating to my disability, and have put drop curbs in, bought ramps, etc. I struggle collecting my son sometimes because the parents are so engrossed in playground gossip they stand in front of the drop kerbs or push through or simply do not hear when I'm trying to get past. We have resolved this problem with my son meeting me at another area of the school.

During the week I go to the local hydrotherapy pool with the MS Society for a swim. I find this helps relax my muscles and helps general moral. They have been a great help with me these past three years, helping with a grant for a standing wheelchair, family days out with my son, and summer BBQ's. I am extremely grateful.

I also help Linda out with computer work and mailings where necessary!

I still have 24 hour care. I am on direct payments which gives me the freedom to hire who I want. I have had previous carers come back to stay for a while which is great for my son, as I'm sure a constant change of carers throughout the years is not good.

I have tried to teach him who the important people in his life are (i.e. Granny, Grandpa and Me), but how do you tell a kid not to love someone who cares for them (knowing

they'll move on the next week). I now with an agency for my Mon - Fri care, and have old carers come back at weekends. This gives a good balance of both staff so the atmosphere is light and happy at my house!

In conclusion, I'm coping with my MS in lots of areas of my life. It has not beaten me! I have loving parents, friends and a support network to get me through any challenges that arise. I am looking forward to a great future with new man by my side and together with my son, I am very happy!

# 147

### Rachel R, USA Jun 2004 – Ulcerative Colitis Mar 2008 - Indeterminate Crohn's Disease/Ulcerative Colitis July 2008 – LDN

In mid 2003 I noticed a bit of liquid stools in the morning, I attributed it to drinking to much alcohol the night before. I ignored it and carried Imodium for when it was needed. I had no idea that this was not normal.

I also developed unexplained hives. My PC, dermatologist and allergy docs all prescribed 40mg of evil prednisone. They DID NOT consult each other.

I developed a cyst (from an ingrown hair) and saw a new nurse practitioner who lanced the cyst and put me on Doxicycline. I had never taken this type of medication before and didn't know what to expect. I started eating Activia and taking probiotics, but the diarrhoea came on and didn't stop after I stopped the antibiotics.

Then the blood showed up in my stools and I lost 35lbs in 5 weeks. By now it was time for my youngest child to graduate from High school and my parents were here to visit and attend the graduation (read: STRESS).

I saw my first Gastroenterologist (GI) in June 2004 and was told that I had Ulcerative Colitis. I was put on Asacol and 60mg of prednisone. I had now been on 40 to 60mg of prednisone for about 10 months.

The prednisone attacked my pancreas and I developed Type 2 diabetes. My hair fell out (I'm a hair dresser, licensed for 30 years) and I knew that it was because of the evil prednisone and the disease.

The GI put me on 6mp, but that eventually shut down my liver and landed me in the hospital for 6 days. And, of course, I picked up C-Diff. I tried Remicade and it kicked in within 48 hours, but I eventually became allergic to it. I tried Humira in various doses and it did not work. I am afraid to try any other biologics.

My uncle (dad's youngest brother) had Ulcerative Colitis, leukemia and other issues, and passed from complications. His son (my cousin) was recently diagnosed with ALS and UC. He was very near death while on Humira. He had his colon removed and Is

now slowly regaining some strength. His girlfriend got him LDN from Skip's, but I don't think he has started it yet.

I have now been on LDN for almost a year. I am not in remission, but I am able to work part-time. My son was married late in 2008 and my daughter got married in June of this year. I KNOW that if it weren't for LDN I would have ended up in the hospital. I did go into a flare after my daughter's wedding, but I only bled one day, and I haven't had an 'accident' in months!

I am having a lot of pain and bloating in my upper abdomen, so my new GI is sending me to the University of Florida in Gainesville for a 3rd opinion from the top specialist in Irritable Bowel Diseases (IBD). Since I won't take the evil prednisone or biologics, everyone says I am a 'complicated case'. I still think that the only reason that I'm not in the hospital is LDN.

I'm presently taking Balsalazide Disodium (Colazal) 3 750mg capsules 3 x per day. I've taken the evil prednisone, Asacol, 6mp, Remicade and Humira – one after the other, all before I started LDN. (I didn't take them all at once.)

The prednisone attacked my pancreas and I am now diabetic. The 6mp shut down my liver and gave me drug-induced hepatitis. After 6 days in the hospital and getting rid of the nasty drugs (May '05) I am only taking Colazal and LDN and Imodium and Lomotil (as needed) for my CD/UC. I use Gas-X and Pepcid complete and Nulev, too.

### 148

#### Ray F, UK 1996 - Multiple Sclerosis August 2006 - LDN

My husband, Ray, was diagnosed about 14 years ago, although obviously his symptoms began many years earlier. After being diagnosed we saw the relevant specialist at the hospital, who basically said there was no cure. We then saw his own doctor who likewise, was very sorry to say there was very little he could do for Ray, but said medication could help. Thankfully, my husband's doctor was always available if we needed to see him.

By 2006 my husband's condition had progressed to the point where we needed a Toyota HiAce with a ramp so I could wheel him into the vehicle and he would be safe in the back. He was also using an electric indoor wheelchair around the house, and a scooter for outside use.

We had joined our local MS branch soon after his diagnosis. Then, in or around February 2006, one of the members suggested my husband look into LDN.

The member said his wife had been going downhill very fast before she trawled through the web and found an item on LDN. She had persuaded her husband to read up on it, which he did. He said he then spent a long time researching LDN before they both agreed to ask her doctor if he'd prescribe it for her.

He told us that, literally within days of starting LDN, she was able to travel comfortably in the car to visit her son a hundred miles away – but that it had taken a while to regulate the correct dose for her. We were also led to believe there were no adverse side effects.

My husband was of the opinion that many alternative medicines had a psychological improvement on ones condition – and as he certainly didn't fit that category, he thought long and hard before taking all the information to his own doctor.

His doctor agreed to prescribe LDN and we sent the prescription for liquid LDN to a chemist in Glasgow. He spent some time experimenting to determine the dosage that suited him best... and to cut a long story short, he now travels in the front of our vehicle and walks around indoors and outside around the garden.

Everyone knows LDN is not a cure for MS. Having said that, I can only say from living with my husband he is definitely not a person to be psychologically affected by medicine. He is a very 'black and white' kind of guy. He has always been determined to get on with his life to the best of his ability, always smiling, always happy.

I am truly grateful to our friend for putting LDN before us, and for our doctor agreeing to prescribe it. Unfortunately, the MS Society has been very lethargic in promoting funding for this medication, although recently there has been an upturn in awareness of LDN. I sincerely trust the research team at Head office encourage a proper trial and thus make it available to everyone out there who could benefit from it.

### 149

#### **Raynor H, UK** 2000 - Relapsing Remitting Multiple Sclerosis (RRMS) 10 July 2009 - LDN

I've had Multiple Sclerosis for 9 years now.

I recently started taking low dose naltrexone (LDN) and am amazed with the improvement I've had for my Relapsing Remitting MS. I'd been suffering with walking problems, and was deeply fatigued. I had to sleep for 2 hours every afternoon.

I now just rest for 20 minutes, and my walking is amazing. I'm really glad I came across LDN because it's changed my life for the better.

More should be done to make LDN available to everyone. It could change someone's life.

# 150

#### Rebecca S, UK 1994 - Slow Progressive Multiple Sclerosis Jan 2008 - LDN

I have slow progressive MS. I was diagnosed in 1994 and am in my early fifties.

I have been on LDN now for about a year. Six months ago, I managed to persuade my Doctor (with the help of the local MS nurse) to get it on NHS prescription.

Ironically it costs the NHS £120 per month to source it when I was getting it for £30 a month from Dickson's Chemist in Glasgow!

I do feel much better. Before I went on it I was starting to go through a bad time, I felt like I was recovering from flu, I had no energy and was sinking into real depression. I noticed almost immediate effects, I don't know if some of it was psychological from being able to find something that might help, but I did feel better and best of all the depression got much better.

Recently I have forgotten to take my LDN for some time and have noticed that I am getting very tearful and upset about things, so am now making sure I take it on a regular basis again.

Yes, I do think it has made a positive difference to my life.

# 151

### Richard, UK October 1995 – Relapsing Remitting Multiple Sclerosis (RRMS) LDN – August 2008

I was diagnosed with Multiple Sclerosis in 1995, although I had my first relapse in 1988.

My father has had a mild form of MS since about 1970, so I knew a bit about it. I have an older sister who doesn't have it and I am now middle-aged.

I heard about LDN whilst a member of Jooly's joint website, a very good site for anyone with MS. After researching the drug I decided that it couldn't do any harm.

My doctor wouldn't prescribe it because it had not been trialled for MS. My neurologist wouldn't prescribe it, and a local private doctor wouldn't either.

I eventually managed to get some through a site on the web 18 months ago. I have not had a relapse since. It costs me about £300 a year but it is money well spent.

### **152**

### **Richard P, UK** DATE - Multiple Sclerosis 25 September 2009 - LDN

I was still a child when I first met my step-dad to be in 1998, but I didn't understand about MS or its effects. All I saw was a man who walked on crutches for short distances and used his wheelchair at other times.

I knew there were problems in other areas, but he and my mum made sure its effects never spilled over to affect us children. Even during times of stress I was never fully aware of MS and its associated problems. That is till about 1993.

One day in 1993, my step dad went into the wheelchair and never walked again. I watched as his ability to do things for himself became more and more difficult. He became more reliant on all of us (mostly my mum) to do everyday tasks that he used to do himself. He could no longer take himself to the car or put his wheelchair away, and h couldn't go out without someone going with him.

Getting out of the bath required help because his arms no longer had the strength that they had previously. If he fell down, someone had to lift him back up into his wheelchair. His legs were getting weaker and wouldn't hold his weight. His hands became useless and at one point, he was unable to cut up his own food.

I used to listen as my mum would tell him to be careful eating or drinking as it was hot. I later realised that his mouth was numb and he was unable to detect heat until it hit the back of his throat. He couldn't pick up things as his dexterity had gone. He was in a pretty bad way, getting more and more depressed. My mum spent a lot of time worrying about him but never let on.

Then mum heard about LDN through a friend and he started to look into it. In all the years my step dad had MS, he had never been given any tablets or anything to help. He was left to 'get on with it' as best he could.

He started taking LDN September 25th 2009 and for me it was like watching a miracle before my eyes. His depression started to lift as he began to become aware of sensations. His legs, which once were a lifeless, dead weight, now had full sensation in them. They began to get stronger and the pain in his legs began to improve. He started sleeping better (which meant he wasn't so grumpy).

His hands began to show improvement. He was able to touch his fingers with his thumb. He could pick up small objects again. His balance began to improve, and soon he was able to sit up in bed without falling to one side.

Now, just over six months later, and he can stand unaided for a short time. He has walked about fifteen steps from the stairs to the bathroom and is getting stronger each

day. He no longer gets bladder infections and over Christmas, everyone was ill except him.

He's going from strength to strength each day, notching up small, incremental improvements, which I hope will one day see him back on those crutches.

## 153

### Roger W, USA December 2006 - Parkinson's Disease April 2007 - LDN

I was diagnosed with Parkinson's Disease in December 2006.

I heard about LDN in April 2007, and fortunately I have an enlightened neurologist who prescribed LDN when I first asked for it, and who is also treating MS patients and other PD patients.

LDN transcribed my brain from somewhat confused, tired, and not well co-ordinated, into an alert physically alert human being, with better motor function, and reduced tremor.

My doctors are somewhat amazed that I have been able to stay on the minimum dose of Sinemet for more than three years.

I still have some PD symptoms that are induced by stress, but overall the progression of my disease is arrested. I encourage you to keep up the LDN message so that all those who may benefit from this serious drug can obtain it without a hassle.

### 154

### Ross S, Australia

August 2008 - Renal Clear Cell Carcinoma - 7.8 cm stage 4 tumour in left kidney, left kidney surgically removed 5.9.08 3 March 2009 – LDN

I visited the Doctor in August 2008 thinking that I may have a prostate problem due to a pain in my groin area. The doctor, at my request, sent me for an ultrasound that showed no signs of disease in this area, so the Radiographer then decided to check higher up in my abdomen. That's when, by an incidental find, a tumour was detected. I was in my mid forties at the time.

Scans taken later in August 2008 considered the finding to be a Renal Clear Cell

Carcinoma of the left kidney. The kidney was surgically removed at a hospital in Brisbane Queensland on the 5th of September 2008 (Radical Left Nephrectomy). The biopsy found the 7.8cm stage 4 tumour had not entered the fat surrounding the kidney, therefore no Chemotherapy treatment was required. Scans also showed no evidence of metastases to any other organs or parts of my body.

I have worked as a technician in the Oil and Gas Industry for nearly 30 years, and the doctor's believe this may have been a possible cause of my cancer?

I started taking LDN on the 3rd of March 2009 after my friend, a Bio Chemist into natural therapies found the information on the internet. I take 4.5mg LDN between 9 and 10pm nightly to help boost my immune system. After starting, I experienced sleep disturbances for a couple of weeks but was full of energy each day.

The other side affect I had was a swollen lymph node in my right armpit for six months, but it slowly disappeared in September 2009. My Doctor had no explanation for this. I believe it was the LDN working in my body, helping clean my system of any infections or viruses.

My white blood cell count is slightly elevated, which my doctor believes is helping fight off infection & disease.

I now find I don't suffer from flu or other infections since being on LDN, and I strongly believe my disease would return if I was not on LDN.

I have emailed and spoken to Dr. Ian Zagon regarding LDN protocols. He is always available to give advice and help a person as required.

I have also spoken with and emailed Cris Kerr, and have read her e-book; 'Those Who Suffer Much, Know Much'.

I am continually researching LDN and other natural products that can help boost my immune system. My household has gone 'organic', avoiding many of the modern day poisons we were surrounding ourselves with.

I have read Dr Burton Berkson's book 'Alpha Lipoic Acid Breakthrough', and I take Alpha Lipoic Acid daily. I also follow Dr Berkson's vitamin protocol, Mary Bradley's Book, and listen to Mary's internet radio show. I have read 'The Promise Of Low Dose Naltrexone' and many other e-books and publications.

Clear cell Carcinomas can metastasise anywhere in the body, so due to the nature and aggressiveness of my cancer I get check-ups every six months.

My last six-monthly check-up was on the 3<sup>rd</sup> of March 2010, and all is well thanks to LDN.

It is still the early stages since being diagnosed. I'll continue to have ultrasounds and blood tests every 6 months, and hope time will prove my belief in LDN.

### 155

#### Sal A, Australia 1980s – Multiple Sclerosis 5 December 2007 - LDN

I've had MS for over 20 years now, and for most of that, my GP would treat symptoms as they arose.

This was because I'd refused to have a Lumbar Puncture (LP) due to past problems with an epidural. As a result, my neuro said he couldn't provide a definitive diagnosis or prescribe the CRAB drugs (which I told him I wouldn't take anyway). I couldn't have an LP or epidural because I was told NOT TO, unless I was in a life-threatening situation, because of past problems.

My regular neurologist, and 2 other neurologists, all said I needed to have a LP to officially confirm an MS diagnosis - even though they all said they were 100% sure I had MS. Then one finally diagnosed me with MS around 2004.

I'd done a lot of research because I guess I have always been a rebel and don't take what the first doctor tells me as being true.

All I can say is that when you do your own research you will find that even the 'experts' can't agree on causes and treatments of MS. The 'experts' all stick to their little book with the MS protocol. Fact is there is no real treatment for progressive MS. None of the CRAB drugs (Avonex, Rebif etc) are for progressive MS. They state that the earlier these drugs are started for MS the better. Once you have progressed they don't work.

I did a lot of research for many years and simply figured that the odds of MAYBE being one of the 30% and getting a 33% improvement was not good enough considering the nasty side affects of those drugs. Then Tysabri came on the market, was withdrawn from the market, then went back on the market. That told me that this drug was also not good enough.

You will find many theories on MS - chicken pox caused it, a virus, a higher prevalence in cold climates. Many areas around the world like northern Europe, Scotland, the southern states in Australia, etc have cold climates and have the highest rates of MS – but now many other people in hotter climates also get MS.

One Italian research team (there have been others too) came up with the theory that MS is a metabolic issue, lack of nutrients such as zinc, copper, vitamin B's, etc. My personal thoughts are that the chemicals in our food have a lot to do with it - maybe these chemicals stop our body from ingesting the normal vitamins and minerals we need.

When you have MS the 'experts' tell you your immune system is over-active and needs to be suppressed, but LDN does not suppress our immune systems, it boosts it.

I found out about a treatment called low dose naltrexone (LDN) when I was researching on the net about 3 or 4 years ago, but I had problems getting a doctor to allow me to try it. Around the middle of 2007 I came across it again. I knew it wasn't a mainstream approved treatment, but it sounded promising and I wanted to try it.

I had stopped seeing neurologists, etc because it was a waste of time and lots of money. I'd refused the CRAB drugs they offered and instead, tried to find my own way through improved nutrition and supplementation, and I'd been seeing a brilliant chiropractor and acupuncturist whose treatments had helped some.

My cardio doc had recommended taking CoQ10, and a good quality fish oil for high cholesterol problems (because I couldn't take drugs like Zocor that make my muscle problems much worse), and I'd also done some research on magnesium and other supplements.

When I asked my GP what brands to buy (good ones), his reply was 'I'm a medical doctor and don't have the time to look at alternative medicine', so when I decided to approach him about LDN, I went prepared.

I'd found the 'How to ask your doctor for LDN' guidelines, but after printing all the info and approaching both my GP and Neurologist, neither would prescribe it for me. They wouldn't even think about it.

I was even prepared to sign a waiver but it was still a no go with my GP. His answer was that if LDN was any good for anything Australia would know about it, bah humbug!!! My GP refused to read the info I took because he had no time. Most of the medical centres near me would not take on new patients, which was another problem. So I dug my heels in and refused to go back to the neuro, and cancelled my future appointment with him.

I needed to find a good doctor. My adult daughter also suffered, from Fibromyalgia.

Well, I finally found a doctor to prescribe the LDN and I started in December 2007, thanks to Crystal of the Yahoo lowdosenaltrexone group.

I started on 1.5mg, and did have some minor sleep disturbances, which happened again when I increased the dose to 3mg. On 3mg I also had increased spasticity and muscle spasms, but I rode it out and they eventually abated, and I stayed on 3mg for 15 months (Dec 2007 to March 2009).

My first improvement on 1.5mg was less fatigue, but nothing else. Once I went to 3mg other things started to improve VERY slowly.

The first real improvement I noted was improved bladder control, but around the same time I developed some digestive issues. It felt like food was sitting in my stomach forever. I also had chest pain, bloating, burping, etc. I posted about this to the Yahoo LDN group and some suggested a change of filler, but I didn't think that would help.

I had an endoscopy, which showed I had gastric reflux. I went onto Zoton for a few months then stopped.

It took around six months, and by June 2008 I was doing really well.

I'm a wildlife carer, and even though we'd recently moved house around that time, I don't think I'd have coped as well if I hadn't been on LDN.

It was a nightmare move, and the house we were moving to wasn't finished and so had workmen there for over a week after we moved in – and it rained heavily during the move. Moving 6 people and 20 birds and 4 possums under those conditions was not easy! The wildlife had a tough time, and I single-handedly cleaned the house we were leaving. It took me a week but I did it.

Meanwhile, my daughter, who had just moved back from the USA, had tried LDN without success and had been prescribed weekly B12 shots by her new doc here, for her Fibromyalgia. (They'd checked her B12 before she left the USA and said it was fine.) The new doc also wanted to run a test on her for heavy metal poisoning.

My daughter's health improved a little after she was off all the awful meds the USA doctors had her on. She was on heaps of meds including methadone for Fibromyalgia. I really don't think she had that at all. I think her problems were from a total hysterectomy she had, ovaries included. She is a manager now in a retail store.

Unfortunately, nothing has really worked for her and I firmly believe she did not take LDN long enough. She only had 1 bottle of 1.5mg to begin with, and I sometimes wonder if it's not MS - following in my footsteps. I also believe the powerful drugs they had her on worked against her. She was on around 6 or 7 heavy prescription drugs. Since going off all the drugs she has improved but still has a lot of muscle inflammation. B12 seemed to make no difference to her.

I have high cholesterol and used to take statins up until 2000, but after my first major MS flare, my body would no longer tolerate them, so I couldn't take statins anymore. I haven't had a cholesterol test since I started LDN, but I think I'll get a test done eventually because I'm interested to see what the levels are now that I am on LDN and not eating the tiniest bit of chocolate. Just don't have the time to do it right now.

In November 2008 I had been on LDN for 11 months when I had to go without it for 2 weeks due to financial difficulties. I didn't expect it to make such a huge difference, but it did. I noticed a change within 2 or 3 days, though not as bad as pre LDN. I was greatly fatigued, and my bladder issues increased, etc. Slowly after going back on LDN those symptoms went away again. So if you go off LDN and then your symptoms worsen I would say it shows LDN was working.

I had to give up full-time work a few years ago due to my MS, but now I'm doing fine and I'm much better than when I started LDN 18 months ago. I'm positive it's the LDN that's working.

Now I'm doing wildlife rescue and care. I actually started an official wildlife rescue group. We formed the group early this year and recently had our incorporation come through. The official launch of our group was earlier this year and we had a federal politician help us launch, as well as a state member and local councillors, etc. We've also had heaps of support from local and international clubs.

A lot of hard work went into getting that up and running. We had an official launch of the group jointly with a fundraiser. It was a HUGE day with politicians and VIP'S. My day started at 6am, feeding 'babies' in my care, loading the car with gear needed for the day, going to the hall and setting up at 9am so the function could start by 11am. ALL

day I was on my feet because it was my job to make sure each area was functioning ok. I had to greet VIP's, do speeches etc, etc. The function wound up at 5pm and then came the cleanup. By 6pm we were cleaned up and packed up. I then went home and unpacked some stuff but left the rest for the next day.

My hubby then took me out for dinner because I was totally stuffed, major sore feet. I had also not eaten much through the day, no chance to. Was home again by 9pm and fell into bed. The next day I took it VERY easy but was soon fine again. I could NOT have done all that before LDN.

Of course I'm not cured but I am performing way better. I have way more energy, some of the symptoms have vanished, and I've had no progression. Of course I still have to be careful, make sure I get enough sleep etc. When I do have a very hectic day I have to take it easy the following day. Before starting LDN nearly every day was a bad day.

When I started LDN I was lucky that besides the LDN stopping progression I did get some symptom improvement. It wasn't an overnight improvement, more gradual. All of a sudden you think, 'Gee, I haven't had this or that, or that seems a lot better'.

Since starting LDN last December 2007, I've followed Dr Bihari's guidelines, taking 3mg LDN because of muscle spasms and spasticity, but I always intended getting to 4.5mg eventually.

Also the effects of different strengths of medications can vary in people. One person can take an antibiotic at 500mg and they're fine. I take the same and feel like throwing up. My doctor advises me to cut the pill in half and I go to 250mg, and then I'm fine.

Some with MS can't take 4.5mg straight away because it can increase muscle spasms and spasticity and that's what happened to me. I had to take 3mg for 2 or 3 days then one 4.5mg then back to 3mg. That went on for about two weeks because adjusting to 4.5mg initially gave me muscle spasms. I'm now fine on 4.5mg, no spasticity and muscle spasms have eased greatly.

For me and my MS, 3mg seemed to be the best initial dose BUT after settling in comfortably with that dose, I finally increased to 4.5mg at 15 months, and I'm fine now - though I did have to keep varying between 3mg and 4.5mg for a couple of weeks before the muscle spasms settled for me. I was determined to get to 4.5mg because it is the optimum dose, if you can tolerate it. Some people have taken 3 or 4 attempts to get to 4.5mg.

Some people get a worsening of symptoms for a while when they start LDN, then things get better. Makes sense to me that worsening symptoms do not occur if nothing is happening, so it must be doing something. For me, that just means the LDN is working!!!!!!

I also take a high-grade fish oil, occasional probiotic, and sometimes other vitamins. I follow a low fat diet and eat very little meat, simply because I'm not keen on meat and prefer fish.

I would never tell people they have to do what I do - it's an individual choice, but it's right for me and seems to be working for me. I have not had any steroids for many years now, have much less fatigue, far more energy, and can do much more now than this

time last year. I do find I need a good nights sleep and can't have 2 late nights in a row, but that's a small price to pay. I do believe that stress is a big factor with MS.

Thankfully, my local GP has now come on board (after I encouraged him to go to the websites while I was sitting there in his surgery). I showed him the LDN web site where it states therapeutic value is between 1.75mg and 4.5mg, the best dose being 4.5mg. He looked at the web sites, and after I told him I had been on 3mg for over a year, he said it couldn't hurt. He commented that as long as I didn't need more and more it was okay. He has now given me a script for 12 months, and I no longer need to travel over a 100 kilometres to see the other doc.

I had one problem last year (2008) where I had a very irregular heartbeat, and ended up being taken to hospital twice by ambulance. The cardio docs wanted me to go back to a neuro. I told them to forget it, that I had fired the lot of them.

I stuck to my guns and refused a lot of what they wanted to do. They could not figure out what had caused the irregular beats. After I got out of hospital I went to see my wonderful local GP, who at first thought maybe it was the LDN, but I told him, "No way" it was the LDN.

During the conversation he mentioned chocolate being one of the things that could cause weird heartbeats, with dark chocolate being the worst. My response was, "Oh hell!" because I'd recently changed to the dark chocolate (because it was being promoted as healthy). Seems that my body does not like the theobromine in chocolate. Needless to say, I've since stayed away from ALL chocolate. I still get ectopics but have always had them.

I only use De-Gas (Simethicone) now for my gastric reflux but I believe the LDN has helped more. When I had to go without my LDN last December I noticed the reflux came back. After going back on the LDN, within 6 weeks the gastric reflux had gone back to minor problems occasionally. Also, thinking of the Mennier's, the LDN has reduced the attacks. I did have a major attack March 2009 where I had to get a Maxolon shot but have had less minor attacks than in the last 4 years prior to LDN.

You have nothing to lose by trying LDN but give it a fair chance because some people have taken almost a year before they see the real benefits. Do I still get fatigue? Only when I have an extremely hectic long day then the next day I have to take it easy.

Just remember that the facts are there that it's working. Yes, some people get a placebo affect from meds. Give them sugar pills in a clinical trial and they swear the pills are working – for a while – but not this long.

LDN is not a magic drug that is going to cure your MS, but it works. One day maybe there will be a cure BUT in the meantime, you will see improvements with LDN if you're patient.

My bladder and bowel issues have improved greatly and I have much less fatigue and far more energy – and I have not had any blurred vision for a year.

My family are amazed at just how much I can do now.

#### Update April 2010

Yes still on LDN and still doing fine. No changes. It's still hectic caring for wildlife here.

# **156**

### Sally D, UK October 2009 - Fibromyalgia February 2010 - LDN

I lived with my parents until my Mum & Dad divorced around 20 years ago. This kind of threw things out of whack for me and even though I was still only little, I'm not sure I ever really got over it.

I spent most of my childhood feeling unhappy and left out of my new family after my Dad remarried. Things were okay. I never went without anything, but I just never felt truly happy. Something was missing.

I first noticed things were not right when I was 20. My Mum had been diagnosed with Bowel Cancer and had been given not very long to live. I was pregnant with my first child and I became very poorly and spent most of my time in and out of the Hospital, on drips and constant medication.

My baby boy was born soon after I turned 21. Thankfully, he was healthy, which had been a concern considering the trouble I'd had throughout the pregnancy, BUT my health didn't change. Then my Mum lost her battle with Cancer and passed away just before Christmas 1996.

I had to carry on, took the prescribed medications, and by the time I was 26 and having my second baby, I was once again back in hospital. Baby number two was fine again.... another beautiful baby boy, BUT after this birth my symptoms grew worse than before. I saw specialists from every field and no-one had any answers. It came to the point where I was having to be driven to the A & E unit at the Hospital nearly every day JUST to have anti-sickness jabs and pain killer injections.

I knew it was becoming ridiculous, but then, what else could I do? I had a massive amount of pills at home but was often so sick because of the pain that I couldn't swallow the tablets. If I did get them down they came straight back up, so there didn't seem to be any answer.

At the time I was moving around the country a bit, so I saw once different specialists in different locations. They eventually allowed me to have my Intra-Muscular injections at home, which was amazing at the time BUT looking back now STILL didn't give me an answer.

By 2001, I had gone from bad to worse yet had two toddlers in tow. I got into a pretty abusive relationship and I guess at the time as I was feeling so very low and in so much pain, I just gave in to getting hit whenever he felt like it... It was not a good time for me, but then I was already in so much pain, what's a bit more?

After finally leaving him and moving on, I remarried. I was still having all the problems and taking all the drugs, and I fell pregnant with my last baby. I was very, very sick this time and was kept in hospital for virtually seven and a half months.

The doctors didn't know how to treat me. I was mainly seen by the nurses, some of which were horrible, however, I am still close to the one who ended up delivering my third son (yes another boy!!). During that time, the doctors would allow me out of hospital for a few days at a time, so in my 5th month of pregnancy, my partner and I decided to get married. I was so very ill, in-fact, so much so that on the day of the wedding, instead of flowers I carried a bag containing all my drugs and injections.

After a week out of hospital I was re-admitted to the labour ward and placed on gas for 3 weeks, along with a mix of opiates. The drugs concerned me such, that I finally insisted that my son be born early. They finally agreed, but said I needed to give birth naturally as it was my choice to have him 7 weeks early. My reasoning behind this was logical. He was better out of me and safe in an incubator that being fed yet more Morphine from me.

After a 3 1/2 day labour, my tiny 5lb baby was born. He was a fighter and left SCBU before his due date. Life for him at the start was dreadful. He suffered with his feeding and had dreadful reflux for a year. I was making constant trips to the hospital with him and I was totally emotionally and physically drained. I started to sleep lots and felt pain everywhere; in my neck, my shoulders, and my legs. My headaches grew out of control, and so did the prescription drugs.

At the time I put it down to my post-natal depression, but looking back it was much more. I was then sterilised because they thought it may be something to do with my hormones.

By now I had developed multiple chemical sensitivities, along with an unusual sensory problem that resulted in extreme sensory issues, such as; hearing problems (everything seemed ultra loud), vision problems (everything was too bright) taste problems (my sense of taste was off the scale so much I could eat in a restaurant and tell you nearly every single ingredient in the dish I was served), and smell problems (which became so bad I would wash bedding two or three times because nothing smelt right).

It was crazy! The sensory issues even resulted in feeling pain from little things, like having a label left in a t-shirt. It would be so uncomfortable I would have to constantly change my clothes or remove all the labels. It was like having some form of sensory OCD.

My son's health began to improve after his first birthday, but mine didn't, and not long afterwards (probably due to an overload of problems), my husband and I separated. We remain friends to this day and he continues to have a lot of input with our son.

After we separated I was alone again, with three children to care for. I struggled through each day taking a massive amount of drugs just to function; Codiene, Amytripaline, Pethadine, Diazapam, Diclofenac, Lyrica, Cyclizine, Ondanzatron, Imigran injections, Bu-trans patch, Mirapexin, Topamax, and Tramadol. This list goes on and on... but still I never felt any better, even though I tried so hard to get through each day and not really let anyone know how bad it was.

I continued to see doctors, and the doctors still had no answers. Why was I feeling this pain ALL THE TIME?

I met a wonderful man (3rd time lucky), and we married. He learned to give me my injections and get my pills when I needed them. Then 6 months into our relationship he went through a very bad court case with his ex-wife. Now although I was ill, I was also a fighter and a strong person on the inside. My husband folded, so I dealt with it all.

I made sure everything was dealt with and won his case for him, but at a cost. I was now having more and more pain, sleeping all day but not sleeping at night at all. I became weepy all the time, couldn't eat, and thought that all the stress had led to depression. My youngest son began to show signs of Autism Spectrum Disorder (ASD) and that diagnosis has since been confirmed, but I still wasn't better.

In June of last year (2009), I hit an all time low. I had to stop my jobs, which were only casual anyway, but I liked working because I would go insane staying in the house. After a very bad 6 weeks of school holidays, my body finally gave up. I went into a full crash and decided to look for answers myself, because I was not getting ANY better, no matter what the doctors did or said, and no matter what drugs they threw at me.

I had developed problems with my bowel and the doctors told me at the time that it may well be Cancer and rushed me in for tests. Yes, there was a blockage, but after the results of a biopsy came back negative I started my own hunt for an answer... and I Googled!

Entering all my symptoms I searched the internet, and time and time again the same word topped the list; FIBROMYALGIA!

I printed all I could and went to see a new doctor, who agreed that 'yes, I had Fibromyalgia', and added that there was no cure and I would have this for the rest of my life. Still in full crash he told me to remain on my drugs and suggested that I try alternative therapies as well, which I did to no avail!!

In October 2009, after receiving my 'official' diagnosis, I continued to go downhill and by January of this year (2010), I was so bad that I was totally bed-bound. My 10 year old son was helping me look after my 5 year old son with ASD, and helping me while my husband was at work. I couldn't walk without a stick and I bought a wheelchair knowing that this was it now.... for the rest of my life... and I was going to have to accept that I had no future, and I was only in my mid thirties!!!

Shortly after my diagnosis, a close friend was diagnosed with RRMS. She refused to give in to her disease and went on the hunt for something to help her. She stumbled across a treatment known as LDN (low dose naltrexone). After she had fully researched it for herself, she told me that I might also gain some benefit from it.

At first I was unsure. After 15 years of suffering and a drug cabinet rivalling that of the local pharmacy, how could this tiny little amount of pink liquid possibly help me?

But, willing at this point to try anything I asked my GP. It had to be prescribed off-label and so therefore, was not as easy as getting a prescription for approved meds, like the opiates I was taking. Then I was told I could not use ANY opiate drugs with the LDN, which meant facing a two week detox before I could even trial it. To say that time of my life was probably the worst two weeks I'd ever experienced would be a total understatement!!! I thought I was going to die, I was in so much pain!

BUT, then the LDN came (February 2010), a suspension in a small bottle of pink liquid. I was told to begin by taking 1.5ml (a quarter of a teaspoon) before bed.

After 2 days I had movement back in my muscles and limbs.

After 3 weeks I no longer needed my stick all the time.

By 5 weeks I could leave the house, all be it for only 20 minutes, but I was able to drive to collect the children from school.

At first I thought it must be a placebo effect: Surely nothing could work that quickly, but no.... the improvement continued.

In March of this year (2010) I joined The LDN Research Trust as a volunteer because I had such a strong feeling about how my Fibromyalgia had taken my life away for over 15 years, along with the added prospect of my health never improving and only getting worse... but within a month my husband had his wife back and my sons had some of their Mother back... just because of LDN.

It is now April 2010 and I've been taking LDN for only a couple of months. I am by no means totally well, BUT sometimes I have to remind myself now that I still have an autoimmune disease because I feel totally different - but I have to remember to manage my days within my limitations.

I've experienced a significant reduction in pain and that has helped my energy levels and general well being. It seems like LDN is my own little miracle.

I still don't get dressed some days and I still need help sometimes because I can still have bad days BUT, in comparison to before... well, there is no comparison!!

I wish LDN was available to everyone, and that's now my hope and my focus. I pray that one day everyone will have access to this drug, and won't have to go through the pain and suffering I have had to endure the last 15 years.

I still have my wheelchair. I leave it in the living room so I have to pass it every night, just as a reminder of what could have been, and I thank LDN for that!

I still have a long way to go, I know, but for now, this is enough. I am ME again (if only a bit of me so far), and I am no longer just my Fibromyalgia!!!

304

## 157

### Samantha B, UK April 2009 – Transverse Myelitis August 2009 - LDN

I was at work one day, March 2009, when I experienced numbness and tingling down my entire left side from the chest down. Thinking it was a trapped nerve I carried on with it for a week and then went to see my GP who didn't really have any answers. He told me to come back in a week if it hadn't gone away.

I went back to him a week later because the symptoms hadn't abated, and I was now also dragging my left leg. I saw a young locum GP who sent me straight to hospital where, after chest X-rays, numerous blood tests, MRI scans and a lumbar puncture, I was diagnosed with 'Transverse Myelitis'.

Why my neurologist chose to give me that diagnosis, I do not know... two GPs stated it was clear from my MRI scan results (which showed 'numerous plaques consistent with demyelination') that I had MS. I was, of course, devastated, although I didn't know much about Transverse Myelitis or MS, other than my condition could continue to get worse and I could end up in a wheelchair.

After the diagnosis I was free to leave the hospital without so much as an information leaflet, and... I didn't hear from anyone again for 6 weeks, during which time I spent a lot of time crying and feeling hopeless and helpless.

The neurologist offered me steroids, which I refused, and gave me a packet of Amitryptyline, which I have never taken. Amitryptyline is a generic drug prescribed for anything from epilepsy to depression, but it did not appear to offer anything in terms of relief for MS. I'm not interested in taking drugs for the sake of it, so I kept the packet, unopened. I knew they were there if there was nothing else to turn to.

Eventually, I was assigned an MS nurse who came to the house and filled in her questionnaire featuring such questions as 'Do you have a downstairs toilet?', and 'What kind of work do you do?'. All very well-intentioned I'm sure, but nothing that really helped me. She finally gave me some information, but I had by that time, taken the initiative and obtained all the same information from a friend who works at a hospital in Derbyshire. In fact, by the time I saw the MS nurse, I thought my symptoms seemed to be a little relieved as I was no longer experiencing fatigue or lack of balance - although the fatigue was to return later.

The pain at night was perhaps the most difficult symptom to cope with, and very weird. The duvet bed covering touching my left torso gave me the sensation that I was buried under rubble and during the day my left side felt as though there was a tight band around it. The pain was continuous and made me irritable, even though it has a lovely name... 'The MS hug'!

Symptoms came more often than they went, and there seemed to be no hope that I was going to have the benign form of MS. I went through periods of deep depression - no

longer able to play tennis, couldn't walk far without exacerbating the pain in my leg, and had to get to bed by about 8.30pm.

Then my father saw an article in the local press about a man who had (somehow) managed to get an LDN prescription for his wife from his GP. His wife had suffered severely from MS for years but had shown almost immediate improvement after taking LDN. I decided I wanted some of that, and was soon on a mission!

Research on the internet kept bringing me to the same doctor - Dr Bob Lawrence in Swansea - who deserves an MBE, the Nobel Peace Prize, and every other decoration going. I spoke to him for an hour on the phone, sent him my hospital discharge papers, confirmed that I was not presently taking (and had never taken) any other drug for MS, and he prescribed.

I was a little apprehensive and scared. My GP had flatly refused to look at all the research I had gathered and did not want to hear my point that if she "wouldn't prescribe it, I would get it from somewhere else!".

One night in August, I took my first 1ml of the liquid, got up the next day, and was virtually free of all my symptoms since my initial diagnosis. Two weeks prior to taking the LDN, I had also started taking all the nutrients that Dr Bob had recommended to aid its efficacy.

After only two months on LDN, I had all but completely recovered. I still got the occasional twinge in my left foot, but it was completely bearable. I still had the slight 'tight' feeling down the left side of my torso, but I only noticed it if I thought about it.

I went back to working full time (even six days a week) as a very busy PA to a College Principal. I climbed to the top of Cheddar Gorge without any problems. I drove a manual car without difficulty - whereas before I had to revert to an automatic. I even played tennis, jumped around on a bouncy castle with the kids, shopped all day, and generally went back to leading a normal life. I have a six-year-old son who keeps me active, and since being on LDN I have not had to let him down by saying "no" to kicking a football around, etc.

My neurologist at Taunton hospital would not agree to prescribe LDN, so I changed neurologists and chose Salisbury hospital. I went to see him even though Salisbury hospital had already written to say they would not prescribe LDN. Just like everybody else, they have chosen not to give me a reason.

I wonder how they'd feel if they, or one of their children, was diagnosed with any of the conditions that LDN helps. Whilst I understand that LDN has not undergone clinical trials for use in MS, I cannot find a single claim that it will do any harm in such low doses. In fact, it seems the only drug that halts the progression of MS and for many, can dramatically relieve many of the symptoms.

If LDN really does prove to halt the progression of MS, I have been very lucky in both being made aware of its existence and getting a prescription very early in my diagnosis. I feel that I, and everybody else diagnosed with MS, should be made aware that this drug exists, and have the right to choose whether or not to take it.

LDN has proven to be of benefit to me, and I have not suffered a single side-effect. I understand a whole lot more about the devastating condition of MS now, but what I

cannot understand is why GPs will not prescribe this cheap drug as a matter of course, or why the Government and others have chosen not to fund a clinical trial and save the NHS billions. If there is a GP out there reading this, who will prescribe, please get in touch with the LDN Research Trust.

### **158**

Samreena K, UK 2005 - Multiple Sclerosis September 2008 - LDM

I am a teacher who chose to start working part-time after my second child in 2001.

I bought an automatic car in 2003, and then in 2005 I was diagnosed with MS. Did someone prepare me for this in a discrete way?

It was my own fault really! I decided that I was going to become fitter and healthier but when everyone else was walking ahead of me and my leg started 'dragging' my brother, a doctor, reminded me that this had happened before although I couldn't remember!

So this is where the appointments began and the hospital visits started.

My doctor referred me to a neurologist who then suggested an MRI be done. As I was busy looking after the children and working I was almost on 'auto-pilot' - going through the motions and doing what the 'professionals' (doctors) wanted me to do. When the diagnosis came, I was relieved. At least I knew what it was and could 'plan, read and understand' what this was all about. As it happens, nothing could have prepared me for this other than my belief that one day I would find a way or perhaps there would even be a cure!

Jumping ahead to 2008 and two relapses later, it was suggested that I 'fit' the criteria for injections. Would I like to go along to a discussion group where I could choose my injections? Once again I went along to a discussion group, but this particular occasion was to be the 'turning point' for my MS.

Within this 'group' there was a person who said, "I'm not here for the injections but the tablets." My brother had accompanied me, so I looked at my brother thinking, 'Did you not know about these tablets?', quickly followed by, 'if you did, you've got a lot of explaining to do!'

I am grateful to my younger brother who, when I came home the following day from work told me about LDN. He had done all the research etc, and I just needed to convince my GP to write the prescription (easier said that done) - but undeterred I found a doctor who was prepared to write a prescription for LDN after having spoken to me, etc.

I informed my 'medical team' of what I was thinking... that I was going to try LDN. No one discouraged me. If it didn't work then there was always the other option of

injections. No-one was going to lose anything, except me, and this was my decision; albeit one I was making alone. But then I spoke to Linda from the LDN Research Trust website. She allayed the fears I had and the first prescription was sent off.

I have been taking LDN for almost one year now. I've had no relapses and I've had less time off work. I feel better, and on most days I have more energy than before LDN. I have visited my GP less, and could go on and on about how LDN has worked for me.

I know that this is a medicine that does work and we need to let 'everyone' know about it so that an individual can make up their own mind if it is for them. I realise it is not a 'miracle' cure, but if it works then why not use it. What I have learnt is that this is my illness, and I am responsible for its treatment. I just hope the man that led me towards this journey of LDN has found it as well.

At the moment I am walking quite slowly and am not sure why, so will see my GP on Wednesday. It may be because I came from holiday last week, or the fact I fell over my son's shoe before I went on holiday. I don't think it is a relapse.

All I know is that LDN does work, when I get the dosing right!

#### UPDATE March 2010

Yes I am still taking LDN and wouldn't give it up. I think I have the dose right, but I do tweek it every now and then.

## 159

### Sandra B, UK 2008 - Primary Progressive Multiple Sclerosis (PPMS) June 2008 - LDN

My name is Sandra and I am 61 years old.

I was diagnosed with Primary Progressive Multiple Sclerosis 2 years ago, but started getting symptoms 2 years prior to that.

I remember having a bath and noticing my left leg was numb. At the same time I was having trouble walking. After 10 to 15 minutes my left leg leg/ankle started to drag.

I went to my GP, who referred me to a Consultant. I was given an MRI scan of my back and the consultant told me I had a herniated disc which was resting on a nerve, but this could be remedied by inserting a metal implant between the discs to relieve the pressure. I went ahead with this operation and when I returned to see the consultant told him that I had not felt any improvement. He said this was because I had not been using my leg and the muscle had wasted and I would need some physiotherapy. I was sent for physio and given some leg exercises to do at home on a daily basis, which I did religiously. There was some improvement as the exercises did help strengthen my leg.

At the same time I was suffering pain in my left hand, fingers and wrist. I was again sent

for physio but the exercises made the pain worse. I was also suffering pains around my middle as if I was being gripped, and I was also feeling dizzy when standing.

Then in January 2008, I woke up to find that I could not focus my eyes properly: Numbers and letters were dancing in front of me when I tried to focus. It was quite a problem as I work on a computer at work. That lasted for 5 weeks, and then one morning it was gone, leaving as quickly as it had arrived.

When I had the vision problems I went back to my GP. He said he thought my problems were further up, not in my back, and I was sent for another MRI scan. I went for the results and was sent to a Neurologist who told me he thought I had MS. There was a grey area at the base of my neck. I had to go for yet another MRI scan. That scan verified his diagnosis, and I was told I had PPMS.

I was put on a 3-day course of intravenous steroids to boost my energy levels, which were very low. This gave me a boost but did not last for long.

At about this time my husband discovered LDN through Dr Gilhooley's website in Scotland.

We found out a lot of information about LDN and how it was helping people with MS.

To cut the story short, Dr Gilhooley sent me a letter to give to my GP recommending LDN. My doctor read up on this, and he didn't have a problem with prescribing it for me as it is taken once daily in a low dose.

That was in June 2008, and I have never looked back.

Almost two years later, 90% of my symptoms have gone.

I have no pain in my left wrist or fingers.

My dizzy spells are a lot less.

I can now have a hot bath, which I was unable to do before because the heat took my energy.

My energy levels are up. I can change the sheets on the bed, clean the bathroom, and vacuum the stairs and lounge in one go without having to rest. I can do my weekly shopping on my own, pushing the trolley around the supermarket.

I can walk for at least half an hour, before feeling tired.

I have no pains around my middle.

Of course I know it's not perfect, but I manage to do everything I need to do. I listen to my body and rest when I need it, get plenty of sleep, and I don't drink alcohol because alcohol does not agree with me. I also take vitamin tablets.

When I first started taking LDN I took 3ml per night, then gradually increased it to 4.5ml, which I have taken every night since at 9pm.

309

When I last saw my Neurologist he was surprised at my improvement, because, he said, "You don't improve when you have PPMS". He has now decided that I must have had Relapsing Remitting Multiple Sclerosis (RRMS) instead. He would not credit LDN with my improvement, but I know differently.

### **160**

### Sandra J, UK approx 1970 - Relapsing Remitting Multiple Sclerosis (RRMS) April 2008 - LDN

I was just under 20, about to be married, a hairdresser full of life... before developing Multiple Sclerosis, diagnosed in approx 1970.

I stayed quite fit over the years but with bad bouts in between of blindness, numbness, double vision, and vertigo, so when I finally went into a wheelchair I was actually thankful, because I never had really bad episodes again.

But once in the chair, I slowly deteriorated. I thought my life was over... until I started on LDN in April 2008.

Initially, I just felt much more alert and noticed more movement in my body. I'd had M/S for 38years and had been in a wheelchair for 10yrs slowly deteriorating, so even though there was no massive improvement I was pleased to notice some... and importantly, those small improvements made me feel better and gave me hope. What a difference... after only 2 weeks... I felt happy and alive.

Over the following months I noticed continuing small changes and improvements, like being able to move parts of my body which I could not move before, being able to sit more upright, being able to feed myself more, and lots of other seemingly little things that cumulatively have improved the quality of my life.

Update Jan 2010: Since I wrote the above... I'm still feeling good and noticing some improvements in my fingers when typing. These little things are happening so slowly you just don't realize until you think, 'God, I could not do that before!!!'.

310

# **161**

### Sandra L, UK

mid 2004 - Primary Progressive Multiple Sclerosis (PPMS)

Sept 2008 - LDN

I am in my mid sixties. I was diagnosed with PPMS approx 5 years ago. As there is nothing to help PPMS at this stage I was interested to read about LDN and I went through to see Dr Gilhooly in Glasgow in the Autumn of 2008, to find out more about this drug.

I decided to try LDN. I now take 3.2ml daily along with various supplements prescribed by Dr Gilhooly.

The first morning after taking LDN (1ml) the night before, I walked unaided from my bedroom downstairs and into the kitchen. The distance is 25ft to the top of the stairs, down 15 stairs, and then approx another 40ft to the kitchen. This however, did not last.

On several occasions since starting LDN I have been able to climb the stairs quite easily without having to pull myself up with the aid of the banister. This only happens now and then. There is no benchmark for me to know what I would be like without LDN.

I still walk short distances with the help of my three-wheeled trolley. If I have to go a distance I need my wheelchair.

I may be a lot worse without LDN, but I do not know what the progression would have been like.

# **162**

### Sandra R, USA

2007 - Rheumatoid Arthritis, Sjogren's, and possible Autoimmune Hepatitis; with Lupus Symptom History 13 November 2009 – LDN

My name is Sandra and I live in the USA. I started LDN on November 13, 2009 to treat my Sjogren's, Autoimmune Hepatitis, Rheumatoid Arthritis, and Lupus, but I can't provide a diagnosis date for any of these conditions with any certainty.

I know as a child, at 10 months, I was not able to absorb iron, and was near death. I have no idea what saved me at that point. At the age of 8, I again was low on iron to the point where the doctor didn't believe I would see my 9th birthday. They were giving me

iron shots, but the iron went right through my body without sticking around to help me out.

I was given a Plasmapheresis just before my 9th birthday, and then given very large green iron pills that I could barely swallow. For some reason, after that I was able to get better. They had diagnosed me with Leukopenia at that point. From then on, I only had problems with anemia from time to time, from the age of 9 onwards. I ate very healthy foods, as well as non-healthy. Gluten filled, soy filled, preservative filled... and had no health issues.

In my early twenties I joined the US Army as a Medic. We were able to do our own blood tests now and then for practice on phlebotomy, and that's when a gastroenterologist came to me and asked if I were drinking heavily. I have never been one to enjoy alcoholic beverages, or the affects they have on me, so my answer was an emphatic NO!

He didn't seem to believe me but did mention that I need to watch my fat intake, as my liver enzymes were high. (I recently read on the net that if the AST is lower than the ALT results, it is an automatic sign to the doctors that it is not related to alcohol, but if the AST is higher than the ALT results, it's alcohol related.)

There was no other mention from that point on, but I continued 'practicing' phlebotomy with co-workers, and all my lab results came back with slightly elevated liver enzymes. I just learned to be careful not to drink during holidays, etc, and assumed my diet was a good one, in that I had the meals that included protein, carbohydrates, vegies and fruits. So I assumed I was being good.

I've never been one to snack on chips or nuts all day long like I see everyone around me doing. I don't drink, and I'm not into soda! I love clean water and drink no less than 64 ounces per day and have always been that way. So, why the liver enzyme elevations?

No doctor ever said any more about it during my military stint, and the only time I had a doctor bring it up was during a gallbladder attack in 1992, which elevated the enzymes astronomically. My gall bladder was removed when I was around 30 years of age, and my enzymes continued to rise and fall whenever they felt like it.

I have finally realized I am a big butter fan, but no more than the usual. I eat it on my toast and potatoes, and that's it. I don't eat red meat and haven't done so since I was 18, so red meat isn't an issue! I should be healthy as can be, right? Should be.

In 1999, I started having stomach trouble along with numbress in my toes and heals. I found my stomach was infected with the Helicobacter Pylori parasite. I was able to rid my body of the parasite but from that point on, my body has gone haywire.

I've had muscle pains, bone pains, muscle spasms, dry eyes, dry mouth, dry vaginal tissues to the point of bleeding without anyone touching me, sores in my mouth and nose, and then became arthritic. My liver started hurting severely along my right upper quadrant. I also noticed a red rash (now known as the butterfly rash) over my cheeks and nose bridge. That rash is what made the nurse practitioner check my ANA and my blood tests were positive for Sjogren's. The ANA was 1:320, speckled.

I have fought and fought and fought with diagnosis from that point on. The nurse

practitioner that noticed the butterfly rash told me she thought I had Lupus (this was in the beginning of 2000), and that's when the tests were done and came back positive. But...she sent me to a Rheumatologist who said I did not have Lupus, and he wouldn't see me anymore.

I later found out that was more to do with my insurance not being doctor friendly. I then had to change primary care physicians and was bounced around to many different ones over a few years, but nobody was able to give me any TRUE diagnosis, and I couldn't get in to any other Rheumatologist as they were all full!

Then my stepson was killed in Iraq in November 2004, and after that the doctors were stating to me that all my pains and other issues were due to grief and depression and I was sent to a psychologist and Licensed Clinical Social Worker. None of that took my pain away.

I finally got into a Rheumatologist in 2007 and she did extensive ANA testing. At that point my ANA result was speckled but only 1:80. The next test result was 1:40, so she said I was negative for Lupus (even with the rash and all other symptoms). She did say I tested positive for Rheumatoid Arthritis, and Sjogren's, and POSSIBLY autoimmune hepatitis. Since then, she has never done a lip biopsy, nor has she tested me for Celiac Disease or Vitamin D deficiency.

That was in 2007, and I was prescribed methotrexate, celebrex, methocarbomal, xanax, Enbrel, Pristiq, and I can't remember what else. I'd also had a total hysterectomy so I was already taking HRT, and because my blood pressure was in the range 340/280, I was on Benazapril HCT (which did bring my blood pressure back down into a normal range and keep it there). I stayed on all these drugs and had blood tests every two months for over 2 years (hurting my liver even more), and then heard about LDN.

My father-in-law was dying from lung cancer and had been told it may help him (he was already in the last stages when he found out he had it, so he didn't bother to try it), but he remembered my health issues and sent me the information in May of 2009.

I did a ton of research on it and tried to get my doctors to prescribe it, but to no avail. I finally had my newest Primary Care physician refer me to a Neurologist at UCSF that is an MS specialist. Much research has been done at UCSF on LDN and he was amenable to prescribing the LDN.

I didn't get into him until November 10th, 2009. He, Dr. Darin Okuda, had no problem prescribing 4.5 mg of LDN for me right away. I've had no bad problems with it. I was sick with flu-like symptoms for the first week, and had nightmares for the first two nights, but other than that, all has been well for me.

The good news is that the LDN has worked very well for most of my issues. It has helped my brain fog, my memory, my focus, taken the dryness from my body within the first 24 hours of starting on it, and the best part of all, it stopped my bladder incontinence on the first day!!!

I didn't even know my bladder issues were caused by this autoimmune mess. I assumed it was just old age. The bone and muscle pains also went away with LDN. But... the arthritis didn't get any help at all. I still have hand and foot pain, as well as finger and toe pain, but on a scale of 1-10, with 10 being the worst pain, my pain is at a 1 or below,

and it's not a big deal. LDN also hasn't stopped the joint stiffness, so I ended up back on Enbrel.

As of yesterday, April 22, 2010, I asked the Rheumatologist to prescribe plaquenil again, and I will use that with Enbrel for one month, then stop the Enbrel, as I've been told that it's not a good medication to combine with LDN.

So, in a couple of months I will be able to tell you if the Plaquenil with the LDN is doing the job or not. LDN did not help my weight issues, nor did it help my blood pressure. It did seem to help my Optic Neuritis, though... so far.

The reason I went waaaaay back to infancy with my health issues is to ensure everyone is aware of what types of things I had that are known possible links to Lupus. I had heard that those with Lupus have a childhood history of Leukopenia, so I'm putting that information in here as part of my adult history, just in case it provides some clues for someone else.

## **163**

### Shana S, USA

#### August 2007 - Secondary Progressive Multiple Sclerosis (then later, Relapsing Remitting Multiple Sclerosis) March 2010 – LDN

I was in my late fifties when I saw my first neurologist and was diagnosed with Secondary Progressive MS. That was in August of 2007. The next two neurologists I saw diagnosed Relapse-Remitting Multiple Sclerosis. I was on Beta Seron shots for 1 month (too many side effects), then Copaxone for 1 year (too many hives and too expensive).

I started LDN in March of 2010.

After having back and neck problems since my early 20's, I felt great in my mid-fifties. My back never hurt. My neck never hurt. Then one day I woke up and was walking like a duck. I had no pain, but my legs were slowly going numb. After a few days, I could barely walk and my abdomen area became numb also. My husband ended up wheeling me into the emergency room.

I was told I had severe spinal stenosis in my lumbar region and would be paralysed from the waist down if I didn't have surgery within 48 hours. I was admitted immediately to the hospital with surgery scheduled for the next morning. During the afternoon and evening, I kept being wheeled down to get MRI scans, and then more MRI scans.

I didn't think much of it until I was brought into pre-op the next morning. The anaesthesiologist came over to my bedside and asked me if I was allergic to any drugs. Just prior to him 'putting me out' for the operation, he said, "By the way, you probably

also have M.S. and should get that checked out as soon as you get out of the hospital from back surgery." He then 'put me under' for the operation.

Later that afternoon, the operating neurosurgeon came in and told me I was probably too old to have MS but that the MRI's indicated that I could have MS. He said more than likely it was Transverse Myelitis. He told me I'd start feeling weird things and needed to get checked out further by a neurologist.

I went through more tests and a lumbar puncture, which ruled out a lot of diseases. Then the neurologist left me a voicemail saying I did have MS. My guess is that bedside Manner 101 is not taught in medical school.

By this time I was in a lot of pain. I had neuropathy (heavy burning sensations and tingling from the bottom of my feet throughout my entire body, except for my head.) I was given Lyrica for the pain. It didn't work.

Eventually, I went to another neurologist who confirmed the MS diagnosis and put me on Hydrocodone for the pain. I spent a lot of time in bed. It hurt to put on clothes. I couldn't put on a bra. I was tired and in pain all the time. I took the Hydrocodone only when I had to go somewhere and get dressed, or the pain was just too much and had me in tears (I'm not a cry baby). I didn't want to become dependent on the pills because I knew I'd just need more and more, and then something stronger and stronger.

In 2009 I went to a third neurologist. I was still in a lot of pain. I was taking Copaxone and still taking pain pills. He suggested I see a pain doctor. Then someone sent me an e-mail saying they heard that LDN worked for MS. I asked my neurologist. He said it was an 'in' thing a couple of years prior but it really didn't work. I continued to be in constant pain and took Hydrocodone, but only when absolutely necessary.

In March of 2010, a naturopathic periodontist that I'm close with was having problems of his own and went to a healing clinic in California with Medical Doctors and Naturopaths. He was told about LDN for his condition and was told that it also helped a lot of people with MS. The periodontist called me and told me about it and asked if I wanted a prescription. I did some more research on LDN and said, "Yes, please." He told me it had to come from a reliable compounding pharmacy, and he knew of one.

I took my first 4.5mg LDN capsule at night and had a difficult time sleeping, but the next day I wasn't in any pain! I couldn't believe it. It worked.

I ended up breaking up the capsules and taking half the amount for a week and then built back up to the 4.5mg. It works better than hydrocodone and builds up the immune system instead of repressing it.

I have now been on LDN for 9 weeks. I do still have days of pain... but not as much pain... and I do still have a couple of days a week that I'm too tired to do much. I do have migraines sometimes, but that I've always had.

Overall, the LDN is working for me. I love that I can get it for \$18 per month without insurance. I love that it's not an opiate and non-addictive. I love that there is a lot of anecdotal evidence that it stops MS Progression, which I'm looking forward to.

I then went for my scheduled appointment to the pain management doctor and told him about LDN. He wasn't familiar with it. He did say he would research it and get back to

me. He wanted to make sure it wouldn't harm me in any way prior to prescribing it. He agreed that it would be great to get off the Hydrocodone. After a couple of weeks, he called and gave me a prescription. My goal was to have a mainstream MD become familiar with LDN and maybe integrate it into his practice. After all, if it helps me, it may help a lot of his patients.

What I find aggravating is that widespread clinical testing isn't being done on LDN because it is a cheap generic and nobody will make money on bringing this drug to the mainstream market. Shouldn't the reasonable cost and lots of anecdotal evidence be a reason for the MS Society and/or government agencies to sponsor large clinical trials?

I can see how drug companies don't want this drug known. But aren't there others who care more about the well-being of those with auto-immune diseases and cancers who will step up? Don't we want to lower the cost of medical care? That's what we're told. Are there any lobbyists that are for the people?

Please check out the main LDN websites Idninfo.org and Idnresearchtrust.org. LDN is supposed to help a lot of diseases. In fact, at first, I was highly sceptical because it seemed too good to be true, but it is worth it for others to try it. It's not going to break your pocketbook. It may not work for everyone, but it works for me and a whole lot of other people. It is not a miracle cure but it's as close as I've found to one.

# **164**

#### Shane – Anon, UK 2005 - Multiple Sclerosis March 2008 - LDN

I'm nearing 70, a female from southern Ohio in the USA. I've been active and worked all of my life, retiring from pharmaceutical research the month prior to 9/11. I retired because my age was catching up with me, so I thought. In reality I was progressing with MS.

Twenty years ago I began with slight tremors and I attributed those to a probable sugar imbalance. As time passed, extreme fatigue set in at unusual times, short term memory became a major problem, I was losing a great deal of my vocabulary, my mind was foggy, and I lost the ability to reason as I once could.

Other 'unreasonable' symptoms began and no physician could 'understand'. Then, for no apparent reason, I began to fall and have eye soreness and pain. My ophthalmologist considered MS and took it from there. My neurologist came into my life and ordered Copaxone. I continued to worsen, mentally at first, and then physically.

I gave up my home, my cat, my car, and moved to an assisted care nursing facility. I put myself on the DO NOT RESUSCITATE list, and waited... I had been ambulatory with the aid of a walker but at that point I knew a wheelchair was about one week away and I really did not care anymore... resignation had set in along with hopelessness and numbness.

I had not been able to read for quite some time, however a strange thing happened. I picked up a periodical I didn't even know I had, saw an article on LDN and began to read. I used my pharmaceutical experience and began researching. The more I read, the more determined I became.

I understood the FDA approval for another indication, I found few, if any, adverse events and it seemed to be a very safe possibility. The nursing home physician would not consider prescribing naltrexone since it wasn't approved for MS, so my next step was my neurologist... I handed him copies of my research, he read it and he wrote the script. I took it, and the rest is history.

That was March 2008. Within five doses (5 days), I was coming out of the fog and it only got better from there. My attitude changed, my mind cleared, I found some of that lost vocabulary (note the word 'some'). I began to read and reason again.

Within three months I was walking without a walker or cane. I took myself off of the DNR list! I still have RRMS and I still have the symptoms of MS, but they are manageable today. I have continued with the Copaxone. I've become involved in my community and was elected president of our resident council. I'm on the go as much as I want, but I don't have the time to do all that I want.

MS is part of my life but I have a life and it is a pretty good one. LDN is giving that to me. The one and only problem I have is paying for it myself. I turn all my retirement over to the nursing home with the exception of \$50.00 a month... that is the extent of my income... rather tight! It will be interesting to see where this compound will be in the next few years! I'm just glad I found it, now...

## **165**

### Sherri R, USA July 1998 – Relapsing Remitting Multiple Sclerosis (RRMS) May 2008 - LDN

I was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) in July 1998.

I started on the Avonex drug therapy within two weeks. I lived like that for 5 years. One injection a week with a VERY big needle. I really did not like that. My neurologist did not offer me any other choices.

I met my husband at the end of 2003. He also had Multiple Sclerosis. My life was changing for the better. He convinced me to switch over to the Copaxone drug therapy he was on in March of 2004.

A shot a day, but I couldn't really tell any difference. I continued that, for a while, then I got good at hiding. I am not proud of this, but I started to quit taking the injections. I (maybe) took one a week. What kind of life was this? A shot. Why couldn't they offer something else?

My husband & I started to research MS and review the different approaches that we could both take. Bruce still didn't know that I was not taking my injections when he found a lot of information on a drug called LDN. We researched more. A drug that was used for opiate addiction could somehow ward off MS symptoms?

He took the first step. He tried to find a doctor that would actually prescribe this for him. He went through five different doctors before he contacted an Alternative Medicine Doctor who was able to help us.

He started on LDN February 2008, and felt better! I was so excited. I soon made an appointment with this doctor and started on LDN in May 2008. I also confessed my sins to Bruce. He was not happy but he did understand.

Our doctor has many MS patients and more than half of them are on LDN now and are doing better. I think just one of them did not respond to this medication. It will soon be two years for me and LDN. I can truthfully say, I have not had an exacerbation of my MS since I have been taking Low Dose Naltrexone. It has been a \*wonder drug\* for us and our MS.

# **166**

#### Sherri W, USA 2006 - Multiple Sclerosis June 2009 - LDN

I was diagnosed with Multiple Sclerosis in 2006. The disease was rather progressive and I was treated with the typical CRAB (acronym for Copaxone, Rebif, Avonex and Betaseron) MS medications. Specifically, I was prescribed Avonex and Copaxone, with no success.

My MRIs showed 10 lesions upon diagnosis, and that number grew to more than 60 over the course of 15 months. Out of desperation to stop the progression, my neurologist put me on Tysabri, and I was on that for 20 months.

I went off Tysabri in May 2009 because of recurrent respiratory infections and laryngitis. My immune system was no longer able to fight off infections and my neurologist and I believed it was time for a holiday. This was especially troubling given the fact Tysabri carries with it a potentially fatal brain infection. I didn't know this at the time, but my husband feared each day when I woke up that this might be my last day. This is what motivated him to do research on the computer about other treatments for MS that were less deadly. That's when he found LDN.

Ironically, my husband and I discussed LDN with my neurologist a few weeks before I went off Tysabri. She had heard of it and thought I should give it a try, thinking it would help my fatigue. She initially wrote the prescription for 3mg. I had the prescription filled by Skip's Pharmacy, and I took my first dose within a week! The first week I had some headaches and some vivid dreams, but that was it!

After that, I had no side effects (if you call those side-effects). Two months after being on LDN I regained feeling throughout my entire body! I hadn't felt things for two years and suddenly I could. I also had more energy and could walk longer distances.

After three months, I requested my neurologist increase the dose to 4.5mg. I've stayed on that dose and I'm extremely happy with it. I went in for my semi-annual MRI two weeks ago and the results were great - no new lesions! I think even my neurologist was surprised!

Three months ago she wanted me to go back on Copaxone in conjunction with LDN, but I told her I wanted to talk to my other neurologist, the one I see at the MS Center at UCSF before making that decision.

When I met with the neurologist at UCSF, he said there was no need to go back on a disease-modifying drug at this time because LDN seemed to be working well for me. It's Dec 2009, and I've been on it six months now and will continue on it. It's funny how an inexpensive capsule taken at bedtime can improve the lives of people with autoimmune diseases.

I want to tell the world how great this drug is!

## **167**

### Silvia L, UK Nov 2008 – Primary Progressive Multiple Sclerosis (PPMS) 8 January 2009 – LDN

I'd been having problems with my legs and all sorts of things on my left side for ages. So, when the pain became too much, I finally went to see my GP.

She looked at my legs, realised that one of them was thinner than the other, and wanted me to do some exercises to strengthen those muscles. Not being able to lift my left foot off the ground for more than 8 inches, she concluded that I needed to see a neurologist.

For the last few years I'd been telling myself that I was a hypochondriac and that in my mind there was constantly something wrong. Well, I was lucky to have private insurance at that time, and I got to have my MRI within a few weeks.

Two days later, in November 2008, I was told that I had PPMS and sorry, there's nothing traditional medicine can do for PPMS. Great! So I went home, felt despondent and very sad, and scoured the internet - mainly wanting to find people who were experiencing the same as me.

I read and read and read, but in the end it was a very lucky question that got me to where I am now. Somebody had asked; "What exactly is LDN?" I had no idea, but fortunately, I was curious enough to find and read the answers.

I read the name Linda Elsegood. I read Idnresearchtrust.org, and I came across the

book 'Those who suffer much, know much'. The fact that there was information out there that didn't seem to profit anybody in particular, but that was freely given by people who cared about their fellow people was convincing. I asked my partner to find all the negatives he could, and he didn't actually find anything.

I read the book online. I joined the Idnresearchtrust.org, and I got great information about how and when to start (like immediately!). My GP was hesitant to prescribe something she had never heard of and asked for more time. I said that I didn't feel that I had time, as I wanted to halt progression now, not in a few weeks or months.

I managed to get myself a prescription over the internet (e-med) and sent this off to Dickson's chemist in Glasgow. My doctor totally agreed with that approach and since then she has been giving me all further prescriptions, as she can see that LDN is good for me. To start with, I think she realised that it would do no harm and that seemed good enough for her.

I started taking 3mg naltrexone on 8 January 2009, and stayed at that dose for two weeks, then upped my dose to 4.5mg, and have stayed at that dose since, though with occasional minor adjustments down.

In the first weeks of taking LDN, I felt quite tired, to the point of fatigue, but over the initial weeks, my fatigue improved fairly quickly.

I also experienced increased heartbeats and some pounding during the first week, and if I woke during the night, I seemed to be wide-awake. After one week on LDN I had a strikingly vivid dream of killing two rats with my long handled shoehorn. (Doesn't everybody?).

The first really noticeable improvement was the fact that I wasn't getting leg cramps anymore. I had gotten used to refraining from stretching, as that inevitably ended in a leg cramp. So, when I forgot one morning and stretched, I found that my leg didn't cramp, and I was delighted. This was my first realisation that LDN had changed something in me.

The first month on LDN I had been charting my urine in-and-output for my MS nurse. Urinary frequency was high at 9-15 times daily to the loo, with interrupted sleep from getting up once or twice every night. This interrupted sleep and night symptom had been happening for several years prior to my diagnosis.

Six (6) weeks after commencing LDN I took stock of that symptom, because one day I suddenly realised that I'd been sleeping through for several nights. Daytime loo visits had gone down to 6-8, and I'd begun to sleep through most nights without having to get up and go to the loo. My sleep had improved, so I felt more refreshed when I woke.

My cramps have not come back, and my bladder is excellent, even better than it was about 8 years ago. I still have MS, I tire very quickly, I limp, and I quite happily take a nap during the day. I still sway and nearly lose my balance, but I started taking LDN because I wanted the progression to stop, or at least slow down. I didn't expect symptom improvement and relief, but feel very lucky that I got that as well.

I wish people didn't hesitate so long about LDN. With a no-harm-done drug, wouldn't it be a safer bet to give it a go than to wait until more damage has been done?

#### **UPDATE February 2010**

I had many thoughts during these last 13 months on LDN. Like most people, I started worrying at the first glitch, asking whether I might be kidding myself about the efficacy of LDN. Thank goodness I was advised to keep a diary, an advice I now also give to everyone who's starting LDN. I found the reassurance this gave me the most valuable part. Every time I felt down and was getting doubtful I just needed to read old entries and I knew LDN was working.

What's been happening with me since I last wrote?

In August 2009 I had a 'doubting period' and needed to read my diary to feel reassurance that I was a lot better. My fatigue lifted and the energy level was increasing. I didn't even need daytime naps anymore. I reduced my gluten and milk intake. Breakfast changed from toast to muesli, the wheat free variety (gluten free is not to my taste), to which I add a tablespoon of linseed and I mix it up with apple juice, not milk (very tasty!). My digestion is much better for it and constipation is rare. If I do experience it, I can always identify the reason, such as eating pasta or something in breadcrumbs, or following Sunday breakfast that still comes with toast. But I can cope with this level of constipation.

Occasionally I have felt my old queasy feeling (which I experienced for 16 years whenever I tilted my head and looked up at the ceiling) stronger, increased and sometimes it came upon moving my head or even just my glance.

In September 2009 I felt my first real surge of improvement. Yes, things had gotten better all the time but at the end of August, beginning of September, i.e. about 8 months after starting LDN, I was feeling stronger than I had done for a long time.

In October I had a funny symptom, was it MS or just something? It was a 'crawling insect' feeling on top of my head across an area the size of a golf ball. It lasted a few seconds in the morning and overall for a few weeks. By November it was gone again.

This is what I actually wrote in my diary just over a year ago, on 28th November 2008: ' .... Well, is this the end? The beginning of the end at least, or is it the beginning of a new era, my life with disability? I must say, I think, I'd find it easier to look into my own death's face than to look into becoming disabled, dependent, a vegetable. I went to see my doctor neurologist today. She is very lovely and has handled it all very well, but it still doesn't stop her from having to tell me that she is 98% certain that my symptoms and scan pictures indicate Primary Progressive MS. Great. OK, it doesn't shock me completely as I have been expecting some bad news. I've had the feeling that something was wrong for quite a while. I suppose, the consolation is, that even had I gone to the doctor earlier, nothing could have been different. It's not that the disease could have been prevented or caught early on. It's just that I would have lived with the knowledge of doom longer, instead of living with the uncertainty of bad news. Both ways pretty bad. Oh well, what is the future going to bring? At the moment I have lots of thoughts, all negative of course, that's just the negative person I am, I guess. ... '

And this is my diary entry of 28th of November 2009: ' ... I was so lucky to feel as depressed as I did then, to search the internet, to more or less stop what I was doing until then and read. I was so lucky to stumble across these three letters LDN. My life is totally different to what I pictured it to be last year. I am more active than I was for many years, I am not depressed, I have hope and I am physically stronger, too. I am not

deteriorating, if anything, I am somewhat improving. Maybe that's physio and swimming doing its job, but no doubt that's all being helped by a healthy immune system thanks to LDN. The points of sadness I experience most days are the messages I read of people who have lost all hope or who say, if only they had known about LDN when they could still walk, as they would still be walking now. This is the totally unfair bit. LDN is here, it's harmless, it improves lives, it stops deterioration, but unless you are as lucky as I was you won't be told about it and won't actually find it easily. This must change, and this must change soon. ... '

Today in February 2010, I am feeling well, upbeat, and better than for quite a while before and since diagnosis. I walk steadier and stronger than a year ago, I now manage to swim 21 lengths and don't need a sleep after that, whereas last Spring I barely managed 6 lengths and was totally exhausted and asleep in the afternoon after a swim. I am managing to cook and bake again, occasionally having to pace myself and sit down for a few minutes after standing for a long-ish while, but the perch stool which I needed last Spring has long gone into the cupboard again.

I have dabbled with my LDN dosage. From 4.5mg, I reduced to 4mg, then to 3.5mg, with little steps in-between. The day I got down to 3.5mg I experienced bladder urgency. This might have been a coincidence, but it scared me so I upped the dose again. It looks now that 4mg seems to suit me. My legs are not too tight and my bladder is well at around this dose, so I tend to take anything between 4mg and 4.5mg, not fussing about an exact dose within this range. My mother who is making her own takes a teaspoon of her LDN solution, which is about 3mg. No fuss about it and it's working great for her.

The vitamins and zinc I have been taking I tend to forget to take. In October for 5 days only I tried Alpha lipoic acid, which made me feel awful. I experienced weird heat surges and dizzy spells, also diarrhoea. I stopped ALA and within days I felt better again. Maybe it's to do with my amalgams in my mouth, or just coincidence?

I baked a cake, muffins and Christmas biscuits, things I feared a year before that I would never be able to do again. Occasionally when I get tired (and I still can do that), I sit on the worktop to rest for a moment.

LDN has brought lots of improvements for me. Has it improved my mobility? No, I don't think so. But it has lifted my fatigue, which gave me more energy to do more physically. I walk the stairs more often than I did. I exercise more. I swim for half an hour a week. Those initiatives are what has improved my mobility. I don't believe it was the LDN, but my taking advantage of the opportunity LDN gave me to do all the other things. LDN was the start of a chain reaction. I know I still have MS. I can still lose balance, for example, and I still have foot drop; but I am stronger and more confident, mentally and physically.

Life is amazingly better.

### **168**

#### Simon C, UK 22 February 1989 – Multiple Sclerosis 25 September 2009 – LDN

"You have MS, but that's no reason to kill yourself."

The words rang in my ears for the rest of that day, 22 February 1989. The neurologist finished it off with, "You can get more information from my nurse on your way out".

The symptoms had started about ten months before. I had started learning to drive and found I couldn't go around corners. When my instructor asked why I told him I had double vision. He never took me again. I went to an Optician who said there was nothing wrong with my eyes but I needed to see my doctor. I saw my GP and he referred me to a specialist, but the first appointment was 4 months away. My vision was back within a week, so I forgot about it - and not wanting to waste their time, I cancelled the specialist appointment.

A month or so passed, and I started dropping bricks (as a brick layer, not a good recommendation). My left hand was also going numb. I went back to my GP and he made another appointment for a neurologist. In the four months I had to wait, I had what my GP called viral labyrinthitis. I took a tray out of the oven thinking it wasn't hot, and took the skin off my left hand. After a barrage of tests culminating in a lumbar puncture (which hurts), I was diagnosed with benign MS on 22 February 1989. (MRIs weren't yet available.)

Five months later in July 1989, my left foot started to drop. My neurologist then upgraded my diagnosis to Relapsing Remitting MS. In August I was signed-off work, and I got married using a walking stick. By November 1989 I had to go into a wheelchair, and when I became incontinent our 12 x 12 bed-sit became my prison.

It was the only time I considered not being here... 24 years old, not able to walk, when I moved I wet myself, no job, and... they wanted us to move out of the bed-sit because my wife was now pregnant.

We moved to a ground floor flat in January 1990 and had our daughter in February 1991. I got used to living in a wheelchair and controlling my incontinence with pills. It was around this time that I changed neurologists. I was given intravenous steroids in December 1990, and physiotherapy after that got me out of the wheelchair and on to crutches.

During 1991 we were trying for another baby, so I told my doctor I was having sexual problems. After weighing up the options he provided, I took injections that I administered myself, though we never had any more children.

I still had regular relapses during the 90s resulting in regular courses of oral steroids. In 1993 I took on three allotments to grow my own fruit and veg, and try to keep my

exercise up. I also did a sponsored walk, on crutches, to raise money for an electric scooter and got £3500.00.

In 1995 I was told I had progressive MS. My only question was how fast was it progressing? I worked three allotments, had a five year old, and had decorated our flat twice. I'd been hoping to stay out of the wheelchair except for longer distances... but my doctor didn't know how fast it would progress. I put my name down for upcoming trials of beta interferon, the so-called best drug for MS, and was turned down as I couldn't walk 10 metres unaided.

In 1996 my wife left me, and I started divorce and custody proceedings. Suspecting my MS would be a disadvantage, I kept my wheelchair out of sight and got joint custody of our daughter.

I learned to drive as a disabled driver and passed my driving test. In March 1998 I met Rona who would later become my wife. I had an appointment with my neurologist and was told I had Secondary Progressive Multiple Sclerosis (SPMS), and that in his opinion, there weren't any new drugs he felt would benefit me. (In the near ten years I had been seeing him, he had never offered me more than Steroids - IV and oral.)

In August 1998 Rona and I holidayed in Scotland and got engaged. But, Rona wouldn't accept her engagement ring unless I asked her at the top of the Wallace Monument - 246 steps straight up, without crutches.

I did it, and we married on 20 March 1999. That same year I was in another court battle over my daughter. I was determined not to use the wheelchair in court, but I was however, beginning to struggle with crutches due to the stress. In the end I had to walk away, giving up joint custody and hoping social services could protect her. MS had taken its toll but not completely in my legs yet. I was still able to get around on crutches.

In June 2000 we moved to a three-bedroom house with stairs, which needed to be decorated and which we did. I also cleared the overgrown garden and dug two ponds. It took a bit longer than an able-bodied person, but as I'd given up the garden allotments, the new garden became my gym.

In 2003 my daughter came back to live with us because her mother was no longer able to control her stealing and had kicked her out. I thought we'd be able to straighten her out. We now had four children in our three bedroom house - 2 boys (1 with ADHD), and 2 girls. As I was having trouble with the stairs Rona and I moved downstairs and I made a folding bed in the living room.

By 2004 I was more reliant on the wheelchair and my occupational therapist wanted me to be moved to more suitable accommodation, but they had ground floor flats in mind.

In 2006 we moved into a three-story house with the bathroom on the first floor. I was now in the wheelchair all the time. We found a team of community nurses and they told me about an external catheter system - for the first time in 19 years, I was 99% free of accidents.

In 2008 the relationship between my daughter and I ended quite badly. Her stealing and lying became too much and I had to throw her out. It caused major stress, which my MS reacted to, and resulted in a major kick downhill... and for the first time, I became depressed.

In 2009 Rona wanted to go back to her singing. She formed a band, chopped and changed musicians a few times, and in August 2009 met a guitarist whose wife had MS. His wife had the same neurologist as me, but she was taking LDN (not prescribed by the neurologist). She'd been in a wheelchair for four years but was now walking two miles unaided thanks to low dose naltrexone (LDN).

Having MS for 21 years, I'd seen some fads come and go, but they sent me some information and the number of the doctor in Wales who prescribed her LDN. I checked LDN out on the internet and after much reading started to think perhaps there was something to this Low Dose Naltrexone (LDN) treatment, so I phoned Dr Bob Lawrence. We had a long conversation and exchanged a few emails. Dr Lawrence explained LDN - how it worked, what I had to do, and how much it would cost.

Now it was up to me to find the money. We lived on quite a tight budget and £15.00 a month was a stretch for us. In September 2009 I asked Dr Lawrence for my first prescription, and on the 25th September 2009, I took my first dose of 1mg LDN - and slept like a baby. I did have quite a vivid dream, but nothing dramatic.

I also started taking zinc, vitamin D3, magnesium and omega 3/6 fish oil, and I was to increase the dose of LDN by 1mg every five days.

By day 7 on 2mg LDN, I was able to stand better and transfer from the wheelchair to the car. My balance improved by day 15 on 3mg, and I was also more alert than I'd been in years. Day 17 was my first disturbed night of sleep, but it was because I could actually feel the quilt on my legs and the temperature, which was cold... It was welcome though, because it was the first time I'd felt anything with my legs for 20 years! I was also able to shave without cutting myself because my dexterity had improved and I could feel my face.

By day 20, still at 3mg, and I walked from the bathroom to the stair-lift ten feet away, relying heavily on my son and the handrail but... I was on my own feet. I haven't been able to go above 3mg of LDN yet as I suffer stiffness if I do, but after 113 days on 3mg I'm able to stand without holding on, and I can pull my own trousers up.

My sight's improved, though I still wear glasses, they seem ultra clean. I can feel what I touch and can touch the tip of my nose with my eyes closed. I can feel my grandchildren's skin, and I'm able to sense heat in my mouth so I haven't been burning my throat accidentally.

Also, in 2005 I started getting warts. At the time, I was told they were juvenile warts usually caused by a poor immune system. No matter what treatment I tried from the chemist or doctor (some of which destroyed skin), nothing touched them. By day 70 on LDN, there was not a wart in sight and my skin was perfect - visible results that LDN works.

I don't know if I will ever walk unaided again, or how much LDN might help me achieve, but I feel MS is loosing its grip on me. I aim to be walking on crutches by the end of 2010.

#### Sterling R, USA 1999 - Hepatitis C November 2009 - LDN

My story is quite simple. My wife's doctor thought something on her leg looked like cancer and suggested that she see an oncologist. Well, I am not into western medicine so I started to look for alternative cancer treatments and came across LDN.

Fortunately the lesion on my wife's leg was not a cancer, but as LDN seemed to be helpful for my own conditions, Hepatitis C and some Arthritis, I decided to try it.

I can't remember the actual date, but I was diagnosed with Hep C in 1998 or 1999. The last time my liver was checked I'd progressed to Stage 3 Fibrosis, but the liver enzymes were still tracking okay, with only a few slightly high.

After being refused a prescription for LDN by 3 doctors, I found a source on line.

Six to seven weeks later, after taking 4.5mg LDN each evening, I noticed the arthritis in my hand was no longer painful, well actually; I had no pain at all and the swelling had reduced by 70%.

I still haven't had any blood tests since starting LDN almost 6 months ago, but I have read of others with Hep C who've had their blood tests done, and they report their viral load dropping, so I maintain hope.

It's now May 2010, six months since I started LDN, and the arthritis in my hand continues to improve. I have no pain in my hand and the swelling is now down by around 80%. I am sooo pleased. It seems a little thing, but if LDN is helping one thing I am assuming it will help the other.

### 170

### Steve W, UK

20th Sept 2001 - Relapsing Remitting Multiple Sclerosis (RRMS) June 2008 - Secondary Progressive Multiple Sclerosis (SPMS) 19th August 2009 - LDN

I have been a member of the Mysterious Symptoms (MS) club for eight years, and have been steadily abseiling into absurdity. 'I have had five, three day courses of IV steroids. I was bumped up from RRMS to SPMS about eighteen months ago, was given 70mg of Mitoxantrone, having signed a comprehensive disclaimer and being informed about the potential dangers. I have used Copaxone for the last 12 months, have altered my diet, tried acupuncture, and have basically had the attitude that everything is in play.

Hence, two weeks ago, via a circuitous route, I began to self-medicate with 3mls of LDN daily. Common wisdom suggests taking this between the hours of 9pm and midnight, which is what I do. I have already noticed an overall improvement in my condition and the neuropathic pain in my feet appears to be abating. I have stopped taking tramadol, diclofenac and am down to 1200mg of gabapentin a day. This is remarkable.

My simplistic view of the money/politics of LDN, is that there are words from upon high that LDN is a placebo. There is no financial gain for the suppliers of prescribed MS medication. It would appear that the NHS does benefit financially because the majority of MS treatments cannot be taken concurrently with LDN. Is it all possible that the 'perceived wisdom' of MS treatment to flatten the immune system is misdirected and the opposite action of LDN could be a source of embarrassment to MS 'professionals'?

Would there be any merit of LDN users supplying details of traditional treatments that they have stopped taking and totting up the financial benefits to the NHS? Would this equate to the losses experienced by the drug companies? What is the relationship between prescribers and manufacturers?

Having been pensioned out of the Fire Service, would a cure see me 40ft up a ladder again? I hope so.

Day one - Wednesday 19th August:

It was a sleepy morning as usual, so I missed the postman when he rang the doorbell. On finding a card telling me of his inability to deliver a package, I couldn't get to the post office collection site quickly enough. Although extremely tired, I drove up there at the speed of light (well, 'light' exaggeration) to collect my early 'Christmas' present.

Being a bull in a china shop, so to speak, I decided to head straight on in and begin at the top dose of 4.5mls. My logic being, I'll start at the top and work down. I am very robust when it comes to taking drugs. The little bottle, rubber stopper and syringe were a bit of a rigmarole to begin with, so we decanted three 4.5ml doses into some specimen pots I had lying around (not used of course). I decided I couldn't wait and gave in at 7pm, taking the first dose which tastes like Benylin, for those of you who are playing 'what does it taste like'.

First morning after:

I slept pretty well. My feet didn't hurt as much as usual and I had boundless energy. Having completed 4 days chores in 6 hours, I reached for the decanter at 7pm. The effects were less marked the following day, and I did not sleep as well as the previous night.

I kept to this routine for five days and nothing 'orrible 'appened, but my usual symptoms were returning and I was not sleeping well. 'Herself' informs me that my mood and general demeanour were improved. I was finishing suduko puzzles and for the first time in years, I finished the big crossword in the Daily Facist. A little more joint research suggested 3ml between 9pm and 2am, so drinkies took place a little later, around 9pm.

This new regime changed some well practiced night time symptoms, such as 'burning feet' and leg stiffness. I have started sleeping better. I tend to get 7 hours and even by

my standards, the dreams are weird. I have always dreamed in colour, so for somebody who normally dreams in black and white, it might come as a bit of a surprise.

Overall, during the last fortnight, I have experienced general improvements in mental abilities, neuropathic pain, mood and energy levels. As yet, there is no marked increase in my mobility. I have started coming out of a relapse, which I think may have been caused by Pig Pox (swine flu).

As we know with MS, it is difficult to know and understand why and how things are happening, but I do believe that I am coming out of this relapse as a result of taking the LDN.

# 171

### Steven F, UK 2007 - Primary Progressive Multiple Sclerosis (PPMS) November 2007 - LDN

My story started 10 years ago when I was walking along and suddenly, my right leg stopped moving.

I went through several 'specialists' who thought I had blocked arteries, rheumatoid arthritis, then trapped nerves (for which I had an operation on the spine), and several other complaints which I cannot even remember the names of now.

Finally, in early 2007, I was diagnosed with Primary Progressive Multiple Sclerosis - after 5 years of various tests and misdiagnosis. I have a particularly painful version of MS, and the pain control has been the most difficult to deal with over the years.

Having spent 25 years soldiering and being very fit, it was deeply distressing, and depressing, to find myself getting weaker and unable to even do basic stuff in the garden. The MS seemed to be progressing at a faster and faster rate. The prognosis for all PPMS is not good, and all the neurologists agree on is that there is little they can give to help or relieve, other than standard pain killers and muscle relaxants.

In June 2007 I was given a heavy dose of steroids for 5 days which did not have the expected effect, so I was given a further 5 days worth. The end result was that I could barely walk and dragged both feet. I could not climb the stairs, and to cap it all I spiralled into depression.

I had reached a particularly low point where the disease seemed to be progressing rapidly and I was using the wheelchair more and more. I had one at work and another for home, just waiting for me to climb into it.

I'd been reading up on LDN for some time, but had been unsure of this unproven treatment. I decided to try it after reading of several other users whom it had helped, figuring I had nothing to lose.

I went to my GP, and he requested guidance from the neurologist, who unequivocally stated that "under no circumstances should I use it." It was this statement more than anything else that made me decide to at least give it a try.

I investigated all the normal methods of obtaining this drug, which incidentally is widely used in other areas of medicine, but no GP would prescribe it for me, and the neurologist treated my request with contempt. I eventually managed to get it on a private prescription via a Harley Street doctor and sent for it via a pharmacy in London.

I started using LDN in Nov 2007, and the affects were almost instant. I was able to walk again, albeit only short distances, and my fatigue almost disappeared. I could climb the stairs, something had been impossible only a few short weeks earlier.

I noticed within two weeks that I was walking better and did not drag my feet as badly as before, but I was still scared to believe the LDN was really working and refused to go to the doctor until I was really sure. But by the end of the first month I was walking with only a normal walking stick. I was less fatigued at work, and was sleeping better at night.

By the end of my second month I felt that everything had stabilised. Although I knew I would never fully improve, I at least felt confident that LDN did work, and that was a relief. I also had more confidence, especially at work. I moved both wheelchairs to a dusty place in the garage, and that's where they'll stay. I remember thinking, 'whether the LDN will stop or slow the progression of my MS, only time will tell', but I did begin to feel confident that it would.

LDN allowed me to continue working, and it was these changes that eventually led to my own GP, having agreed he'd seen a massive improvement, prescribing the drug for me on the NHS, which saved a huge amount of money.

I have continued to use LDN except for a short period due to having to take morphine to control the pain.

My GP has since retired and I am back to trying to obtain LDN via the internet.

I do not proclaim LDN to be any sort of cure but there are too many incidents of massive improvements for those who have tried it for there not to be something that needs to be looked into properly.

Considering the total lack of any formal medication for Primary Progressive sufferers, and no trials or tests in the pipeline, it is offensive to me that the medical profession will rarely consider prescribing it.

Huge amounts of funding are going into research for Relapsing Remitting, but absolutely nothing for PPMS, so even if it only gives minor help, LDN should be made freely accessible to all.

I'm now just over 60 years old and I continue to work full time.

#### Steven N, UK July 2006 - Multiple Sclerosis April 2007 - LDN

My 20-month experience with LDN

I have now been on 3mg capsules of LDN for 20 months

I haven't had a relapse or exacerbation in that time and other than existing symptoms returning, especially when I am tired or overdoing it, I feel fine.

Until the medical profession can come up with something better and/or prove than LDN doesn't work I'm sticking with it.

I was diagnosed with Relapsing Remitting Multiple Sclerosis in the summer of 2006. I woke up one morning and found the side of my nose was numb. By the end of the day one side of my whole face was numb. By the time I had an appointment with the local hospital I was losing the feeling in my legs.

An MRI and painful lumbar puncture test (which gave me such severe headaches that I had to lie flat for a week) confirmed multiple sclerosis.

Looking back, I had signs of MS since about 2002 - if I drove long distances I had terrible stiffness in my legs, and numbness in my left hand was put down to a trapped nerve by a consultant.

Before LDN, I had 10 months with no medication and was having a major attack every three months. Then I had an attack of optic neuritis in April 2007 and the vision in my left eye was permanently damaged. The image is now slightly fuzzy and colours are shifted towards the blue end of the spectrum.

As a lot of my work involves photography (I work as a business journalist and photographer), I had to learn to use my other eye.

Enough was enough!

I went on the prescribed drug Avonex for six weeks in September 2007 and have never felt so rough in all my life. I got to the stage where I dreaded Monday nights - Avonex night!

I used to take four paracetamol before my wife gave me the painful deep-muscle injection into my thigh (she's a GP) and would sweat and shiver myself to sleep. One night I took four Mucron by mistake and almost shook the bed to bits. My wife went downstairs and slept on the floor. I eventually got to sleep about 2am.

Avonex would make me feel ill for two days after the increasingly painful injections. After six weeks I said enough was enough and stopped them.

I felt a complete failure - I had stopped the only drug that the Government would let me have.

I had heard about LDN before I started Avonex, so I renewed my research into what it was and how it worked.

My consultant was neutral on the subject (as I expect him to be). He said there had been no clinical trials and therefore he was reluctant to recommend it. He added he had other patients on it, but didn't really want to commit to saying whether it worked or not.

I eventually started LDN in November 2007 as I felt I had nothing to lose. My GP was great about it and my wife (also a GP) was happy to try it once we researched it thoroughly.

I have to have yearly blood tests to make sure that my liver function is still OK, but there have been no problems.

I finally settled on getting my capsules via mail order from Dickson's in Glasgow after previously having to order them over the counter in my local chemist. This became a real pain each month.

Anyway, what has my experience been like?

• Am I getting worse? Not much I think. The progression now is very, very slow, if at all.

• Does it repair existing damage - nope! I still have a wonky eye and have lost some feeling in legs and feet. My legs are very stiff and I have to be careful walking down stairs. But, and it is a big but - it doesn't stop me from leading a full and normal life and I have never lost a day's work as a result of MS. Only through the lumbar puncture to diagnose it!

• Have I had any new numbness, clumsiness, optic neuritis or bladder problems since starting LDN? Not at all!

While the medical profession may be sceptical about the use of Low Dose Naltrexone (LDN) for Relapsing-Remitting MS, there is strong anecdotal evidence that it works. It also appears to have minimal to zero side effects and is very, very cost effective.

I think the biggest disappointment is that many people don't know about it and there is very little support for structured drug trials - the pharmaceutical industry wouldn't make any money out of it.

Because of this LDN remains a potential treatment for a terrible progressive illness that would only cost the Government a few pounds a month. As it is, the government still recommends the CRAB drugs (Copaxone, Rebif, Avonex and Betaferon) with their terrible side effects and high cost.

It is a scandal!

Until something betters comes along I will stick with LDN.

### Sue G, UK

#### January 2005 – Primary Progressive Multiple Sclerosis November 2009 – LDN

In December 2004 I retired from my job as Lab technician at a senior school. I was around 60 years old, and I was feeling very tired and seemed not to have much energy for anything. I had felt like this for a few years but had put it down to getting older. I had always been serious about exercise, and walked my dogs twice a day rain or shine, for at least 4 miles at a time.

In January 2005 on one of my usual walks, I had a problem: My right leg gave way and I seemed to have no control over it. I had to lean on my friends arm to get home. The people I was with thought I'd had a stroke. I went to my GP who sent me to Guildford Royal Surrey Hospital's Neurology Dept where they did an MRI scan. At a follow up soon after they told me I had PPMS, with plaques at the base of my brain.

I also had a Lumber puncture, the result of which was normal.

I really had no energy at the time, and I got very tired with the slightest effort. I had been prescribed a tablet called Tegratol to prevent me from having the sensation of pins and needles and I was taking 200mg each night. Unfortunately it was waking me up at night and not helping the tiredness during the daytime.

Then last September 2009 one of my friends gave me an article about Linda Elsegood and LDN that was featured in the Daily Express. I looked up LDN on the internet to learn what I could, and I've been taking it as directed by E-med since the middle of November 2009.

Since starting on LDN, I've been to Australia for a month and have joined a gym (because I had a fitness assessment and was told I'd lost a considerable amount of muscle on my right side). I was told to 'use it or lose it', so I am now doing three sessions per week.

I've also been doing aqua-aerobics because exercising in water is easier, and it does help.

Altogether I feel that, although I can't do as much as I did before MS, LDN has given me a new lease on life because I feel almost like my old self. I do have to sit down and rest from time to time, but not as much. I can't walk for more than ten minutes outside because my leg becomes wobbly, but apart from that everything is pretty good.

#### Sue G, UK 1991 – Relapsing Remitting Multiple Sclerosis (RRMS) 1999 - LDN

I thought I was fit and healthy until April 1991 when my legs went numb to the top of my thighs whilst on a week's break abroad. I was currently holding down a very stressful job as a Staff Manager in a large firm of Accountants. Luckily private health insurance came with the job and after a number of tests in Harley Street (including an MRI scan and a lumbar puncture) I was quickly diagnosed with MS.

Once back at work I was able to continue on a full-time basis for a further 7 years. During that time although I only had 1 more episode of numbness I did slow down considerably and found latterly that I needed to use a walking stick as my balance was so bad. I only worked on a part-time basis for a further year then retired on ill-health grounds in 1999.

It was only after I'd retired that I even thought about taking something to help and I saw an article in New Pathways magazine all about LDN. At that time I wasn't eligible for any of the approved drugs because I didn't have relapsing-remitting MS. However, I did find that the LDN helped to keep me stable enough to join a local gym and go swimming regularly. I used to drive which I found very liberating.

In February 2007 my husband Steve and I decided to move from our 3 up 2 down house in North London to a bungalow near the coast as I could no longer get up the stairs. After just 6 months in our new location I had to give up driving.

I decided to try another remedy which was not only very expensive... I was also told I had to stop taking the LDN. I carried out instructions as recommended for 3 months but not only could I see no tangible improvement but I was definitely going downhill rapidly.

I started the LDN again as soon as I could and immediately felt better and stronger. It seemed that I could never regain what I had lost but at least I felt more positive again - until, that is, somebody stopped the import of LDN from the USA. I had to switch from taking capsules to a liquid suspension which took away my independence as it took two of us to measure it correctly. We encountered some problems with delivery of the suspension which meant me going without the LDN for a short while. It did affect me again, I felt sluggish and my hands wouldn't grip anything.

Thanks to Dr Lawrence I am now back on track. The LDN definitely makes a difference and this has been proven to me several times over the years.

I hope this is of use to you.....

Sue

### Sue T, USA December 2004 - Multiple Sclerosis Nov 2005 - LDN

I used to live a very active life - walking, youth hostelling and camping holidays with my husband and 4 children. One holiday I fell over - for no apparent reason. Then I had real trouble climbing over rocks. On other occasions I just fell over. The GP said it was a trapped nerve. I had tingling in my hand, and my GP said it was from too much time on my laptop, not an injury, etc.

In 2004 I began to fall over more so my husband accompanied me to the GP. I was then referred to a neurologist. He diagnosed MS, and said I needed to have an urgent scan and a lumbar puncture to confirm. My parents paid for a private scan, so my diagnosis could be confirmed quickly. He said it was mild, and that he knew loads of people with MS who played golf. (No money/time for golf!!)

Before starting on LDN in November 2005, my mobility had deteriorated dramatically. I had to hold my husband's arm for support when I walked and the distance I was able to walk became less and less. I was also walking around less and less at work. Initially after taking LDN, my mobility improved dramatically.

I had an appointment with my neuro. She hadn't seen me for about 18 months and appeared surprised that I was really struggling to walk. She referred me to Addenbrooks and said they may give me medications.

That's why I stopped taking LDN for about 6 months in 2007. As soon as I found out they wouldn't give me any treatment, I started LDN again. During that time my bladder problems returned, I was very fatigued, and my mobility deteriorated further.

Since restarting LDN, bladder problems and fatigue have reduced, but my mobility is still bad. I can't walk without sticks, and then only a few steps. I use a wheelchair at work. At home I walk using sticks or walls. If I need to go from room to room or hang out washing, etc I use my scooter.

I still take LDN. I get it prescribed online and dispensed from Dickson's.

I still work full-time as a head teacher, but my mobility continues to deteriorate, and I now use a wheelchair.

I think LDN helps alleviate my fatigue.

My Neurologist is anti-LDN and I daren't tell her I'm on it!

I would like to see it available on the NHS. I think I would have benefited from better guidance on dosage, etc.

### Suzanne H, UK July 2009 - Relapsing Remitting Multiple Sclerosis (RRMS) 18th February 2010 - LDN

My name is Suzanne and I'm in my late thirties.

I live a happy married life, have a beautiful 11yr old son and own my own business.

I was officially diagnosed in July 2009 with RRMS. Before I was diagnosed with MS, I can truly say life was pretty good!

Then I lost most of the feeling in my lower body, was in a lot of pain, and was admitted to hospital. Within 2 days I had tests and an MRI that revealed the awful truth of MS. To say I was in shock is an understatement.

Within only a few days I had my life ripped out from underneath me.

The world of MS was alien to me. At first I started doing some homework and thought I could handle the knowledge that was being put in front of me. However, where I would normally gather info and weapons to fight something, this time it was different. Looking back, I think I went into denial. I tried to ignore things in the hope that I would not get worse.

I recovered from the relapse by about 80%, and returned to running my business from home. I had to reduce my work hours from an average of 10-12 hours per day, to 6hours on a good day and 0-4 on bad days because of the unrelenting fatigue.

Once in this place, mentally, I could deal with the reality of MS, but I turned my back on the genuine support of the MS Centre (lovely people) and the MS Nurses who can be lovely but who I felt were trying to push me towards injections, which is not where I wanted to go.

I tried half-heartedly to take Vit D's, Vit B's and fish oils, but I was not really doing enough. I will soon be looking into what should be the optimum dose to help my body and will be starting on them soon enough.

With the latest relapse in February 2010 I felt I had hit rock bottom, so I started to seek out information about the pros and cons of interferon injections. When I opened my eyes and researched this issue online, one of the things that came up was the subject of LDN on the MSRC site. I was truly shocked by what I saw. The potential of this drug, its positives, with no or little side effects was amazing.

Weighing this up against the interferons was a no-brainer!! I researched thoroughly and then I went to see my GP. I took with me specific points raised by Dr Chris Steele (who's lobbying for LDN), and other research about small trials that had been done on LDN for

MS with positive results. It took him 2 days to come back to me and agree to privately prescribe LDN.

When the LDN arrived I was 2 days post-steroids. I started taking LDN on Thursday 18th February 2010. My health at the time was very bad. I had major spasticity in my arms and legs, my left eye was 50% blurred, and my speech slightly impaired. But, the most debilitating symptom was the fatigue. It was truly awful, and all I could manage to do was get up, get to the bathroom, then go back to bed and rest/sleep! I thought that was it and was considering closing my business, selling my car, and moving to a bungalow for wheelchair access. I believed at that time MY LIFE WAS OVER! DESPAIR!

Two days after starting only on the lowest dose, 1.5mg of LDN, I was back on my feet. Yes, I was still dealing with the symptoms, but they started reducing rapidly. A further two days and I was able to return to work. I was and still am truly in awe of what LDN has done, especially because it seems to do the complete opposite of the drugs offered by the NHS!

I had a little exacerbation of some symptoms when increasing my dose, but they went away pretty quickly.

Every day is a better day, and each day I get stronger and stronger, I am truly looking forward to the day when I wake up and don't immediately think about the MS. This will happen, but I need to be patient and give my body time to heal, with the immense help of LDN!

I just wish that this incredible drug had been approved when its benefits were first realised back in the mid 80's. I carry the immense sadness of losing my mum to cancer 4 yrs ago. This may not have happened had she had access to LDN.

We MUST raise awareness and get LDN out there for all those people with the wide range of conditions that it may help.

### 177

# Tamar C, UKFebruary 2006 - Relapsing Remitting Multiple Sclerosis (RRMS)March 2009 - LDN

I have been taking LDN since last March 2009, so pretty much one year exactly.

I have RRMS although I only ever had one relapse, which is what led to my diagnosis.

I started the LDN because I had a few niggling little symptoms that were getting a bit much all together. I am now almost normal!

I was in the local paper about LDN a few months ago.

LDN has allowed me to live a normal life, work full time, study for another degree and go on surfing holidays. LDN has been a life-saver and has given me my life back.

### 178

### Tami M, Canada 1995 - Relapsing Remitting Multiple Sclerosis (RRMS) April 2009 - LDN

I am over 50 years old, and I was diagnosed with RRMS in 1995.

I've used Avonex, Rebif and Methotrexate over the years, with some success using Rebif.

Last year, we lost our son to cancer. He was only in his mid 20s. During that period, MS symptoms (all of them) assaulted me, and I spent a year away from work trying to wait it out.

I was sent an article about LDN, and after researching it and asking a lot of questions, I proposed it to my doctor.

He agreed to prescribe it for one month and recommended a pharmacy that could compound it.

I have only been on LDN for 3 months at 3mg strength. At the two-month mark, I was able to walk unassisted for an entire day, which I have not been able to do for some time. Other improvements are also apparent but the mobility issue was the most apparent.

My husband and daughter-in-law noticed a vast improvement. I was so impressed that I was anxious to increase the strength to the 4.5mg maximum, but I suffered severe headaches for days and was told when I asked that I increased the dose too quickly. I am now back to 3 mg until things settle down and I look forward to further improvements as time goes by.

### 179

Tammy, USA October 2008 - MS 30 March 2009 - LDN

I was a very active person. I worked in construction for many years, and if any of you have done that, know it's a physically demanding job. I loved it though, and I also did

woodwork projects at home. I had 4 children. The last 2 were twin boys, plus taking care of our house, yard and garden. I was 116 pounds and could bench press 180 pounds. I could out-work and out-lift most 20-year-old guys, and I was proud of this.

I also worked in building maintenance for 6 years. I would've kept going with it too, except things happen that are out of a persons control. I put a halt to a lot of things in my life after I tripped and went headfirst into the side of a Bobcat Utility Vehicle at work.

This accident turned out to be a lot more than I had ever expected. Thinking I'd suffered a neck injury, I started with a chiropractor. But just a couple of weeks after I started seeing him I started having problems driving, then noticed other odd things, like numbness or tingling in my hands, and upper body weakness.

I continued working for a month being careful about what I did because I also injured my left shoulder. Then after about a month I was hanging sheetrock on the ceiling and my left shoulder gave out. The doctors took me out of work at that time.

After x-rays, I was sent to Physical Therapy. After 1<sup>1</sup>/<sub>2</sub> months, there was no improvement, and in fact, I had several new symptoms... seizure-like full-body muscle spasms, pain shooting down my spine, function problems in my fingers, extreme full body weakness (couldn't walk or move my arms), and many other symptoms.

My doctor had no idea what to do with me, and by now, I'd grown scared. I saw 2 different Neurologists, a Neuro-psych doctor, physical therapists, orthopaedic doctors, and a general practitioner doctor over a period of 9 months. All they could come up with was, "It's stress manifesting itself". When they told me that I cried for hours. I knew it was more than that. I felt like they didn't believe me. I would try to do things and my body would freak out on me, but unfortunately, it only happened a couple of times while at a doctors office, which was probably why they didn't believe me. They didn't see it.

I started seeing a wellness chiropractor at that point. He believed what I told him about my symptoms and thought he could help. He actually got me back to work part-time, within 3 months. I had to watch the types of things I did, and how long I did them for, but all in all, I thought I was doing pretty well. I was back working 3 hours per day, when I was again injured... this time by an auto accident on the interstate.

Long story short, we were thrown into an embankment by a semi-trailer truck travelling at approximately 70mph. This forced me back out of work, and the really bad symptoms started again. After seeing more doctors and specialists and having more tests done, I was diagnosed with MS in October 2008.

Finally, something to explain what was happening to me! After careful consideration of the options I was given I was put on Copaxone injections. My Neurologist never gave me any other alternative, other than the injections. I had to find out about LDN from my mother-in-law, then ask my doctor about it. They knew it existed, and had many patients on it. I don't know why they didn't tell me about it! Anyway, I started on 4.5mg LDN on March 30th, 2009.

I started noticing changes for the better within the first 2 weeks of being on it. Just before I started LDN, I was having problems walking 3-4 days per week, and was having every day ups and downs in weakness and other symptoms. I had episodes of speech problems and thinking problems. Sometimes I could think things, but it was

delayed getting to my mouth. I had function problems, balance problems, anxiety, seizure-like muscle spasms, shooting pain in several areas, etc.

After one month of being on LDN, the majority of these symptoms were down to only once a month. After two months I was starting to build up muscle again. I was still limited, but now I was working towards a goal. It took me 6 months, but I was able to do most things for myself again, all but heavy lifting stuff. I rarely had problems with my walking, and all my symptoms were down to a minimal, to the point where I could hardly tell they were there anymore.

I've had another setback since though. I had another car accident and had to go without my LDN for 2 months. Most of my original symptoms reappeared. Thankfully, I'm back on LDN again now, and have seen many improvements since. I'm still a little scared about my future, but I have hope in sight, with LDN.

Thank-you to whoever came up with it, as it has given me a chance to live a normal life.

# 180

#### Tanja H, USA March 1987 – Multiple Sclerosis October 2006 - LDN

I was diagnosed with multiple sclerosis (MS) in March 1987. I first visited the doctor with numbness and tingling in my lower extremities in December 1986. I was hospitalised December 19-23, 1986 as the initial 'full body' MRI (magnetic resonance imaging) led neurologists to believe I had a tumor on my spine. Even though the surgeon went as far as to mark my back for surgery, additional tests showed I had a small calcified area in my spinal region rather than a tumor. "Yeh," I thought. I was released from the hospital and placed under the care of the first of several neurologists who in time diagnosed me as having relapsing-remitting MS, i.e. by March 1987.

MS symptoms were minimal for the first 7 years. No meds, sometimes forgetting I even had MS. I relocated my home from Northern Virginia to Baltimore, MD in 1991. I still worked for the Department of Veterans Affairs (VA), but I now worked out of the Eastern Area Office located in Baltimore, MD rather than at VA headquarters that is located in Washington, DC. During 1995, my newly assigned job as project manager to a major work effort required me to travel frequently from Baltimore, Maryland to Chicago, Illinois.

Still seeing my then neurologist annually, I arrived in January 1996 at his office for my yearly appointment. He always watched me as I walked from the waiting room to his office. First question out of his mouth was, "Why are you dragging your left leg?" My response? "I'm not." Talk about denial. Zap... one Betaseron prescription coming up as well as one round of intravenous (IV) steroids! By that time, I had remarried and my husband gave me shots of Betaseron every other day. I also self-injected from time to time.

Long story short: From January 1996 - October 2006 MS symptoms progressively

increased. Let's see, blurry vision, lethargy, numbness, tingling, burning, spasticity, poor balance, etc. Meds also increased. Steroids (both IV and pill form), Betaseron injections, Depakote, Beta Interferon (Avonex injections), Tegretol, Di-tropan, Macrodantin, Paxil, prescribed support hose.

Oh yeah---one Canadian crutch to two Canadian crutches, to a walker, to a manual wheelchair, to a power wheelchair. My left arm and left leg no longer move much (is that also known as paralysis? The thought frightens me!) and, I took 'early-out' retirement at the end of December 1997. In 2000, my neurologist classified me as having secondary-progressive MS. By 2004, I learned how to type with one hand as the left hand was no longer cooperating. I've gotten pretty good at it although it was quite challenging at first.

My husband retired August 2002 and we moved into our newly built, handicap accessible retirement home September 3, 2002. I found a local neurologist; and, in 2004 I joined a couple of MS 'boards' on the Internet. It was while visiting and chatting with my MS cyber friends that I first heard mention of LDN (low dose naltrexone). Sounded like some pretty good 'stuff!

I looked LDN up on the Internet and was led to several LDN web sites including one in the United Kingdom. My research showed lots of plusses---only negative I noted was that LDN was not FDA-approved (Food and Drug Administration) at the 4.5 mg dosage---only at the 50 mg dosage.

After 18 months of research, I talked to my husband and indicated I wanted to stop ALL meds and only take LDN. We discussed this desire with my family doctor who asked me to discuss it with my neurologist. That we did and he was not willing to prescribe LDN off-label for me in light of the fact that there were no clinical trials showing the drug to be effective in the treatment of MS.

So, I went to the phone book and called several local docs to see if any would prescribe LDN. Receiving all negatives, I set up a phone consult with Dr. Bihari in New York. Preferring to remain under 'doctor's care' while taking LDN, I cancelled the New York appointment and made an appointment with a doctor at the University of Pennsylvania (I think it was).

I then started calling pharmacies and asked if they knew of any local doctors prescribing LDN. The very first one I called said yes and they were willing to give me the name and number of the wellness center in town that was participating in a study using LDN for autistic children. I finally made contact with that office, went in for a consult late October 2006 and began taking LDN that month. I have been taking it ever since!

I stopped my injections and in time had the courage to stop several other meds. At this time I only take 4.5mg of LDN, Paxil, and Di-tropan! Hallelujah! The progression of deterioration in my central nervous system STOPPED! I have had no new symptoms since October 2006 and none of my existing symptoms have gotten worse!

My most recent MRI of the brain shows no new lesions and the only one noted is on the 'Pons' of my brain stem. Am I pleased? Yes! Am I convinced that LDN is effective in controlling the progression of 'my' MS? Yes! I still see my current neurologist annually. He is not thrilled with the lack of FDA approval of LDN, but he has not stopped seeing me. Some studies have now occurred, but I really don't know where LDN is as far as the approval process is concerned. Truly, it really does not matter to me. I will continue

taking LDN even if the FDA never approves it! My long-term goal is to walk again---with or without crutches!

# 181

**Terri H, USA** 2007 – Autism June 2008 – LDN

My son Matthew was almost 4 years old when he was diagnosed with Autism in 2007.

We started seeing a DAN (Defeat Autism Now!) specialist in June of 2008, which would put him on the path to healing. As apart of the intensive testing and therapeutic methods we would use to recover our son from Autism, LDN was used to help modulate his immune system.

Like many children with Autism, my son's immune system was not targeting the pathogens like yeast (candida) and bacteria (clostridia) that had taken over his little body, producing toxin by-products that would impair his neurological functioning and compromise his health. Instead, his immune system was fighting his own body, even reacting to the food he was eating. He also had widespread inflammation and oxidative stress, all contributing to the behaviors we associated with Autism.

In addition, my son's immune system did not function in a way that was expected. He had chicken pox at 6 months AND 3 years of age, neither time running a fever. In fact it was a VERY rare occasion for my son to even run a fever and when he did we would notice improvements in eye contact, cognition and focus.

My son's Defeat Autism Now (DAN!) doctor told us to do research on LDN to make sure we felt educated and comfortable with this treatment, so I read Dr. Jacqueline McCandless' book 'Children with Starving Brains', where she describes LDN and its function for children with Autism. I also did research on the internet.

We decided that we wanted to try this therapy and began applying 3mg cream (naltrexone & Emu Oil preparation) nightly. We used LDN cream in conjunction with many supplements and some prescription medications my son needs to address medical issues.

Once we began LDN we noticed very big gains socially. My son had been in a public pre-school program for children with special needs. He has recently been released from the Autism specific program in favor of more inclusion in the integrated classroom. But still, socially, he was very behind compared to his peers.

After we started LDN, he began requesting 'play dates' with other children and began becoming attached to peers at school. This was the first time a 'friendship' had developed between him and any another child.

And in addition, although we have not repeated many of the same immune panels that we first ran, I can tell his immune system functioning is better. When he's sick, he's

sicker for shorter periods than his peers, and his body is now able to better and more actively fight pathogens such as yeast. In fact, although this is not proven, I have a strong suspicion that LDN helped him get a handle on yeast as we had done many, many yeast treatments prior to starting LDN without much success, and have been able to get it under control since starting LDN.

My son is now fully mainstreamed in the first A+ rated charter school in our state. (The school is highly academically focused and not a special needs school). He is functioning without an aid in the class and the teacher does not even have to leave a note to any substitutes about his sensory issues, behavior, etc, (issues that are normally associated with Autism), and none of the parent volunteers can tell he has Autism! This fall/winter at school, all but 6 children fell ill with flu symptoms, and my son was just 1 of the 6 that were not sick.

Many of the group of 6 had just gotten over illnesses prior to the latest round of illness. There had also been multiple rounds of strep that made its way through his classroom and my son did not get that either. I think LDN has not only modulated his immune functioning but also benefited his social skills.

After watching the changes in my child and seeing his health flourish, I think almost everyone should be on LDN! I think it is safe and beneficial, and I'm so grateful for what it has done for my son and as a consequence, our whole family and quality of life.

His recovery has been long and arduous, but so very worth it - and LDN has been a key component of his recovery.

# 182

### Tim D, USA September 2007 – Fibromyalgia July 2008 – LDN

I became ill in July of 2007 with what seemed to be an intractable flu. I suffered a recurrent fever, massive fatigue, overwhelming insomnia, and constant severe body ache. I was treated for suspected Lyme with twelve weeks of antibiotics, and tested for everything from AIDS to Hepatitis C.

I came back positive with many 'past infection titers', like HHV6 Epstein Barr, Toxoplasmosis, Parvo B19, but nothing to explain my illness. Over the next two years I would come to see five infectious disease specialists, two neurologists, three GPs, two rheumatologists, two immunologists, one Lyme specialist, one pulmonologist, one endocrinologist, and one Ear, Nose & Throat (ENT) specialist... I was the elephant in the hands of the many blind men! One said, "It is all in your head". Most said it was Fibromyalgia. Others admitted they 'didn't know'.

Only a few would admit to the possibility that a Hepatitis B vaccine given just prior to onset of symptoms could have caused distress to my immune system. All the trouble started a month after the final Hep B vaccine booster, with many strange symptoms developing in the weeks after the injection.

I missed three months of work during the onset of this illness, and was in and out of work over the next two years depending on my pain and fatigue levels. I researched endlessly on the internet and often, would take my ideas to the doctors.

It's ironic... they had little to offer in the way of treatment and yet were surprised that I'd suggest new drugs to try. One of the immunologists did offer to give me Adenosine Monophosphate injections twice weekly, which I did for six months, and it did help somewhat. That was the first doctor I approached about LDN treatment. He refused to prescribe it saying, "You aren't that sick" and that it was "dangerous". How he could reconcile a person taking Tramadol every day for pain and living half a life was 'not that sick' is still a puzzle.

Since I found no doctor willing to script LDN, I purchased it online from a Canadian pharmacy. I then set about preparing an experimental trial by home compounding the LDN myself from 50mg naltrexone tablets (the readily available form).

Home compounding isn't difficult. LDN solution is usually mixed as 50ml distilled water containing one 50mg tablet, therefore, one ml (millilitre) of solution equals one mg (milligram) of naltrexone.

I bought a pill cutter, a mortar and pestle, a graduated cylinder to measure the distilled water, a resealable airtight medicine bottle, and most important - a medicine dropper of excellent calibration. I found a medicine dropper that was calibrated to one mI when full, so it was easy for me to draw an accurate dose every time. I found the best medicine droppers to be the plunger types that look like hypodermic needles, without the needle.

My local pharmacist kindly provided me two medicine bottles free of charge, and each holds 25ml comfortably. I make two x 25ml batches. I cut the 50mg pill and grind a 25mg half in the mortar, then pour in 25ml of distilled water from the graduated cylinder. I mix it well and pour it into a medicine bottle kept in the refrigerator. Mixed LDN solution must be kept in a refrigerator! It keeps it stable and extends its useful life to at least a month. The dry tablets from the pharmacy will store far longer even at room temp.

I had to wean myself off Tramadol in preparation for the LDN! No small matter considering my degree of chronic pain.

After two weeks of no Tramadol, I began taking 1ml LDN at bedtime along with my other meds (AmbienCR and 5 HTP for sleep) and Mirapex, which did somewhat help with pain levels. The first obvious effect was more disturbed sleep (dreams, and waking up) and a metallic taste in my mouth the next morning.

During the first week on 1ml, I began noticing less pain and fatigue. After one month I increased the dosage to 1.5ml. Now, I am working overtime at my job for the first time in over two years. The pain and fatigue are not gone, but are reduced to levels where they no longer dominate my every waking moment!

My blood-work shows nothing unusual as yet, three months into taking LDN.

My GP will still not script LDN as, like other doctors I have seen, he knows nothing about it and fears being called on the carpet by the insurance company - but he is able to order my blood work based on my being diabetic.

So, based on the results so far I plan to continue use under his monitoring. I have not decided to experiment with higher doses (2mg to 4mg), as I have been so pleased with the results at 1.5mg, but I may do so later in hopes of even greater symptom relief.

## 183

### Tim W, UK 2007 – Multiple Sclerosis 10 July 2007 - LDN

This is my personal experience with MS and how LDN has helped me.

My life change started with my balance, which my GP told me was vertigo. It was slowly getting worse. It made me feel sick and made my eyes unsteady when walking, so I asked to see an ENT doctor.

When I got a reply I was told it would be an eight-month wait on the national health, so I decided I would pay to see one because I was really struggling at that point. When I paid and saw him two weeks later, he spotted that my eyes were not steady or tracking very well. He also told me I should see a neurologist, which would be quicker if I paid again.

When I saw the neurologist I had already had a few problems with my bladder and my walking so he checked me over and spotted a few other things wrong with me. He then booked me for an MRI scan and said he would see me on the NHS from that point on.

Two weeks later I had my MRI scan: Another 3 weeks later I was told that I had MS and that I would be admitted in a few weeks to have some treatment. When I told my mother she immediately started looking on the net for info and medication that could help, and she found Dr Bob Lawrence.

When I first spoke to him I liked the sound of not having any side effects with the LDN, unlike the NHS stuff, and it wouldn't harm my immune system. It is intended to try and get the balance restored to what it should be, plus it is only one tablet before I go to bed. I told my doctor that I would be trying LDN, so he cancelled the NHS treatment and was in agreement with the decision I had made.

I'm nearing 30 now and have had MS for nearly 3 years.

The advantages I have found with the LDN are;

- (a) my balance has improved;
- (b) I don't feel sick anymore;
- (c) my eyes are steadier;
- (d) I don't trip on the floor as often now;
- (e) my bladder isn't retaining much now, and;
- (f) I feel more alert and pretty good.

The fatigue is still there and I did need to stop working as an electrical contractor as this was too physical for me, but the job centre has got me started on a computer course so that I can return to work with new skills. I'm trying to avoid eating food with gluten, dairy, or red meat in them; although it's a little hard because those foods are tasty.

The things I have found helpful are aloe Vera juice, which makes passing water easier. I haven't had any water infections since I started drinking fruit and barley water every day.

I also take vitamins every day, including vitamin D, calcium/magnesium, antioxidants, copper and zinc for energy, EPA fish oils, and B50 complex to give my body the building blocks to repair the damage.

I'm optimistic about my future now and I'm going to the gym on the doctor's recommendation, to keep my strength up. I'm really happy with the way the LDN is going for me as it's so cheap and easy. I'm also hoping things keep improving. Even if it is slow, I know I'm not getting worse.

### 184

### Tina D, USA January 29, 2008 - MS August 2009 - LDN

I have MS, and before LDN I was going downhill quickly, relapsing every couple of months.

I lost my vision and didn't have a very good quality of life because 75% of the time I was in bed due to MS fatigue and pain.

I now go to bed and sleep through the night, which is something I haven't done in 15 years. This medication has given me back my life. My vision has improved, and I was able to continue my job as an Administrative Assistant.

I was filling out my disability retirement papers when I decided to give myself one more chance by researching and finding LDN. What a chance that was!! I am an advocate of LDN and although my Neurologist wouldn't even think of giving it to me, I had to think outside of the box and I found a doctor in my hometown that would give it to me. She is now one of the most special people in my life!! She did what those neurologists and other doctors wouldn't do, she took a chance on me and I'm so very thankful!

My marriage suffered while I was going from doctor to doctor trying to figure out what was wrong with me, and I went through a very painful divorce which was finalized early in 2008.

Then I was diagnosed with MS on January 29, 2008. From that point on, things went downhill drastically and I was losing hope very quickly. I even talked with my kids about

funeral arrangements. After losing vision in one eye in April 2008, not getting it back completely, then losing vision in my other eye, I started researching.

I was given the name of man in my hometown who has had MS since 1979. John B told me about LDN. He's in a wheelchair but he hasn't relapsed since 2000 when he began taking LDN. He felt he wouldn't be in a wheelchair today if he had taken LDN prior to the relapses that put him in the chair, and he is a huge advocate for LDN!!

I owe him my life!!! I began LDN at the end of August 2009 and I was able to go to my class reunion three days after starting LDN. I was starting to feel a little better even after just three days of the medication. At the reunion I reunited with a man whom I'd gone to school with since 2nd grade and we've been together ever since.

Life is so good and I owe it all to the Lord for giving me the ability to research and find this medication and to the medication itself!! What a Godsend!!!

I have been on LDN since the end of August 2009. I now have my life back!

Thank you for all you do for LDN research!

# 185

#### **Tina E, USA** 1979 - Cytomegalovirus Chronic Fatigue Immune Deficiency Syndrome (CFIDS) June 2009 - LDN

I would like to share my experience using LDN for Chronic Fatigue Immune Deficiency Syndrome (CFIDS).

I have been dealing with autoimmune issues of one kind or another off and on for over 30 years. I became ill and was initially diagnosed with CMV – Cytomegalovirus with extremely elevated liver enzymes first, then misdiagnosed with Biliary cirrhosis of the liver – an autoimmune inflammation condition of the bile ducts in the liver.

After being given a diagnosis like this – a terminal liver condition - and told by my so called expert gastroenterologist that I would most likely need a liver transplant in 10 years, I elected to move on to alternative treatments and care as I have done over the years. I have spent over \$50,000 US in the last 4.5 years in alternate treatments trying to heal or bring myself to a functional state.

I was able to arrest the CMV virus, however, ended up with CFIDS. With the help of a wonderful naturopath, supplements, diet, exercise, and various forms of energy medicine I was better but not what I would consider anything near a normal functioning state. I had bouts of remission sometimes 6-8 weeks after one treatment or another, but would return to a state of extreme fatigue and susceptible to any virus, cold or flu that came along within weeks.

LDN has been nothing short of a miracle for me. Yep, that's for real. I have been taking it for 6 months to help with CFIDS that had destroyed my life as I knew it. I had tried everything to heal myself - you name it, I've tried it; including hypnosis, EFT, EFX-CIO Energy healing, Acupuncture, etc. But LDN, even with the side effects and a rough start-up with some rather serious insomnia has been the only thing I have tried that has had this miraculous result for me.

Is it perfect? No. There are side-effects that I've experienced: very light sleeping, 4-5 hours max, I cannot drink alcohol in any form or I get sick, I cannot eat unhealthy food – high fat or carbs – even one time or I will get sick with IBS, fatigue and viral type symptoms. My once natural long fingernails are now peeling and short all the time I need to take naps occasionally because of the light sleeping. Is this really all from LDN? Probably not. I think some of this is from my compromised liver condition even though my liver enzymes are now within normal limits.

However to have near normal energy and my life back, these side-effects are minimal and welcome for the benefits I reap from LDN. I now have the energy and health to work full-time again after barely working part-time for 5 years. I exercise daily - cardio and strength training, play pretty hard and now have the time and energy to spend with those I love. It feels like I have my life back.

LDN is my miracle no matter what some say about it.

I owe it to the kind and generous Yahoo group members, the dedicated group for helping me through the dosing changes, telling me about Black Cohosh not working with LDN, at one point taking too much Melatonin causing morning fatigue 'melatonin hang-over' and seeming as if LDN was not working.

I might have stopped taking it after a few weeks, thinking it was not working if not for the help, support and suggestions OF the LDN Yahoo Group. So A HUGE THANK-YOU to all of those that have supported me.

Tina E, USA

# 186

#### Tina F, UK May 1990 - Multiple Sclerosis 2003 - Secondary Progressive Multiple Sclerosis (SPMS) November 2009 - LDN

The night my life changed!!!

My problems began on a Saturday night in April 1990.

After a day shopping with my children I settled down to watch TV. I had a strange feeling that was slowly creeping up my leg, then my arm until it reached my face I just looked at my Husband and said, "Phone the doctor". His usual response is to say

"Why?", but he just got up and phoned the out-of-hours surgery, passing the phone to me to explain the reason for me wanting a visit! Within 30 mins I had a doctor examining me all over. He asked if I was taking the pill.

As I was taking the pill, he requested I stop taking it because he thought I was having a stroke!! He gave my husband strict instructions to phone if my symptoms got worse! I was taken upstairs and told to rest where I promptly fell asleep. On Sunday at 8.30am in the morning I was woken by the phone. It was my GP phoning to see if I was ok? As I felt as if things were returning to normal, I said all was fine I was told to report to the surgery when it opened the next day! I put the phone down and burst into tears saying I must be really ill because GPs don't phone you on a Sunday morning!!

My foot felt strange the entire day. I wore flip-flop like slippers and it was only when I looked down that I realised I was only wearing one. I felt as if I still had it on!

The next morning I reported to the surgery and was told to go to hospital for checks!

Over the next few weeks my symptoms returned. I was admitted to a ward at the QE Hospital and given an MRI scan. I was in hospital for a few days and was still being told I'd experienced a slight stroke! But then I was told to return in 2 weeks time for a lumbar puncture to rule out MS!! MS? I had never heard of the condition before. I felt if the doctors were saying it was a stroke, then that is what it was!!

The day of the lumbar puncture I went back to the same ward. I had the lumbar puncture and was told to stay flat for 2 hours after. This was ok as I had a good book to read! My turn came to see the doctor, and I got ready. I was poised!! When his phone rang he told me "sorry" and off he went! When he returned I was still on my side when his stomach started rumbling!. "Can you hear my stomach?" he asked. "I need my lunch." I'm not normally rude but on this occasion I said, "Well just get on with it, then you can eat.".

After he'd finished I was asked to stay flat on my back and offered a meal of grated cheese salad, lol! Two hours later my husband came to collect me. He looked at me and said, "What's that in your hair?". I had strands of cheese all around my head. I recommend no one try and eat grated cheese on your back!!

The doctor who did the lumbar returned again, this time minus his rumbling stomach. He informed me I could go home and that he thought the test result would come back negative.

As the doctor wasn't worried about the test results, I didn't return to hear the results for 6 weeks, and I wasn't worried because all feeling had returned (apart from my big toe being numb which I'd put down to an ingrown toenail.)

My husband wanted to come in with me to hear the test results, but I told him I wanted to go in alone! A consultant I'd seen for a few seconds when I was in the ward was in the room when I sat down, but then I was told they hadn't received the results so I was to go outside again, sit and wait!. Ten minutes later I was called back in. I sat down and was knocked with the biggest blow I had ever been given!! "YOU HAVE MS"!!

I was given a leaflet to read, an appointment for 6 months hence, and shown the door!! I walked out to join my husband, my face not wanting to scream "WHAT?". We walked to the car and it was then that I cried!! My Husband held me, then he turned and told me

something I would always remember, "Good job I had a new wheel put on the wheelbarrow cause I can always wheel you around if need be!!! Bless him! I can always rely on him in a crisis!!

Over the next 13 years of RRMS, I had odd days where I was too tired to do things. I was prescribed various potions and pills but found Carbamazipine helped with the nerve pain I was getting. I visited the consultant every 6 months for my 5-10 minute check-up and was asked every time I went in, "How's your water works?". "Fine" I always replied. It got to the stage after 10 years of him asking the same question that I'd reply "Mine's okay, how's yours?".

Then 7 years ago I had a bad virus that set off a chain of events. As I was getting over it I noticed my thumb was getting numb and then gradually, the tingling began to creep slowly but surely further up my arm, almost on a daily basis. After about a wee, I had no feeling in my arm. I would wake up in the night not knowing where my arm was and often finding it above my head, or I'd be woken by my husband because I'd hit him! I decided to use a sling so I knew where my arm was because by now, I had no awareness of it!

Then the numbness crept down my right side, taking my leg with hit, so I was unable to get up the stairs to bed. For the next few weeks I slept in a drug daze down stairs! I was admitted into hospital for 3 days for steroid treatment, but I was allowed home each night!

My diagnosis was upgraded to Secondary Progressive Multiple Sclerosis (SPMS), but I was still working, so I had to have 6 months off work.

Slowly the feeling in my leg returned but my hand and arm felt heavy. I had to start using a stick because my right side was now a lot weaker. I was still only taking carbamazipine and pain killers because no other meds were offered. Beta Interferon had been mentioned by my consultant in hospital but when I asked him for it, he'd give me a reason why it would not benefit me, such as 'you can still walk x yards', and even though my mobility continued to get worse, the next time I'd ask he'd say 'you can still walk x amount'. He seemed to change the guidelines every time, and in the end, I felt the goal posts kept getting moved.

In November 2009 my Husband was reading 'The Daily Express' when he saw an article about a woman with MS who was taking a medication called LDN. It went on to explain how it had changed her life.

I read the article, got my laptop out, and typed in LDN! This was the start. I next went on to Facebook and typed in Linda Elsegood's name. I was on a roll and found her, so next I emailed her asking how I could obtain the medication!

Within hours I had a reply stating how I could get hold of LDN.

That all happened at the beginning of November 09. By the end of November 09, I had my first delivery of 'jungle juice' (my husbands name for it). My Own GP was all for it and had given me the letter to fax to the e-med compounding pharmacy.

So there I was at 9.00pm the first night, carefully measuring out the red liquid, and being pleasantly surprised at the taste because it reminded me of a cough mixture.

Each night at 9.00pm I repeated the same procedure and slept all through the night, not even waking to go the loo!

Over time I started to decrease my other medications. I went from 6 tablets per night to 1 per night! I also started to stay up later. Instead of going to bed around 9.00pm I was still up and having conversations with my husband and family at 11.00pm. It had been years since I had done this!

I also noticed I wasn't so drained or tired at work, my energy was a lot better, and people began commenting on how well I looked!

I've been on LDN for 5 months now, and I know it's still early days. My walking is still poor but I've put that down to a hip replacement and not having the right after-care of physiotherapy, etc because I'm nearing 50, not because of MS, but that's another story!!

I went to see the consultant and he told me how well I looked!! You should have seen his face when him I was taking LDN. His face was a picture!! He then asked how I had got it! As I was leaving he said he hoped it worked. I felt like saying, "20 years of being given the same old meds by you and it's taken 20 years for you to say I look well!"

I now have a little of my life back!!

Hope this story helps someone else.

### 187

#### Tracie Q, USA 1997 - Multiple Sclerosis 31st July 2008 – LDN

I diarised some of my early experience with LDN, so this will be a detailed story.

On 30th July I went to my neurologist ready to fight to get on LDN. She prescribed it for me within a few minutes of my asking (without a fight). She sent me to a local pharmacy that was able to make them for me with just a short wait. They cost me \$10 for a one-month supply. My neurologist said only one other patient in Eastern Maine had gone on them for MS and that was 5 years ago.

On 31st July I took my first dose of 1.5mg LDN at night and only got up once as opposed to 4 or more times every night before. I slept until 8:30, when I usually wake up at 6:00. I hoped this wasn't a one-night thing, but if so, I figured at least I got a good night sleep for the first time in over a year. I was hoping for continued improvement, but wasn't too confident that it would happen. When you've had MS for 12 years it's hard to get your hopes up that anything will work.

I woke 2 times during the second night and only slept until 7:30. When I woke, I had incredible pain in all my joints, which was a new symptom for me, but the pain was gone

an hour later. My arms didn't feel as heavy as usual, but I was also tired and 'crashed' around 4:00pm, needing a nap. I didn't seem to have to urinate during the day as much as usual. Being a teacher with summers off I didn't have to go anywhere so I gave in to it and rested whenever I could. I continued to get headaches, which for me was fairly normal.

My third night was another good night, but during the day I was very emotional. I wasn't sure if it was a symptom or stress. The urgency to urinate wasn't as strong. I didn't feel like I had to rush to the bathroom to avoid an accident. Even though I was getting more uninterrupted sleep, overall I was more tired.

By day 4, urination issues had continued to lessen by the day. I no longer had to go every hour - day or night. Things seemed to be becoming more normal in that respect. When I dared go out without pads, I considered the condition was under control. The tiredness lifted a little, though I still needed to nap during the day. My balance seemed better than 'usual', but my weakness seemed the same. I didn't seem to be slurring my words as much. By emotions were more even so I may have just been stressed.

By day 5 I was up early because I didn't sleep well. I had insomnia for the first part, but still only got up 2 times - 2:30 and around 5:30 am. The urgency to urinate came back around 5:00 pm and went away again by 9:30pm. Does the medicine wear off until the new dose at 9:00pm?

I was having lots of naps so that could have affected my night sleep. One good point was that I was able to walk 8 feet with out the rollator or furniture or walls. I hadn't done that in many months! That was very exciting for me! It was the feeling that I had better balance that allowed me to even try.

Because I fell a lot, I didn't usually go more than 2 feet. The spasticity in my legs seemed not as frequent as it had been. My legs only had a tight feeling once during the night/morning as opposed to 5 or 6 times. I was wondering if the changes were just from wishful thinking, but hoped some of them would be long lasting, and that only time would tell!

ONE WEEK on LDN and improvements came and went in waves. The only consistent symptom improvement was less frequency and urgency in urination. With the other stuff I had good days and bad days, though I was still sleeping better most nights, I had a few nights of insomnia too. I had heightened emotions on one day. I had better balance on one day. The coldness in my feet went away for a few days. My speech was better for a few days. My arms felt lighter for a few days (when usually they felt like they weighed a ton).

My stamina had not shown any improvement. I still had about 12 'spoons' a day, but my spasticity had improved a little. Weakness in my legs came and went, though my left leg seemed a little better as I didn't have to use my hands to lift it as much and was able to put my left leg on the couch or bed some days without help or as much help. Any change in one week is good, I expect more changes as I am on it longer.

I still had foot drop although that also came and went, and always has. I didn't think I had swallowing problems as much while drinking. My headaches hadn't improved, and I had a headache for most of one week, in the temples.

Having said that, overall, I felt like LDN was helping, and couldn't wait to report progress again after one month.

DAY 31, and after one month on 1.5mg LDN, I noted that I only got up twice during the night and overall I was feeling really good. I seemed to have more energy and stayed up later and I was rarely tired during the day. My moods also improved and overall, I felt life was good!

I noted that after starting my 'period', it didn't seem to make me as tired as it had previously. My arms feel lighter, my balance seemed a bit better, I didn't feel as weak in the legs, and I wasn't choking as much when I ate or drank.

I had a great first week back at work (I'm a teacher). I had been nervous that I wouldn't make it a full day and was wondering how I would survive without a nap, but by the end of the first week, it was like a normal routine and I wasn't even tired! My speech got better as the week progressed, and I wasn't even slurring by the Friday. I walked without assistance a few feet. I had been getting used to using hand controls in my car, but didn't seem to need them as much.

My spasticity had reduced so much I had forgotten to even mention it in my LDN diary! Although there were times when I was still tired, I didn't seem to have to have naps as much, and my vision problems had improved.

I had good days and bad days. Days when I would use only my power chair were followed by worse days trying to walk it seemed, so it seemed nothing had changed.

I should note that during the first month, apart from starting LDN, I also had a lot of stress to deal with. My teenage daughter almost cut off her middle toe stepping on a broken bottle. She cut through toe and tendon, it took 15 stitches to close the wound, and she needed lots of attention and care. Then came the news that they were admitting her to hospital because her foot didn't heal properly, and she had to have an operation on it. The operation was a success, she got the stitches out, but was in a lot of pain, and she also had to be put on IV antibiotics.

In addition, my husband had an operation on his shoulder during this same period, and I returned to work. I was extremely tired from doing more than usual, because instead of my daughter waiting on me, I was helping her, and I was also preparing my other daughter to leave for college.

After one month on LDN I increased the dose 3mg, and pretty much always took it between 9:00 and 9:30 at night. I found it curious that when I woke at 3:20am (to urinate) I had no symptoms of MS. It was very weird.

I was still optimistic, but wasn't sure if it was a 'miracle drug'.

Past the first month, I began walking around the house without the rollator, and advanced to using my rollator instead of my powerchair at work. I was still having good days and bad days, but more good than bad every month. Before LDN, I was going downhill fast. Now I was not. I no longer needed to wear incontinence pads, and it made a huge difference in my life not to have to worry so much about bathroom breaks and accidents. Although I got tired after a long workday, I wasn't fatigued at work and no longer required naps.

I wasn't choking, and was less embarrassed when eating in public. Most days, my arms had lost the heavy feeling. I was able to move my foot and use the foot brake easier most days when driving. My balance seemed better and I was able to alternate feet when going up stairs. My speech was still slurred, but others said it was better in the mornings.

My gait was not good when walking, and I still couldn't stand for long periods of time. Writing was awkward. My fine motor skills were still affected.

After 1.5 months on LDN, I had laid around the house doing nothing one day and my legs seemed to be worse from not enough use, and I had a little trouble and needed to use hand controls more when driving, but I slept through the night without any 'potty' breaks at all for the first time in a long time.

Over the next few months, symptoms continued to improve, though still in waves, up and down. For example, one day I realised I hadn't had a headache in months, and I was feeling as though the progression had stopped, but I also developed a new symptom: Instead of cold feet, I had burning hot ones! I wasn't sure if it was a side effect of LDN, menopause or MS! Except for burning feet, nothing had gotten worse while everything was constantly worsening the year before I found LDN. I feel like it was a miracle!

I spent the year before LDN going downhill fast, but I diarised that after 3.5 months on LDN, I no longer had daytime fatigue. My arms never feel heavy anymore. I always slept through the night with one pee break at most. My handwriting had improved. The slurring and volume of my voice was still not great, but I no longer choked when eating or drinking. I could alternate feet going upstairs most days. My shower didn't wipe me out for a long time anymore.

I sometimes needed to use my hands to lift my left foot, but this came and went. I needed to use my hand controls for the gas accelerator less and less, and most days I used my foot for the car brake as well. My energy was pretty good. My spasticity had improved. The frequency in urination had gone way down, but urgency had picked up a little, but I was still able to hold it for longer periods of time than before LDN. I no longer had the major headaches I was having in the beginning of taking LDN, which was a relief. I no longer had mood swings. Overall I seemed happier and felt could always be a lot worse.

Then on 1st November 2008, I went to my neuro for a check in. I had been on LDN for around 3.5 months. By then, nights and mornings were better than afternoons, which I found interesting. Nights were not good before. My ability to drive using my foot had gotten better. The neurologist was pleased there hadn't been any progression in my MS since starting LDN. In fact, she saw the improvements I'd had.

I always seemed to have problems with season changes, so in the week leading up to the appointment, a few things got a little worse: My balance, falls, and urgency got a little worse, but still not as bad as before LDN.

Then in mid November I got a message from an LDN group member asking if my MS was affected by the full moon. I was shocked when I reflected on this, because I realised, the times I always seem to have my worse times each month are around a full moon. She also asked if I had trouble sleeping since taking LDN. I seemed to dream

more, but I was still getting 8 hrs of sleep most nights with one bathroom break around 2:30 - 3:30.

In mid January 2009, after 6 months on LDN, I began taking Copaxone along with LDN as a precautionary measure. My daughter really wanted me to do it because I had been going through a lot of stress with my marriage and though my MS had remained pretty stable, I had experienced more bladder urgency that I hadn't seen in many months - though frequency was still down. Everything else seemed the same to me, though I dreamed more than I used to, but as I was MS free in my dreams, I liked them!

My daughter noted in May 2009 that she thought I was experiencing more stiffness in my legs. I think they did seem stiffer, but I'd heard that can happen. Someone suggested LDN could be taken in the morning but I take mine at night.

I hadn't updated my diary for a while because everything was going so well I forgot! Things had improved like bladder and fatigue. My stamina was much better. I slept through most of the night and it was wonderful! One time was the most I got up, and it was almost hourly before LDN! I am almost 'normal' in the amount of times I go a day!

I didn't plan to ever go off LDN! I did use Copaxone for a while too, but more for family members than because I felt I needed it. I guess I saw it as a back-up that wouldn't hurt.

I felt stronger most days although the full moon, once I took more notice of it, did seem to affect me - weird I know. Also, on 'those' 3-4 days each month, my MS was horrible.

After 11 months on LDN I wrote, 'I have been on LDN 11 months now and I think it has saved me!!! I started using a treadmill and did 11 min. If you had told me a year ago I would be doing that I would have said you're crazy! I am so happy with what LDN has done for me. I have vivid dreams at times, but I sleep well and it gets longer all the time. I do have spasticity but it is a small price to pay for bladder control and the halting of the disease.'

When I looked back at my profile, I noticed a major decrease in symptoms after starting LDN. I had gone downhill a lot right before starting, then I saw a major decrease in symptoms, but then my daughter's hospitalisation sent my symptoms skyrocketing again and then I returned to LDN 'normal' and have slowly decreased symptoms since then.

The most noticeable to me being bladder control, less choking and more recently, improved speech. When you live with it day-to-day it is hard to remember the changes because they are so gradual, but I am now able to drive with my feet, not hand controls, in my van (because my feet remember what to do and do it)!

It is now September 2009, and I have been on LDN just over 12 months. Recently, the urgency with my urination has increased and my foot drop is a little worse. Other than that, things are normal!

I am back working from summer vacation, so fatigue may be a factor! I decided to stop using Copaxone.

I am now using a treadmill 10 times a day for 3 min each, but I stress, I built up to that very slowly. That may not sound like much, but after being in a wheelchair it is

wonderful. I am sleeping through the night almost every night. I can survive on less than 8 hours sleep and not get tired! LDN has changed my life!

To everyone who is just starting on LDN, I say give it 3 months at least. That is what I was told! I'll never go back to using anything else. I only need incontinence pads as a precaution when I leave the house now. I rarely have accidents, much better! God bless all living with this disease and 'Good Luck' all!

# 188

### Trish B, UK Jan 2005 - Myalgic Encephalomyelitis (M.E.) May 2006 - LDN

In 1995, I was diagnosed with a very serious viral condition which took me 12 months to recover from. One of the main symptoms was fatigue, and even though I managed to fight the virus I was left with the fatigue, along with other weird and wonderful symptoms. I continued to suffer from those for a period of approx 10 years, and during all that time I was put on many different types of anti-depressants by my GP (which actually did nothing at all for me).

It was after meeting my now husband, who had suspected MS, and conferring with him about symptoms, that I started to think I might also have MS. Shortly after we got married, we found out that I was pregnant, and although being overjoyed, my symptoms got ever so worse (especially during the first trimester). As a result I had further medical investigations, eg; an MRI. The results came back negative, but I continued to suffer the symptoms, and had to take time off work as a consequence.

Following the birth of our daughter, by caesarean, and breastfeeding difficulties, I became extremely ill, and so did my husband.

When I think back to those days it all feels like it was a very bad nightmare, and I often wonder how we all survived. BUT WE DID.

Whilst I was extremely concerned for my new baby, which led me to trawl the internet, I was also very concerned about my husband. I trawled the web for potential cures for MS. It was then that I came across LDN, and the hope and relief it was giving to so many MS sufferers. During my research I noted that the symptoms LDN was able to alleviate were very much like mine. I then wondered if it would benefit me, along with my husband.

I then found Linda's contact number and email, and without hesitation contacted her with regards to obtaining LDN. Linda was a tower of strength, and so was Ted Heath who visited my home following a very painful phone call, which I had made to them. I can't thank Linda and Ted enough for what they did for me, and my family, for they gave us the gift of good health.

I managed to get a prescription, and Linda gave me assistance on the best place to get it dispensed.

When our delivery arrived, I can remember both my husband and myself being a little worried about what it might do, and how it would affect us, but we bit the bullet and started LDN in May, 2006.

We started taking a very small amount initially, gradually building the dose up over a period of a few months. I can remember that, at first, I started getting some of the very old symptoms I had had years previously.

They were brief fleeting glimpses of the past that lasted a very short time (minutes - a couple of hours), then just passed, as if they hadn't been there at all. The more I took the LDN, the more my strength improved, and so did my husbands.

Within a few months of starting taking LDN I was able to return to work (July 2006), and my energy was not only back to what it had been on my very good days, but back to the way I had been when I was a much younger person. I was able to do things again without having to plan rigorously for consequences. I WAS ABLE TO REALLY LIVE!!

I no longer get the weird and wonderful symptoms I was previously plagued with, and have forgotten what most of them were. It is only when I forget to take my LDN for short periods of time (once it was a month) that I'm reminded of why I take LDN. Once back on LDN it doesn't take long (a couple of days) before I'm back to feeling really good again, but even on the worst of those days, I'm still able to function normally.

I hope this little summary will help others who find themselves in a similar situation, and will assist Linda and the LDN Trust in their endeavours to have real clinical trials done in this country. Because anyone who suffers from a condition that robs you of your vitality for life deserves all the help we can give. I believe that having the courage to try LDN was the single most important thing I ever dared to do, and I am now reaping the rewards from that demonstration of courage.

# 189

#### Trish K, Australia 1995 - Secondary Progressive Multiple Sclerosis (SPMS) August 2009 - LDN

My first severe MS attack occurred when I was in my mid teens and lasted 6 weeks. I wasn't diagnosed as having MS at the time, and the doctors were quite flummoxed.

After my very first major attack, I had a few minor attacks over the next 30 years, then experienced another severe attack with identical symptoms, severe spasms and pain at night and being unable to straighten my left leg until midday each day. I was in my mid forties when it happened and I was finally diagnosed with Secondary Progressive Multiple Sclerosis (SPMS). Since then, I have not taken any MS medications.

Pain and spasticity have always been my worst symptoms. In the last 15 years, and in spite of following a low fat diet and taking many supplements, I continued to progressively deteriorate.

I had a baclofen pump implanted in April 2007, around three years ago now, to help manage severe muscle spasms, intense pain, and some of the spasticity. I went with the pump because I have always been so allergic and sensitive to everything.

Then I heard about LDN and read all I could about it. In August 2009 I started taking 3mg because I'd read 3mg was a better starting dose if you'd experienced bad spasms (and I had).

After taking LDN for 3 weeks my stiff leg became more flexible at night. Over the past ten months the flexibility has steadily increased to the point that I can now kneel, which I have not been able to do for 15 years.

The dexterity in my left hand has improved (my left side is the one most affected by MS), and this improved co-ordination has made typing possible again (though still slow).

My balance has also improved and I can now stand on two legs in front of the wardrobe to choose what to wear without falling in. My mobility has improved and I can now walk (though wonkily) without any support the full length of a room.

I used to have frequent sinus attacks and they'd lead to exacerbations of my MS symptoms. Since starting on LDN ten months ago, there have been no sinus attacks.

I was gradually losing my voice, but have now regained about 98% of my voice.

I lost most of my taste and smell 3 years ago, but since starting LDN, have regained 95% of my sense of taste & smell.

Now to my Side Effects...

I haven't slept well for 16 years, but, the insomnia since starting LDN has been a big problem. I stopped taking LDN for a couple of weeks to try to desensitise myself to it and when I stopped, I was able to sleep for 3 to 4 hours before waking.

In the last few months the spasticity has got worse. I know I can improve this by increasing the dose of baclofen I get from the pump but would rather not do this as it does make me weaker.

Over the last 10 years I have become increasingly allergic to everything; food, supplements, anything synthetic, especially drugs! Kinesiology has been a lifesaver and the only thing that has worked on these allergies.

After starting LDN I experienced worse hot flushes and hot hands (in bed at night) and tinnitus, which I know for me is an allergic reaction. Since then I have gotten rid of the tinnitus and hot flushes, and have improved my sleep pattern to only waking every 2 hours and being able to go to sleep quite quickly again.

Due to my sensitivities I'm going to try taking LDN transdermally, using an LDN cream instead, to see if this will help improve sleeping, spasticity, and allergic reactions. If I can decrease the spasticity, I will also try increasing my dose to 4.5 mg to see how it goes.

Nonetheless I love the LDN and will continue, no matter what.

I think LDN is the best. I have had MS for around 45 years, but I have seen all these improvements in one year and am expecting to get better and better. It has truly given me my life back. I am normally a positive and happy person, but now I am ecstatic!!!!! I try to spread the word about LDN whenever I can.

I'm hoping down the track that the LDN might even make it possible to do away with the Baclofen pump altogether.

I feel great and LDN has given me my life back.

# **190**

Trish P, USA 1998 – Multiple Sclerosis October 2009 – LDN

I was diagnosed with MS 12 years ago after having symptoms for 15 years.

I've been taking LDN for just a few months, and I started it because it was time for me to go off Tysabri after being on it for two years.

LDN is going really, really well, for me. It provides me with a slow-burn, consistent energy that I've not had in years. It's not manic- just consistent... and what I have longed for.

LDN hasn't improved my bladder or cognitive issues, but has greatly improved my energy, relieved fatigue and weakness, and helped the sensory stuff. It's also helped quite a bit with my persistent and omnipresent depression. More than I could possibly have hoped for, really.

I'm still on a very low dose (very, very low-dose of naltrexone), but I'm going to very, very slowly build up the dose. I've had to adjust to the dose I'm on, in terms of the insomnia it was causing. I've gotten that managed so far but haven't successfully increased it higher than 1.5mg yet. I'm not sure how important it is to get up to the max dose of 4.5mg because I hear conflicting reports. For now, I'm going to stay where I am because I don't like the sleep issues I experience at the higher dose.

For the past year and a half, I've also done the MS-Diet (gluten-free, dairy-free, soyfree) and that cleared up some of my cognitive issues when I started it. I believe that the combination of both the diet and the LDN are working better for me than anything in the last 15 years. If I make a mistake with the food, I suffer for it - it shows up as fatigue and weakness. But, when I'm on track I do pretty well.

I used to work full-time but now work part-time. That's allowed me the time to do research on both diet and LDN. I don't know if I would have gotten here if I'd kept working full-time.

I don't know why LDN works. After I read about it I felt intuitively drawn to it, so I thought I'd try it out.

I'm lucky to have a wonderful holistic neurologist about 30 miles from me, and she's the one who prescribed it. My mainstream neurologists nearly laughed me out of the office when I brought it up. I don't know if the effect of LDN will be consistent over time - that remains to be seen. For now, I'm grateful for the time I've had over the last few months.

### 191

### Trisha C, UK July 2001 - Multiple Sclerosis 10 March 2010 - LDN

I was diagnosed with MS in July 2001. Even though it's never been mentioned by my doctors, my research led me to believe it's probably PPMS.

Today is May 7, 2010, and I'm presently taking 3.5mg LDN each night.

I started on 1.5mg on 10 March 2010, and I've been building the dose up gradually by .5mg every 2 weeks.

My MS story began in my late thirties when my first symptoms developed, but I didn't know at the time what they were. I was not an excessively active person, but did I enjoy walking, travelling, horse riding, and gardening, and I had a responsible job managing a Europe-wide sales team for a US company.

I began to experience a lot of fatigue (not simple tiredness), and when walking my knee would sometimes feel odd and 'floppy', and I'd sometimes turn my ankle unexpectedly. My right finger would also get 'tingling' sensations.

By the time I hit my forties, I'd left my non-working husband and moved in with my best friends husband whom I'd known for 10 years but only just realized I had fallen in love with! Sounds like a romance novel but this is not recommended if you need to avoid stress! We also upset 2 other peoples' lives too, which we will always regret, but it turned out to be for the best in the end. At least I had no children and his were both grown and had left home.

My first visit to a physician consultant was early in 2001, we (both my GP and myself) suspected a trapped nerve in my back. The back specialist had a limited MRI scan but

ruled out a trapped nerve and passed me on to a colleague, a neurological specialist. That specialist tested the strength of my right arm, and I think, suspected the problem straight away, but sent me for a second and more extensive MRI scan.

Only after his suspicions were confirmed (quite rightly) did he tell me that I had MS. It came as a shock. My GP was also surprised but has always been supportive and gave me a short course of steroids on the advice of the consultant. These helped a lot the very first time I took them and got me through the 'shock and denial' stage, but even with long gaps between courses they have never been as effective since.

The costs associated with the diagnosis were all met through my company private health plan.

When we finally got the diagnosis of MS, my partner and I had only been together 18months. My mother, then in her 70s, had accepted the end of my marriage and given us lots of loving support, (which was more than I got from my sister), even though it was a shock. My mother was, however, worried he wouldn't stick around once the MS was diagnosed, but she didn't yet know him so well!

It was becoming increasingly difficult to work as well as I had before, and even though the company remained supportive, I took a voluntary redundancy in my mid forties, opting for a lower but earlier pension on reaching 50.

My partner and I spend most of our time in the South of France where the drier climate seems to suit me! He's been a wonderful support to me, not letting me give up on anything, and is always there to help when needed. I'm not sure how I would have coped without him even though I have a strong character.

Following diagnosis I constantly checked the MS charity websites to see if any research project was showing potential (and even volunteered once for a clinical trial), but nothing seemed to offer any hope, especially for primary progressive MS.

All of my problems were associated with my right side; some leg cramps/spasms but otherwise no pain, thankfully (I know I'm lucky, really !), I started to train my left hand to do a lot of things but couldn't write left-handed no matter how hard I tried. I am just able now to thread a sewing machine left-handed, so the perseverance is paying off!

By the start of 2010 my walking was noticeably worse, as was my balance. Writing was virtually impossible... and we had even considered buying a folding wheelchair for times when walking was necessary for us both to still enjoy life!

Then I heard of LDN through a friend of a friend who has MS and whose doctor prescribed LDN.

I have never been told if my MS is Primary or Secondary, but my own research on the web suggested Primary. I couldn't find any research indicating positive outcomes for PPMS drugs, and as only a small percentage of all MS sufferers have PPMS, I guess drug development is not such a high priority.

After jumping through the NHS hoops for a couple of months, my consultant still wouldn't advise my GP to prescribe LDN because he said he had NO PROOF it would work! The only solution he'd ever offered me was steroids when I was first diagnosed

back in 2001, but they worked once and never again, as well as contributing to increased weight.

Well, he had no proof that LDN didn't work either, and I now have over 8 years of progression in MS, which I doubt can be reversed!

I was finally able to start on LDN, many thanks to Linda Elsegood who pointed me in the direction of E-Med. Both E-Med and Dixon's Pharmacy have put the NHS to shame with their customer care and efficiency, and I am now up to taking 3.5mg of LDN, with no side effects to-date.

So far, I have only positive things to say. LDN has improved some symptoms, even though the best I had hoped for was a delay in progression.

I feel stronger, and my bladder control is better (sometimes even sleeping through the whole night). Walking has improved. I can lift my right foot a little now. I can stretch my right toes a little for the first time in nearly 8 years, and my writing ability has improved a bit too!

I feel I can do so much more and in a relatively short time, LDN has improved quality of life for both of us. I know that if I can do more I can improve the condition of my muscles again, so fingers crossed, it will keep improving little by little. Even if it never gets better than what I've gained to-date, I know my health is better than it was before LDN, and I also know it is not my mind playing tricks! I'm not as 'fatigued' now either.

I'm deeply disappointed in the NHS because LDN could have been given to me 8 years ago to slow progression, when I had fewer problems to cope with. I personally paid for Top Rate National Insurance but got nothing from them at my 'point of need'. Even my diagnosis was paid for by my company health plan, and the NHS continue to do nothing for me except provide an annual 'flu' jab and some 'foot drop' support. I feel very let down by them.

I've kept notes on my symptoms and it's helped to monitor my progress on LDN:

Looking through my diary I see many little improvements that have enhanced my quality of life already: Showering and getting ready in the morning is easier, and I can peg washing on the line now because I can hold my hand up long enough to operate the peg! There is still a lot I can't do that I could do 8 years ago when LDN might have stopped all this progression, but I'm grateful for every little improvement no matter how small. All I was hoping for was an end to uncertainty for the future.

I realize I'm actually very lucky. Many people have pain and medical conditions much worse than MS, some even terminal. If LDN can help lessen someone's pain, help them live longer, or like me, improve their quality of life; then a caring health service should be doing all it can. At the moment this is not the way I can describe the NHS!

For those who want more detail on what I experienced, I've included progress notes below:

Symptom Status: Before LDN - 9 February 2010

I noted that before starting on LDN, I couldn't walk without a foot drop support, that my ankle turned, and that I was tripping because I couldn't lift my right foot. I was using a

stick for support because my balance wasn't good. Stretching my toes was impossible. My right leg/foot always felt cold. During the winter my right foot had turned blue, and that had caused me to worry about circulation. When I asked my GP about it, he checked the pulse in my ankle and decided there was nothing wrong with the blood circulation and that it must have been due to nerve circulation. After that, I noticed both my hands and legs on the right side had gotten much colder than those on the left side.

I was still driving occasionally to keep in practice but had decided I would soon need an automatic car. My fatigue levels were high. My concentration was deteriorating. Sleep was disturbed and I'd average 5 hours sleep a night due to visiting the toilet once or twice. I noted pelvic floor exercises had helped improve bladder control a bit, but as I'd had the bladder problem for several years and was middle-aged, I wasn't really sure if the bladder problems were MS related or not.

I'm right-handed, so writing legibly was nearly impossible as was using cutlery to cut my meat during mealtimes, and; needless to say, cutting my toenails was almost impossible.

My blood pressure seemed OK, regularly measuring between 110 and 128 over 80 plus or minus 3.

Symptom Status: 1 week on LDN

I've taken 1.5mg LDN daily at night for one week and plan on continuing that dose for 2 weeks in total before increasing by half a milligram. I find the liquid difficult to administer (given the problems with my hand), but I have a wonderful partner who helps me a lot and doesn't let me feel sorry for myself.

I'm expecting symptoms to worsen at first, and I'm not expecting anything to improve particularly, just hoping to slow or stop progression, though measuring that would be difficult.

No dreams so far. My balance seems a little worse, but note that I can lift my right leg 1" off the floor, and I can also stretch my right toes a little, neither of which I have been able to do for years.

No improvement in the use of my right hand yet.

Bladder seems about the same, unsure, but maybe a bit better. Sleep varied but that is not unusual. It could be contributing to increased fatigue. I'm very tired.

Symptom Status: 2 weeks on LDN

At the end of my first 2 weeks, I feel better in myself but that could be a combination of the fact that I'm doing something about the MS and that Spring is here, which always lifts my spirits!

My writing seems to have improved a little but it's hard to tell. I may need a bigger change to really tell. I will write the same thing every few days and write the date to test this.

I'll be increasing my dose my half a milligram tonight, 18<sup>th</sup> March, and from now will be taking 2mg per night.

Symptom Status: 3 weeks on LDN

At the end of my third week on LDN (and one week at the increased dose of 2mg), I've experienced no adverse effects except for a heavy cold that's slowed me down, but this is something I've suffered since childhood and is nothing unusual!

I have noticed, however; that I am lifting my right arm a little higher than I was able to before!

Symptom Status: Almost 4 weeks on LDN

I increased to 2.5mg LDN, and I'll take that for 2 weeks in total. I seem to be stronger and am walking better, perhaps because I lift my right foot better and don't drag/trip which is much less tiring. All other improvements are still there.

Symptom Status: Almost 5 weeks on LDN

We're still noticing minor improvements, which we can detect, but more importantly others can detect too, some of whom don't know about me taking LDN. We have a very busy week ahead of us, and we'll be entertaining on 2 of those days.

(I managed the entertaining and cooking (with lots of help!), although we are BOTH very tired!)

Symptom Status: 2 May 2010 – Almost 8 weeks on LDN

I increased to 3mg on 21<sup>st</sup> April, and to 3.5mg last night, 3 days ahead of schedule. I'm feeling stronger all the time, and even a little progress seems huge to me after years of frustration. I'm looking forward to the next increase to 4mg on 16 May, near my mum's birthday! I wrote her card! Major progress!

# **192**

Vicki F, USA 1998 - Progressive Relapsing MS October 2005 – LDN

This was written by my best friend, my nurse, in September 2005. Nurse Judy saw me daily, weekly and saw what was happening to my life.

' ... My friend Vicki is a vivacious, articulate, beautiful, fun-loving woman. She is the woman I see and know today. She is not the same woman I knew a year ago. Vicki has Multiple Sclerosis and has struggled and suffered for the past 10 years or so. Her life has not been easy, nor that of her family.

I first got to know Vicki around the time she was diagnosed. I remember how devastating that diagnosis was. She was determined to stay active and to fight its progression as much as she could. She did all the 'right' things, took the prescribed,

medically accepted medications, and hoped for the best. Unfortunately, over time she continued to deteriorate.

For five years, up until almost a year ago, she took Avonex injections weekly, another form of standard treatment for MS. I'm a Registered Nurse and administered those injections every Monday night. She continued to deteriorate. I watched for 5 years as my beautiful friend became weaker and weaker and grew mentally more confused and forgetful.

Vicki often arrived at my home on those Monday nights dragging her leg, rubbing her thighs due to nerve pain, unable to stand for more that a few minutes, and often in tears. It was heartbreaking. Being a nurse and having taken care of patients with MS, I knew what most certainly lay ahead for her. It was not a future anyone should have to face.

When Vicki first spoke to me last Fall about the possibility of taking LDN, a drug she had researched, but which was not a mainstream treatment for MS, she was very excited but also very afraid. What if she gave up her traditional treatment for this and only got worse? It was an unknown. But what was known, was that after 10 years of standard treatment she was most definitely getting worse. And for the past year the decline was increasing. So, she took a leap of faith and hasn't looked back.

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I went to the doctor in 1996 complaining of some tingling and numbness in my arms and legs. In 1998, after two years of testing, I was finally given the diagnosis of Progressive Relapsing MS. By then my symptoms had worsened; balance, memory, speech, sensitivity to touch, spasms, extreme pain, fatigue, bowel and bladder problems and various other symptoms of MS had become my way of life.

We were given information about some of the different therapies that they were using for MS. We came to the conclusion that we would try one of the ABC drugs, Avonex. Later they added another injection, Copaxone, and the group is referred to now as the CRAB drugs. I began the weekly injections, which for the 9 years I was on them had horrific side effects - flu-like symptoms, fever and chills. I stayed on Avonex for the next six years and was still progressing at a rate that I felt was alarming.

By the end of my time on Avonex I had spent most of my time in bed or on the couch. My pain was unbearable throughout all of my body and I decided to start trying other drugs that some MS sufferers were finding relief with. Neurontin, Baclofen, steroid infusions and a list of other medications that would fill this whole page, not to mention two infusions of Tysabri before it was pulled from the market in 2005 for causing a rare brain disease resulting in death.

The MS was still progressing over the years, so my doctor decided Avonex had run its course and they changed my injections from Avonex to Copaxone. The side effects from the Copaxone eventually put me in hospital. No longer able to tolerate the Copaxone, I started Rebiff. The Rebiff turned me into a mental monster, not only was I hating life and everyone around me but the progression and pain of my MS was becoming unbearable.

The last six years were spent on vicodine. I was taking 10 to12 10mg tablets a day. Because of the high doses of codeine my doctors thought it best to start using the morphine patch. I then became allergic to morphine, so it was on to Oxycontin. I spent

the following years in bed or on the couch, as this was the best way to cope with the pain, hating life, and depression.

I had to give up my greatest passion, golf. I could not even ride in the cart. My husband riding over the smallest of bumps would send even more pain throughout my whole body. Before the second hole he had to take me home where I would go to bed and cry because I no longer was able to endure such a simple task. It's funny how we take the simplest of daily tasks for granted.

In October 2005 my husband, the biggest sceptic of all, came across a drug that he had read about on the Internet called LDN (Low Dose Naltrexone). After some diligent research on the drug we decided that I had nothing to lose, and some of the stories that we read from others who were on it were very inspiring. Naltrexone is an opiate antagonist used effectively in rehab centers for the treatment of recovering heroin addicts and alcoholics, but for this treatment, less that one tenth of a dose and a tiny pill was all it would take to stop or slow the progression of my MS, with no side effects. I had to try it.

You can't have any opiate-based pain medications in your system when starting LDN. I had to detox for two weeks. Those were the hardest two weeks, horrible shakes, sweats, and crawling skin. My only thought was this had better be worth it.

I started on LDN at the end of October of 2005. I felt an improvement within two days. My energy level was amazing. Still unsure of what was to come, I continued the LDN and kept my fingers crossed.

By the end of 6 months I was pain free, the numbness and tingling were gone, my memory had improved, my balance and walking were no longer a problem, and other problems I had developed were gone. I was loving life again, my family, friends and myself. I was no longer on any medications except my vitamins and my LDN. I was, after 9 years, no longer on any anti depressant, and I was truly thankful I'd found LDN when I did.

Another year and I would have had to use a walker because I was losing strength and the will to walk.

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Update from Nurse Judy, September 2007

"Nothing short of a miracle", is a phrase that aptly describes my friend Vicki. Diagnosed 11 years ago with MS, the ensuing years have been physically challenging and mentally devastating. Living with a chronic, debilitating disease that over time eroded and completely changed the person she was would be enough to make most people give up. But, Vicki continued to hope SOMETHING could be found to help her.

After years of belief in standard medical treatments, even in the face of continued deterioration, four yeas ago Vicki made the very difficult decision and stopped all currently approved medications. Years of horrible side effects had taken their toll. She had heard about and investigated the treatment of MS with low dose Naltrexone, which was being used off label and seemed to be helping people with few or no side effects. As Vicki's 'nurse friend', she asked my opinion as an RN and someone had in fact given

her weekly shots for five years, and couldn't deny the fact that she was much worse than she'd ever been.

So, my advice was, why not try what just might give you some quality of life. In the past two years I have seen a transformation that really is a 'miracle' of sorts. Vicki has gone from a woman who lived with constant pain, usually couldn't walk without dragging her right leg, was exhausted, unfocused and at times confused, to someone who is unstoppable! She is clear headed and articulate, requires no pain medication, can walk miles and still have energy and has a zest for life I last saw in her 11 years ago.

The person I see today is so incredibly different. She can't get enough of life. She has a passion and a zest she never had. More importantly, physically she's unstoppable. Life used to consist of many days of getting from bed to the couch and back again. Today, you can rarely catch her at home. She has energy, she's virtually pain free, mentally she's sharp and clear, and on her MRI, some of her lesions are changing.

Will this last? Who knows? There are no guarantees in life for any of us. We have to take advantage of the time we have. I do know that had she not done this, she would have been headed down a dead end road. My hope and prayer is that she will remain healthy and strong and continue to light the world with her radiance.

She truly has found the self she lost! She's even considering going back to work, something that was totally unthinkable two years ago. I cringe to even think where her life and health would be today had she not started the Naltrexone. My prayer for Vicki is for continued good health and many more years of all life has to offer....'

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My Update July 20, 2009

By March 2008 I hadn't been to the ER, and I hadn't had to visit my doctors every other month. I hadn't had an attack, nor was I on any medications except the vitamins and LDN. What did I owe it all to? Ask the LDN. I was back playing golf, my energy level was amazing, and I was no longer in the horrific pain I once lived with. YES life truly was good once again.

It is now July 2009, and I still keep asking myself, 'Why don't more people know about LDN'?

Then I ask myself, 'why doesn't our government do more to provide funding for research for drugs such as LDN, and why aren't there more drug companies funding research for such a 'wonder drug' that has helped thousands around the world'?

October of 2009 will mark my 4-year anniversary on LDN. What a difference it has made, I'm back to work, no longer on disability, haven't been in the ER, and have saved my insurance company a lot of money! And most of all I am able to help others once again. Sure, I get tired once in a while, and a little achy, but only if I forget and eat junk or don't get enough rest.

I still have MS, but it no longer controls my life. I no longer take the costly, invasive injections. I don't miss the years of weekly flu-like symptoms that I had for 6 years when taking Avonex, when I felt horrible, weekly. I don't miss the morphine, Norco, Oxycontin,

the fatigue, pain, and countless nights of sleep I would miss because it hurt so bad to lay down.

The brain fog is gone, the feeling of self worth is back, and I owe it all to a drug that Dr. Zagon discovered by accident in the lab years ago. Dr. Zagon is a brilliant scientist and we can't afford to ignore his research any longer. Our economy, government, and doctors need to know what LDN is and what it can do. We need to bring this inexpensive, off-label drug use to the front of medicine, where it belongs.

Too bad LDN can't make huge profits, everyone would be on it and the drug companies would make it, and well, let's just say they would all be flying private jets.

I'm grateful to Dr. Zagon, for the discovery and to Dr. Bihari for having the interest in reading the research and thinking about us, the patients, instead of the interests of the drug companies.

## **193**

### Vickie A, USA December 2006 – Multiple Sclerosis August 2007 – LDN

I had a sudden onset of symptoms beginning April 26, 2006. Most notably was the girdling or MS hug. I was misdiagnosed by a GP but eventually referred to a neurologist. I had test after test, including MRIs, and was originally told I had a syrinx. This didn't feel right to me. I took my MRIs to a neurosurgeon who told me I had transverse myelitis.

My symptoms continued to progress so I had a lumbar puncture and in December 2006 I was told I had MS. In January 2007 I started on Rebif.

Over the course of the next seven months my physical condition deteriorated. I had to take naps, sometimes on the floor of my office. I didn't think I was going to be able to continue working.

I felt as though I had a large boulder on my shoulders. My lifestyle had become increasingly limited and restricted by extreme fatigue. I shuffled along slowly. I used a cane if I had to walk any distance. On the rare occasions I went to the grocery store I had to use the carts, so I had begun 'shopping' for an electric cart because I couldn't walk.

This was a very difficult time for me. I'd spent twenty years in the military and was very fit mentally and physically. During all those years I was always the person others had a hard time keeping up with when walking, but I'd reached a point where I didn't feel like doing much of anything. I'd go to work, come home, sit for a little while, then sleep.

I wasn't getting anywhere, and my first neurologist didn't listen and didn't seem to care. Once I made up my mind to discontinue the CRAB medication, I cut my ties with the intent of going it alone. In July 2007 I stopped taking the Rebif. I just couldn't bear the thought of another shot. As each day passed I felt stronger and stronger.

Then, during my travels over the Internet I came across the low-dose naltrexone treatment (LDN). I was intrigued. I had a good doctor but he appeared to be influenced by the Rebif people – and he certainly wasn't open to alternative medicine.

I took a leap of faith on 1st August 2007 and started LDN. I'd read a lot about LDN. I was hopeful it'd halt progression of my MS and I also hoped to benefit from symptom improvement.

During the same period I also tried Prokarin for a very short time, but I found it too difficult to work with and stopped taking it.

I now go to the Veterans Administration for my MRIs and medications. I have not discussed my taking LDN with the VA. I'll raise it after I see the results of the MRI at the end of the year.

My condition has improved greatly. If nothing else LDN has increased my energy level. I think it also helps me sleep. I've been able to cut my use of Baclofen and Lyrica in half.

I had MRIs of brain, cervical and thoracic spine in December 2007. The neurologist told me that the lesion over T8 was inactive, no change when the contrast was introduced – and there were no new lesions in my brain.

I've also found an ecological internist. She's started me on high doses of D3, shots of B12 and a box full of supplements. I was tested for allergies and have been working hard on cleaning up my diet.

I'm not 100% yet but I work all day with no problems. In fact I feel like I'm more productive. I can go out with friends. I can stay up late, like a grown up! I can go shopping. I can walk my puppy.

Now I feel like I've got my life back I want to tell everyone who might benefit about LDN. Some people are very receptive, others not so much. But I figure if you plant the seed, when they're ready they'll remember. Low-dose Naltrexone has given me my life back so I'm sharing my story in the hope it'll inspire and benefit others.

July 2008: Changed from liquid LDN preparation to compounded capsules. Also switched doctors. The new doctor is an M.D. who runs a clinic offering infrared sauna, acupuncture and other services. I am starting chelation therapy in a week to reduce my heavy metals load. I'm still benefiting from LDN and will continue to take it.

July 2009: 3 years later and I'm still taking my LDN, and I've also done 18 chelation therapy treatments.

I went back to Hippocrates in W. Palm Beach Florida in March 2009, and spent three weeks doing wheat grass, juices, raw food diet, mineral pool, infra-red sauna. I did great.

When I came home I purchased a portable infrared sauna and a dehydrator. I'm juicing daily. I also started seeing a true osteopath in town. I believe he is helping me a great

deal. I'm doing manual medicine treatments and also attending a healing circle two or three times a month.

I'm being very proactive about my health, and it's paying off.

### UPDATE January 2010

I have completed twenty chelation treatments to deal with the heavy metals in my system. I now try to go once a month for chelation. From October 16 2009 to January 1 2010 I was unable to take LDN due to a shoulder surgery and subsequent use of pain medications. During my recovery period I did Manual Medicine Therapy as well as Physical Therapy.

I added Dr. Keith Barbour, an Osteopathic Medicine doctor, to my 'arsenal'. I do aqua therapy and regular manual medicine treatments. My orthopaedic surgeon was actually surprised at how well I was doing at my three-month check up.

I still try to watch what I eat although I sometimes struggle. I have cut my coffee consumption greatly. I still juice and buy sunflower sprouts at least once a week to add to the juice. I recently attended level 1 of an Esoteric Healing class so that I can understand energy work and use it to help myself.

I no longer use Baclofen and the spasticity is not a problem. Neither is the fatigue. I take 100mg of Lyrica twice a day and on a long day I may take a 50mg between. I am using Wii for exercise and walk my dogs at least once a day.

My only real complaint is the neuropathy in my legs and feet, but this doesn't stop me from walking or working full-time. I am grateful that I found LDN and alternative medicine treatments.

# **194**

## Vickie J, Canada

1990 - Relapsing Remitting Multiple Sclerosis (RRMS) 2008 - Secondary Progressive Multiple Sclerosis (SPMS) 4 February 2010 - LDN

Wow, I have had a lot of people wanting LDN and info on it!!! Awesome. Yes a GP can prescribe it but most GP's and Neuro's won't because they don't know about it or don't believe it will help, but believe me dear it does!!! I have had MS for 20+ years. I was diagnosed with Relapsing Remitting Multiple Sclerosis initially, then about a year ago I was told it is now Secondary Progressive Multiple Sclerosis. I was sliding downhill fairly quick.

I did some research on LDN and wanted to try it, and lucky enough my neurologist was one that would prescribe it!!

I started at 3mg. I noticed small changes the next day, and within a week I had my life back!! It's like I went 10 years back in time, just wonderful!! My biggest complaints with

my MS were weakness all over, but my legs were the worst; bad fatigue and balance, bowel and bladder trouble, just to mention a few!!

Get on LDN. It's not a cure, and it doesn't help everyone, but it's worth a try!! Inexpensive, FDA approved in Canada, and very few if any side effects for around 7 to 10 days (but I never had any!!).

And it's a pill!! If you're not on LDN, what's holding you back?!!

I started on 3mg LDN on Feb 04, 2010 and I'll be increasing my dose to 4.5mg on Saturday March 6, 2010.

# 195

#### Wanda L, Canada June 2006 - Fibromyalgia, Chronic Fatigue Syndrome (CFS) 27 February 2009 - LDN

Here's my story, quick and to the point.

In June 2006 I became instantly sick. I was diagnosed with Fibromyalgia/Chronic Fatigue Syndrome.

I reacted to all the drugs that are supposed to help, so I swore I would never take those awful pills again and would fight this thing in other ways.

Some helped, but my joints still ached and 'creaked'.

When I learned of LDN I went to see my great doctor, who thought, 'why not'.

I'm still only on 3mg LDN, but I have to say that I feel GREAT!

I have my life back, and I am so appreciative of that I want to share LDN with the world, as we all do.

My moods are much improved, and I have crazy improved self confidence. It gets so much easier to make healthy lifestyle changes when you are on LDN... at least that's what I've found. There is no pressure.

Pretty soon I'll be increasing my dose to 4.5mg, so I will know more when October 2009 rolls around. In my city of there are only 4 people on LDN, yet our province has a high percentage of MS cases. The ignorance must be stamped out and the sharing of knowledge given birth!!

## 196

#### Wendy – ANON, UK 2000 - diagnosed - Multiple Sclerosis July 14 2009 - LDN

I will be seventy in October and was diagnosed with MS in the year 2000.

I have a slowly progressive form of the illness, which was treated only to alleviate the symptoms.

I wasn't happy with the results from steroids or Mitoxentrate and researched LDN on line.

Having spent six months trying to persuade my neurologist and my GP to prescribe LDN on the NHS I contacted the LDN Research trust. I decided to go on line and fund my medication for a trial period.

On July 14th this year I started taking the medication and within the first month my balance and co-ordination improved.

I felt the grip in my right hand tighten and had far more energy.

The only side effect was a brief disturbance to my sleep pattern.

I am into my second month now and my mobility is noticeably improved, I have managed to resume doing some gardening and can walk for thirty steps without any aid. My previous record was twelve and I hope to improve still.

#### UPDATE March 2010

Yes, I am still taking LDN. I have maintained my improved mobility and balance. Downside is chronic fatigue and disturbed sleep still, after 7 months, however; this is far out-weighed by the advantages.

# **197**

### Wendy L, Australia

1956 – Intellectually Disabled, 1994 – Autism, 2009 – Colitis, 1969 - Ankylosing Spondylitis (AS), 2004 - Coeliac Disease, Autism, 2009 - Microscopic Colitis Sept 2009 - LDN

Wendy, now an autistic adult, talks about growing up and about LDN.

As a small child...

Basically the world went on around me! I was scared of sudden noise, and would jump at invasive sounds. During thunderstorms I hid under the table... and sometimes didn't come out for hours. I 'played' by myself and was very content on my own. I loved the garden, as long as my younger sisters did not interrupt me. But my strongest fascination was with the sea, which was not too far away from my home.

On many occasions I actually escaped from the garden and walked to the sea by myself. Its ability to woo me and draw me into itself was very strong and I had no fear at all. I was separated from the shore on one occasion and my neighbour rescued me from the incoming tide. Although my mother chastised me for "going off" I really didn't understand what all the fuss was about!

As an older child...

Between the ages of 5-11, I lived very isolated from the world. My only attachments were my pets. I loved the kitten that my Grandmother gave me for my fifth birthday and he was my constant and only real companion. At school I felt confused and alone. I was constantly teased and mocked by other children. I just didn't know what was going on. I did my best to please the teachers and loved to listen to the voice of one teacher in particular.

I found school rules difficult to understand and so I was often in trouble. I hated school dinners in the primary School because they usually had hard foods like 'peas' and I couldn't eat them.

At home my diet was fairly limited. It consisted of mashed potato, carrots and gravy, white bread and butter with various fillings such as marmalade (minus the bits), jam, meat or fish paste, and cheese with tomato. The only cereal I ate was cornflakes, as long as it had the top of the milk on it, (the cream) and I never ate greens, rough meat or egg whites. Textured food that was not smooth made me gag and I felt like I would throw up if it stayed in my mouth.

For my eighth birthday I was given a new red bicycle. I loved sitting on the floor of our driveway and spinning the wheels of my bike. I loved the way the silver mudguards shone in the sunlight as they went round and round. I had learnt how to ride a bike by taking my mother's bike and standing upon the pedals to propel the bike forwards. I went for many solitary rides upon my bicycle.

One day I was following a big red bus when it turned out onto the main road. I thought that it was OK to go because the bus went. However, I was wrong and I was knocked off my bike by a passing car coming in the other direction. They took me to hospital in the ambulance but I never saw my bike again.

When I was nearly ten years old I had to go to hospital for almost a year because of a bone infection in my leg. Although this was a very traumatic time it was also very stabilizing because the ward routine gave me a measure of security. The thing that I hated most was waiting for visitors at visiting time and usually no one came. I couldn't understand at that time how difficult it was for my mother to visit me in a hospital 14 miles away from home. Especially when she didn't drive and visiting times were when my younger sisters were coming home from school. The sad thing is that no one ever talked to me or explained anything, it was just done.

For my tenth birthday the nurse's brought in a small cup cake with a large white candle in the middle. All the children sang 'happy birthday' and gathered around my bed. I dived under my sheet and pretended to be asleep for probably ten minutes, until they gave up and went away. I couldn't face them because I didn't know what to do. My heart beat fast and I felt really scared so I did what I usually did and that was play 'dead' and hope it would all go away. This was a common way of coping. If I didn't understand something or was unsure of how to respond I ignored the situation. I stayed in a world of my own that I had the control over and when that failed I returned to various obsessive behaviour that gave me back a sense of connection.

#### Teenage years

From age 13 to 19 I began to grasp the reality that I was different from most people around me. I found this realization quite depressing and worked extremely hard to discover how to be like others. I had few friends that tolerated my 'strange behaviour' and when I did find a friend then I latched onto that person in an obsessive way. That person dominated my existence.

At the age of seventeen I was committed to a mental institution, labelled schizophrenic and treated with anti-psychotic medication. For the following 25 years I lived with that diagnosis, and was on and off medication whilst going in and out of hospital. I received my current assessment of high functioning autism in my early forties.

#### Adult life

At age 20 I married and eventually had four children. After nearly 20 years I divorced and life seemed very bleak for some time. Today I live with my partner and I recently passed a PhD in psychology at Deakin University. My youngest son, now 28years old also has Asperger's Syndrome. He is working as a chef in a busy inner City Deli in Melbourne.

I have a few ideas about some of my experiences:

#### Emotions

Most of my life I feel like I am outside of what is happening around me. I rarely am able to identify the emotional environment of either myself or others, unless it's strongly felt. Life tends to be either 'happy' or 'not happy', 'angry' or 'not angry'. Until recently I always believed that if someone close to me was 'angry' then it must be because of me. Now I realize that people can be unhappy or even angry for many different reasons. In fact it may have nothing to do with me at all!

I think my anxiety can be extreme because for much of the time I am excited and enthusiastic, irrespective of how others may feel, and when those emotional states are not confirmed by the words of others I don't feel confident that I am OK. Sometimes the 'in-between' emotions on the continuum get missed. I jump from calm to panic in one major step!

#### Behaviour

I am much more 'in touch' with the world and 'in control' of how it affects me. This is because I have more understanding of what is happening and I can make decisions about it. If 'things' become too much, I can experience a sensory overload. I withdraw and recoup. I don't like change but sometimes changes occur when I least expect them and then I have to gather myself back again. This I do by 'self-talk'. Years ago this was out of reach for me because I was too immature to understand. Now I can practice this with a measure of success.

#### Sensation

I have very sensitive ears, eyes and skin. Certain noises 'hurt' my ears and certain lights 'hurt' my eyes. Strip lighting is one of the worst and lights that flash. If the strip lights have a grid covering them I cope better. I have an insatiable appetite for touch and love to feel the roof of my mouth, especially when I am either insecure or very secure! I love soft material and soft skin but I hate to feel my own skin against myself. This means that I need to wear PJ's in bed or put the sheet between my legs so they don't come into direct contact.

I jump at sudden noises and shake or flap my hands when I am excited. At times I twitch or shake involuntarily for no apparent reason. All that I can tell you is that it feels like an electric impulse passing through my body that I need to respond to.

I remember being a third year at University studying Social Science. When we came to the end of our first semester I walked around and around the table in the cafeteria feeling devastated because school was ending and I felt so miserable. Some of my fellow students thought that I was crying for joy because the exams were over, I told them the reason that I was upset and I think that it was quite hard for them to see my point of view.

I don't know what the future holds, but I'm sure I'll continue to write and share my life as an AS person. I am where I am today because certain people (and myself) believed in me. I would encourage any parent or professional not to give up on autistic people but to remain patient, consistent and caring. I know much can be achieved with time and persistence. Growth and development take years for non-autistic people. Lots of developmental delays are happening for us but the emphasis is upon 'delay' rather than cancellation!

I have 'woken up' over the last fifteen years. It may have taken me a lot longer to grow up and I still have a long way to go, but it's pretty scary to think that I could have been closed off forever, if certain people had not taken risks with me, or had given up on me completely!

My experience with Low Dose Naltrexone (LDN)

I first discovered LDN over the internet as I read about auto-immune disease and the positive results many seem to be experiencing from taking this medication, especially those with MS. A friend of mine in the UK, who had been diagnosed with Giant Cell Enteritis put herself on a trial of LDN and suggested I do the same.

This meant finding a doctor who would prescribe the medication for me. I don't have MS, but I do live with Ankylosing Spondylitis (AS), Coeliac Disease, Autism, Microscopic Colitis and Generalised Osteoarthritis. One or other of these conditions is crippling for me on a daily basis.

The above physical conditions cause me much pain & discomfort but I am unable to tolerate traditional anti-inflammatory medications and so I take Lyrica for pain. Lyrica, a

medication for seizures, kept me sane but made me sleepy. At first I was unsure how Lyrica and LDN would interact together.

Upon consultation with my doctor I was told the combination was safe but might make me even drowsier than I already was. I cut down my Lyrica to one at night, from 3 a day, and in September 2009, added the LDN.

It was interesting because the first few nights I couldn't sleep at all. No drowsiness in sight! This was distressing. I had never been good at sleeping but I usually managed some sleep, 4 hours at best, on a good night.

After about a week I settled into a good routine and found that I was able to get some sleep most nights, even though it was not as much as I would like. I don't mind too much about my inability to sleep well because I find I work best at night when others are sleeping and the household is quiet. As a writer I need a quiet environment to think and to focus upon my writing.

I have now been taking LDN at the dose of 4.5mg for six months. Some of the things I've noticed have been quite subtle changes but definitely for good. I notice I seem to get less tummy upsets and have a general sense of well-being. For quite some time I was only able to eat a very bland diet of mashed potatoes, pumpkin and chicken, fish or scrambled eggs.

These days I eat normally, although as a coeliac I have to be gluten-free. There are occasions when I have a stomach upset, usually if I eat out and the food is processed too much rather than freshly prepared. But I at least can eat a variety of foods not just bland ones. My diet isn't that exciting because I prefer to eat simply, but, at least I can eat spaghetti bolognaise now if I want to without feeling ill afterwards!

For the first few months my blood pressure seemed to stabilise and hover around 120-130 over 75. This past couple of months it's gone up again. I've noticed that I'm more stressed than usual with needing to finish a manuscript and living with some family relational issues. So, maybe the blood pressure stuff is connected to this?

When I first started taking LDN I gave up drinking wine. Then, after a month, I started having a glass of wine with my evening meal and made sure I had four hours before I took my LDN, at bedtime. I realise that LDN needs to be taken on an empty tummy and also without alcohol. This seems to suit me very well but it might not suit others.

I still have quite a bit of pain in my joints but for the past 3 months I've mostly walked without a walking stick. I know my knees can be better at times and worse at other times so I'm not too sure if the reduced pain and increased mobility is connected to LDN or if it's just that my knees are going through a better patch. I guess I'll need to revisit this in a few months time and reassess then

For now all I can say is that taking LDN is the only 'different' thing that I have added to my lifestyle. I am happy to keep taking it and I am happy to be suffering less from tummy upsets and less from joint pain. I'll keep aiming to increase my mobility, decrease my weight (wish me luck with that one) and keep an eye on my blood pressure. If I have time after all of this, I might write another book!

# **198**

#### Wendy L, UK 2003 - Multiple Sclerosis 3 Oct 2009 - LDN

I was officially diagnosed with MS in 2003, though interestingly, when I tried to join a drugs trial in 2008 the research Neuro retro-diagnosed the MS back to 1997 because he said there was ample evidence that I had MS in 1997. I was not shocked by that statement as I'd been arguing the same for years, even though my initial symptom presentation was atypical (epilepsy!), and I had no classic numbness at first onset; which resulted in doctor after doctor refusing to agree with my assertion that I had MS.

As my MS progressed it fell into a more typical pattern, so I was eventually diagnosed 6 years after my first episodes of illness. I have subsequently been told it was a political game to stall diagnosis because Neurologists knew the Risk Sharing Scheme for Disease Modifying Drugs (DMDs) limited recruitment to recently diagnosed subjects!

So I've had MS for 13 years, even though the official diagnosis didn't occur until 2003.

I began taking LDN on 3<sup>rd</sup> October 2009, one day after our little girl's 5th birthday.

I'd relapsed badly 3 times since my daughter's birth; had required steroids and hospital admission, and was so poorly between relapses I believed I'd moved into the Secondary Progressive phase, and; I retired due to ill health.

Now, however; I believe I'm having my first REMISSION in 5 years!

My friend who'd been taking LDN for years recommended LDN to me, though I had not given it any serious thought as I believed it was just for those with Primary Progressive MS as there were no other mainstream drugs to treat it. I also stalled because I was on Rebif and was too scared to stop the thing I had fought so hard to convince myself to start.

Eventually my curiosity got the better of me and I began reading EVERYTHING. (I'm a retired Occupational Therapist). Convinced by the evidence of studies and testimonials, I decided to give it a go and take both Rebif and LDN together, as I'd noted someone else say she was doing the same.

I put the subject to my Neurologist but they got defensive. I called the SHO, but they declared it "Nothing more than a placebo and not licensed to treat MS". I argued that hadn't stopped prescriptions for me in the past as I was on Modafinil (licensed for narcolepsy) on a Named Patient basis. Then the Neurologist said, it was "not at all dangerous in tiny amounts"; and that was all I needed to hear.

The Emed system of ordering and paying such a small amount is great, and in three days I had my first bottle! I tried not to have any expectations. I took the attitude, 'I have nothing to loose, so I'll just see'.

The next morning after an unusually great sleep and just 2.5mg of LDN, strange things had happened!

1. My right hand, usually tight with spasm and painful was COMFORTABLE though swollen? ! That had never happened before. It did not look like a placebo effect that's for sure! Within one hour of waking there was no swelling and I had a fully functional hand without stiffness, pain or tremor!

2. My left foot was the same as my right hand, but the swelling went more quickly and left me walking well.

3. My VISION IMPROVED! This, I could hardly believe. I could see the end of my garden more clearly than ever! (I've had countless attacks of optic neuritis, which have left me with some permanent vision loss).

4. NO OPTIC NERVE PAIN: Since beginning LDN my eyes have been comfortable! Previously, as my fatigue peaked, my eyes would hurt daily.

5. VASTLY REDUCED PAIN: This had also put me off LDN. I could not imagine getting through the day without codeine. Now paracetamol and/or ibuprofen are enough! (I did have some increased nocturnal spasticity during the first 3 days, but it passed.)

6. ZERO VERTIGO! My walking is better, and my balance is now good! I can look up, and look quickly left and right when crossing the road. (Following a brain stem relapse in 2005 this had been a big problem. Back then I could not move my head without toppling over from my chair.)

Thank you all at LDN Research Trust for being the beginning of a new life. Next month I'm going on holiday for the first time in 6 years! I'd not been stable enough before.

I'm not cured. The fatigue and old symptoms still bother me, but no new symptoms equals good news!

I hope and pray we all stay well (for us) on LDN!

I wish Dr Chris Steele success in his campaign to show the Government the potential of this amazing CHEAP drug.

Here's to all autoimmune sufferers.

# **199**

#### Zillah B, UK Mar 1994 - Relapsing Remitting Multiple Sclerosis (RRMS) November 2006 – LDN

I was diagnosed with MS in March 1994. I was told that stress was probably the trigger and working six days a week for about 10 hours a day didn't help.

I was not ready for this news and after a course of steroids helped me to fully recover from my episode I felt sure that I could carry on working the same 10 hours a day.

I was wrong! Approximately two months later I relapsed yet again and was quickly taken back to the hospital. I learned I had Relapsing Remitting Multiple Sclerosis (RRMS), and was provided with a wheelchair from Scope and told to expect to be using it much more within a year. This was also very unwelcome news.

After my recovery the second time, I decided that using the wheelchair sooner rather than later was not going to happen and I started to learn to manage the situation.

The symptoms I experienced were numbress and weakness in my legs, and some tingling in my arms. Providing I didn't overdo it and rested if I got fatigued, I seemed to do fine.

On the whole, I feel I managed the MS well over the years, although there were times when I felt despair because I was so young when it first presented, just out of my teens, and I felt it was so unfair this had happened to me.

I've had MS now for 14 years. I've had some relapses during this time - some more frequent than others - and various symptoms.

I've had relapses and they've typically occurred around major events in my life; such as moving house, redundancy, and preparing for my wedding. This taught me stress and anxiety play a major role in the occurrence of relapses, however; on my actual wedding day, my health was very good (probably the good adrenaline!).

A couple of years ago I had a relapse. The steroids didn't help recovery anywhere near as much as they used to when I relapsed, so I decided to see if there was more that could be done - rather than dosing up on steroids, which no longer helped me.

I asked around, and a friend told me he had heard about something called High Dose Oxygen Therapy (HDOT). I did lots research, made some enquiries and found The West of England MS Therapy Centre in Nailsea, near Bristol was offering the therapy.

I was very surprised to learn the centre was established way back in 1985, to provide support, advice and therapies for people with MS - also that they were one of many such centres around the country! Why aren't all patients with MS informed of this?

I went to the centre every day for three weeks. This is the recommended 'saturation period', and it also helps practitioners determine the best treatment level for each patient. I started noticing some lessening of fatigue after the first week, but my balance and mobility were still a problem. After the second week, urgency to go to the toilet considerably improved, and my mobility also began to improve.

For the first time in as long as I can remember, I began to sleep through the night without needing to use the toilet. I felt the oxygen was definitely helping. I began attending the centre regularly, for one or two sessions a week, and was very surprised by how many visitors used its facilities.

While attending the MS Therapy Centre I chatted to others with similar problems. Most were using the HDOT, but some were also having other therapies the centre offered, such as physiotherapy, counselling, reflexology and aromatherapy. The centre offered all their therapies at low 'donation prices', and I thought, if they helped MS sufferers it was definitely worth it.

I also learned of another medicine that was said to help MS - an alternative to Beta Interferon which, I'd been told, was not justified for my level of symptoms and progression. I found out that, although not readily available in this country LDN had been used in the US for many years to help MS sufferers.

Other people at the centre were taking Low Dose Naltrexone (LDN) with good results. I'd never heard of this before, so I researched further. I discovered plenty of information about the medicine from the internet, particularly from the LDN Research Trust website. I must say, I owe a big debt of gratitude to Linda Elsegood who owns the site, and Dr Bob Lawrence, because both helped me learn more about LDN.

I found a doctor who was familiar with LDN, and gained a prescription. I was monitored carefully by him throughout my first few months.

I started taking 3mg and continued that for the first month, then moved up to the optimum higher dose of 4.5mg and have been on that dose since. I've been taking LDN ever since.

Although at the start I noticed some minor re-occurrences of old symptoms, such as tingling in one leg, I'd been forewarned this could happen and so wasn't worried. I just waited patiently for it to pass.

I felt the LDN was definitely helping to stop me from slipping back. In fact, my health continued to improve and the initial recurrence of symptoms dissipated soon after.

In terms of improvement, in a reasonably short period of time I no longer had an urgent need to go to the toilet, my energy and mobility greatly improved, and although I still had some difficulty with balance from time to time, even that was slowly improving. Fatigue was no longer a big issue, as long as I was realistic and sensible.

For me, the combination of LDN and Oxygen Therapy was the key to my feeling so much better, on more fronts than I had in years.

Over recent years, my life has undergone some fundamental life-changing events.

The first was on Boxing Day 2006 when my stepson complained about discomfort in the hip and his mobility was affected. My husband ended up spending a couple of hours with him in casualty. He was scheduled for a follow-up hospital appointment in early January 2007, but none of us suspected how serious his condition was, not even the hospital staff.

After his tests, and quite suddenly, everything changed. He was suffering from a very virulent form of Cancer of the ligament, which is extremely rare. An oncologist was called in.

Both his mother and my husband took it in turns to be at his bedside - my husband usually there all night. I visited as much as I could, but the shock hadn't done much for my health. In fact, both sides of the family were regular visitors to his bedside. The way he dealt with this final illness, at only 14 years of age, was truly inspirational, but sadly, it claimed his life only 4 short months after being diagnosed. You can imagine our feelings at his loss.

My husband was devastated, and although I tried my best to support him he was unable either to share his grief with me nor witness evidence of my own personal grief. Unfortunately he became more and more distant, spending more and more time away from home. We eventually parted, without acrimony, just before Christmas 2007 when I finally made the move to live geographically closer to my family because my health was now suffering considerably. I spent a short while living with my mother until I felt able to move into my new home.

Even though I experienced 3 major stressful events over an extended period of time - bereavement, a marriage break-up, and moving house (twice) - I did not end up in hospital. I'm convinced, if not for LDN, I would have been in hospital and on steroids. These 3 events, so close together, did cause a relapse, but nothing as bad as one would expect under these circumstances.

I've recently been working on building myself back up again; and on the positive side, I'm now able to work four days a week (2 in the office and 2 from home).

I've been seeing a physio and it's helped with mobility, but unfortunately I can't take additional time off to go for oxygen therapy. I'm more tired and getting aches and pains, and in particular, the pins and needles have become more pronounced, so I plan to go back to Nailsea and resume the oxygen therapy. I feel the LDN and oxygen therapy combined may work better for me while I'm trying to rebuild myself.

It is now 14 years since I was told that I would be in a wheelchair within the year. Although I use a scooter to walk the dog (he's a collie and needs a lot of exercise), and I occasionally use the wheelchair when shopping (e.g. for clothes), on the whole I'm still using my own two feet; even though I sometimes use crutches.

My experience has also helped others. A friend and colleague's wife was recently diagnosed with MS and immediately came to see me for some advice, because they felt I was doing quite well.

I wish I'd heard about LDN earlier. There isn't a cure for MS yet, but I'm convinced that LDN is a great help in minimizing its impact.

Update - August 2009: I don't really have any additional information or events since the last update I sent you. I am still taking the LDN, and it is still helping. Not a lot has changed since the last update, I am still working 4 days a week and living in my own house.

## 200

Zoe K, UK 2006 - Crohn's Disease late 2007 - LDN

In 2006 I was diagnosed with Crohn's disease.

It started with a chicken leg and a classically English BBQ. I found the host sheltering under an umbrella with a disposable tray of coals, guttering under the weight of tepid food. Later, to be polite and because I worked as a cook, I took one bite of the chicken before realizing it was gelatinous and raw at the bone.

Four of us came down with food poisoning that night and it was only me that didn't get better. Six weeks later after losing a stone and feeling that something wasn't right, I went to my doctor. The antibiotics didn't work but then I became one of the lucky ones so to speak medically. After a colonoscopy, I had an instant diagnosis of Crohn's disease, or in gruesome detail, ulcers were spreading like chicken pox along the entire length of my gut.

At first, I felt vindicated, there was something wrong with me and I wasn't being pathetic, as I'd felt before. But if I had the label, so too did the doctors and therefore there was treatment. Prednisolone was mentioned, not as a choice but as my only option and so I began what they told me would be one month on and one month tapering. It helped, I realized I had energy, I wasn't continually on the toilet or writhing in pain, and as someone obsessed with food, I had my appetite back

It was great if I discounted the manic highs and lows, the not really sleeping and the breakout of spots on my face. Which, at first, I did thinking this was necessary. The month passed and I began to taper the dose. As the mg's came down, so too did my weight, my appetite and my mood. And so began the yo-yo. I was on steroids for over a year and a half. The doctors tried to get me to change onto something more long-term, but now I didn't trust it. I looked twice at the possible medications, after all, this one hadn't worked out like they said. For all my life I had perceived doctors as infallible, and now I realized with the best will in the world - there is much that they don't know, especially in the arena of chronic disease.

Everyone had advice and worse, warnings about what to eat, what not to eat, and their own prejudices about doctors, treatments and medication. Navigating it all was a sea of confusion with a foggy steroid-filled head and gut instincts that were decidedly queasy. I tried diets. I tried wormwood. I banished all yeast from my life (nigh on impossible). I reverted to babyhood and drank only white liquid from a tin, even though as a baby I had rejected anything but the breast.

One of the topmost Crohn's specialists in the UK said this was the best option and so for 6 weeks I blended my morning tin of nutrient milk shake and carried a flask, trying to convince myself that chewing was over-rated. Then came weaning food back in, more difficult than the first time for sure, especially as my health was worse than at the start. Food went through me in less than four hours. I timed it. My life shrank and was consumed by the disease. I shrank too. My weight changed daily. For a few weeks I'd gain weight and skip around thinking it was all over, and then the bottom would drop out or as I started saying with a wry smile to anyone who'd listen, the world dropped out of my bottom.

My starting weight was around 10.5 stone, I'm over 5' 8". It dropped to less than 7 stone, a B.M.I of 14. The doctor repeatedly threatened hospitalisation. Having moved back into my mother's house I spent weeks in bed, tended to by my mother and sister. Terrified of eating, but even more terrified of the consequences of being empty. The worst part of it was coping with the cycles, the few weeks of hope and conviction that I was getting better, then it slipping away and the cramping beginning again. Each time was more depressing than the one before, the mental drop crashed onto and compounded the recurrence of symptoms.

The doctors shifted in their tactics. Now, instead of the disease, it was me that was being difficult. I was not accepting the gravity of my situation and ignoring their advice was risking my future chances of health and happiness. By not switching medication, one doctor told me I was signing myself up for a future of bowel operations and pain.

To me, the medications on offer didn't sound so great. Azathioprin, they said, would hold down my faulty immune system with a strong arm to stop it playing up. The other option would coat my entire intestine via 16 pills a day to stop the inflammation. I wondered what benefit could possibly be accrued by further weakening my immunity.

Surely at my tender age, still well under 30, my already battered system didn't need to be messed with? I kept stalling, and the weight kept falling off and with it... my quality of life. Then my uncle, an open-minded doctor in the States had a patient mention to him an alternative use of Low Dose Naltrexone. He looked into it and tentatively suggested it. My GP here was willing, once I presented the evidence.

He said he'd prescribe it and let me trial it, with the condition of weekly blood tests, weigh-ins and the understanding that if it didn't help, I'd play ball with the specialists. Through Linda at the LDN Research Trust, I found Dickson's chemist and received my first batch through the mail. The only concern I had was the side-effect of interrupted sleep, but then I figured, not much could be worse that 10 toilet trips a night.

During the first week my dreams were a little odd, but then I was at least sleeping enough to dream. I continued with the steroid at the same time, and at first, no-one would say which drug was helping. But the blood tests told the story. Each week my inflammation indicator levels dropped down. By week three they were approaching normal, and I was gaining weight, fast.

My doctor was overjoyed. I was too, but the long months of yo-yo-ing hovered in my mind and I waited, quietly hopeful, but at the same time dreading any new downward slope. The blood tests became fortnightly, then monthly. Then, I got the most welcome advice I'd heard in a long time. My GP told me to go away and avoid doctors. I did.

I was lucky enough to have the luxury of taking the time to heal myself. I followed the birds and flew south for the winter, becoming the houseguest that never leaves at my cousin's in Florida. I watched my diet, eating the now familiar soft pappy food and only slowly bringing in new tastes and past loves. I gained weight and strength and most importantly, learned to trust my body again.

It took another year before I looked at salad and popcorn with anything other than distrust mixed with intense envy of the people enjoying it. Now almost two years in, with a tiny 4.5mg pill each evening, I eat what I want and I appreciate every ounce of energy and freedom that life affords me. I know that my gut is a weak point, and if I get run down it acts up, but that is life. Everyone has their Achilles heel, but now mine has protection.

# 201

### Zora T, West Indies 1983 – Probable 'Multiple Sclerosis' in London 1983 – Definite 'Multiple Sclerosis', Slovakia, Bratislava Sept 2004 - LDN

This is what I have written on my web page. Yahoo is scrapping geocities this October 2009, so I have to find another place and also to update it.

I have been on LDN since September 2004, 5 years as at September 2009.

I use and prefer taking liquid LDN, so I place one 50mg Naltrexone tablet in 50ml of filtered water to dilute it, then draw up a 4.5ml dose each evening.

Why this method? I have two daughters in Canada and we find it is much easier to get the 50mg tablets. That way, I need a prescription from my doctor only every 3 years or so, and there are no additional fillers to worry about.

Before LDN, I was slowly but surely going downhill. I was reading message boards in Yahoo for a long time before I made my mind up and gave it a try. The most attractive thing was that it was readily available and not expensive.

After a while I noticed that I was not deteriorating as before. I now do not feel fatigued at all, I have more strength in my hands, and I manage to do a lot of other things.

Other than the above I did not notice anything else different about my body.

People say the response depends how long a person has the disease and the damage that has already occurred. I've had MS for a long time, so ceasing the deterioration was welcome. I definitely will not stop this medication.

Update – May 2010

Yes I do still take LDN every night, though I do miss it occasionally. I now take 6-8mg each night but do not measure the dose precisely. My MS is at the same level, but other things are creeping up, like arthritis, which I guess I cannot escape. I'm also experiencing problems with skin healing due to sitting down all day long. The skin on the sitting area becomes sensitive, can break up, and it's a real fight to heal it.

### ACKNOWLEDGEMENTS

### The need to raise awareness of LDN unites us all.

Many volunteers have worked tirelessly over many years so you too will learn of, and WE ALL HOPE, benefit, from LDN.

In particular, Linda Elsegood would like to gratefully acknowledge the dedication of the following International LDN Awareness Week volunteers who contributed generously of their time to support this ebook project in the interest of international unity and raising awareness.

### 2010

Sincere thanks to Jayne Thomas, Sherri White, and John Donnelly for all their hard work collecting stories for this edition.

### 2011

And thank you in advance to Jayne Thomas, Sally Darin-Brame, and Suzanne Harvey for collecting 2011 stories.

### 2009

### **Malcolm West of Practical Communications Group**

MS Patient, LDN Advocate, and LDN Aware website manager <u>www.ldnaware.org</u> Contact <u>malcolmwest@comcast.net</u>

### SammyJo Wilkinson of LDNers.org

is an MS Patient Advocate who has been helped immeasurably by LDN, and who has worked tirelessly to raise funding for LDN research and awareness. SammyJo co-authored, with Elaine Moore, the book 'The Promise of Low Dose Naltrexone Therapy: Potential Benefits in Cancer, Autoimmune, Neurological, and Infectious Disorders'. Contact <u>redtruck99@yahoo.com</u>

### Julia Schopick of HonestMedicine.com



Julia Schopick's website, HonestMedicine.com, contains information about treatments like LDN, which save lives but aren't well-known. In 2009 Julia compiled the Int'I LDN Awareness Week ebook, 'The Faces of LDN'. Julia's next book, 'Four Lifesaving Treatments that Could Change Healthcare' is due out in 2010, and LDN is one of the featured treatments. You'll find Malcolm West's story featured in both this book and in Chapter 14 of Julia's new book. Contact JuliaS1573@aol.com

the primary LDN info website is located in the USA Dr David Gluck, Editor, primary LDN website www.lowdosenaltrexone.org

### ACKNOWLEDGEMENT

Editing and production of the 2009 ebook '100 Reasons Why', and 2010 ebook '201 Reasons Why' was contributed by Cris Kerr of Case Health.

Cris has long been advocating for scientific recognition of the value of patient testimony to health systems, and has been turning up the volume so patient voices are heard and afforded the credibility they deserve... beginning with her 'Case Health – Health Success Stories' website; 2001 to 2009.



Cris continues to produce the free LDN resource book 'Those Who Suffer Much, Know Much' annually. The 2010 edition (5<sup>th</sup> revision) of her book contains an impressive volume of evidence with over 50 LDN case studies, 18 interviews and perspectives from health



professionals familiar with how LDN is benefiting patients, explanatory articles, and a comprehensive collection of studies, clinical trials, scientific research and references.

The 2010 edition is again available free of charge or expectation, and Cris continues to encourage everyone to adopt the same philosophy and 'share it forward'.

You can obtain your free copy from the LDN Research Trust website here http://www.ldnresearchtrustfiles.co.uk/docs/2010.pdf or email Cris <u>casehealth@optusnet.com.au</u> to request your copy.



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