

International LDN Awareness Week

19th - 25th October 2009

We need your help, please.....!



We are planning an International LDN Awareness Day and need the help of as many people as possible who use LDN to treat any of the very wide range of conditions wherever they live in the world. All media coverage will be added to the website.

What we need from you:

We need you to e-mail us with your LDN story. It doesn't matter how long your text is, or whether spelling or grammar is not your 'thing', because it will

be edited for inclusion in a Press article. You will, of course, be sent a proof before submission.

Together with your story you need to include your full name, address and permission to be contacted by your local paper, radio and/or TV station.

What we will do:

We will contact the media in your area, submit your story and our Press Release for the LDN Awareness Week. Hopefully the media will follow

it up with an interview.

We will contact the national media once we have enough local stories.

We really do need everyone's input for our endeavour to be a success, and if you wish to help raise awareness of LDN, here is your chance to become involved. We really do need your help, so please, please do help us!

Please contact us by e-mail contact@ldnresearchtrust.org with your story as soon as possible.

We must act NOW!!!



LDN Polo Shirts and Free Car Window Stickers

We hope everyone will be displaying an LDN sticker ready for the awareness week, it would be great if you can get as many family and friends to display one as well, email contact@ldnresearchtrust.org with your name and address and how many you would like. We mail worldwide and a donation towards postage would be welcome if possible.

Support us by wearing an LDN Polo Shirt for details: http://www.ldnresearchtrust.org/default.asp?page_id=127



UK Members:

A Brand New Fiat 500 could be yours!

Here is your chance to win a NEW Fiat 500, It is low emission, safe and stylish. It's the car that has got Jeremy Clarkson raving *"...my God, you come away from an experience behind the wheel absolutely loving it. It's cheeky and nonthreatening without being pathetic. It's practical without being boring"*.

Tickets cost £2, the LDN Research Trust will receive £1.90 of every

ticket sold.

We really need YOUR help to carry on the work we do and this is a fun way of doing it.

Get your family and friends involved. Please buy your ticket securely online by clicking www.everyclick.com/ldnresearchtrust

Your help and support is appreciated!

My hour on the plinth - Brian Longsdale



“I know at least two people were helped by my talk, as two of the Artichoke staff said they found it interesting as their mothers had MS. I was told that, during my talk, another 25 signatures were added to the petition, and another 100 had been added five days later – clearly not all due to me but I’m glad to have contributed”.

When Anthony Gormley started his Fourth Plinth project I suggested to my wife, Mary that she should go up onto the plinth to publicise a petition on the Government website. The petition asks the government to arrange for LDN to undergo trials, as it is only available off-licence at present and many doctors are reluctant to prescribe it. Mary was game but she would need a constant carer (me). Unfortunately insurance prevents more than one person being on the plinth at any one time, so I said I’d go up if my name was drawn – fool that I was?

My name did come up of course, and then they asked me if I wanted to take up a cancellation in three days time. I said “I’ll ring you back in 5 minutes”. Of course I had to take it! I have to say I was very nervous and only finished preparing for my stint at 1.00am on Friday morning but it turned out to be quite good fun really.

When we arrived at Trafalgar Square, the production company, Artichoke, were very helpful and allowed us to park in one of their allocated spaces. My mouth was already dry so I welcomed the cup of tea on offer. I then had to be interviewed, fill in a disclaimer, and have my photograph taken. I asked if somebody would look after Mary while I was doing all that and also when I did my thing on the plinth. They said not to worry they would do so, and they did much more –

they asked Mary if she would like to go and watch me on the plinth and if she got cold they would bring her back into the warm portakabin.

I was finally taken to the plinth on a platform-crane and changed places with the ‘cricketer’ who was on before me. My nerves had obviously kicked in by then, as I took the hand-outs and the petition forms that I had with me up onto the plinth – silly really, my arms are not that long. Luckily a couple of ladies, who had been told I would be there by Dr Lawrence, turned up with some leaflets and started handing them out. It seemed like it took ages to put posters up before I started to talk but it was only a couple of minutes and I filled the time by talking to whoever was listening on the internet! I was a bit annoyed with myself really, as I dropped one of the large posters and the wind blew it away. Anyway, now the moment had come!

I looked round to see how many people were there (it’s a good view from up there). There were quite a few people and Mary sat in her wheelchair, looking very comfortable, with a couple of helpers in attendance. I started by saying I would speak for about 10 minutes and then repeat myself about 5 times, as I couldn’t think of enough to say for a whole hour. I briefly explained our situation – how Mary had contracted MS a year into our marriage 48 years ago (initially misdiagnosed as Epilepsy), and

how it progressed slowly after that, until she had to go into a wheelchair in 1984. 1984 was the year Dr Bihari discovered LDN – **25 years ago and nothing has been done about LDN since then!**

I then went on to describe how, when Mary was losing the use of her last limb, her right hand (at that stage she could not even hold a mug in her hand), we heard about LDN and after a bit of a struggle got our doctor to prescribe it. It was fantastic. Mary recovered the use of her hand within days. Now, five years on, she can still hold a mug in her hand – it doesn’t sound much but that bit of independence is worth holding on to.

I said: “After all you only live once and a long time dead!!”

I explained, again briefly, how LDN works, by creating endorphins which in turn boost the immune system. I then listed diseases that LDN helps, like MS, Parkinson’s, HIV/AIDS, Rheumatoid Arthritis, Crohn’s disease, Colitis, Fibromyalgia, Infertility, and even some cancers, as well as other diseases of the immune system. I managed to repeat this twice in each session, saying everybody must know somebody with one of these diseases.

It was at about that time that the heavens opened. I looked down at Mary and she was alright! She had two people fussing over her. She was covered by a large golfing umbrella, with a blanket over her legs and another umbrella keeping her boots dry – the rest of us got saturated!!

Volunteer Transcribers Needed

Julia Schopick -- a health writer and patient advocate who often writes about LDN for her website, www.HonestMedicine.com -- is doing her part to make Global LDN Awareness Week a big success.

She could really use your help transcribing audio interviews for an ebook she plans to share with the media and the public.

Julia will be putting together a pdf file (an ebook) of LDN-related articles and resources, which she will offer FREE throughout the month of October to both the press and the public. This ebook promises to be filled with information, which will further our goal of educating the public about the wonders of LDN.

As part of this ebook, **Julia plans to include transcripts of several of Mary Boyle Bradley's wonderful interviews from her Internet Blog-TalkRadio LDN show** www.blogtalkradio.com/Mary-Boyle-Bradley.

As those of you who have been downloading these shows know, every week, Mary interviews leaders -- both physicians and patient advocates -- in the LDN arena. Among those she has interviewed so far: SammyJo Wilkinson, Dr. Phil Boyle, Dr. David Gluck, Dr. Ian Zagon, Dr. Burt Berkson, Vicky Finlayson and Dr. Skip Lenz.

If you haven't already listened to these interviews, please check them out. You'll enjoy them.

So, here is where Julia needs your help:

Are there a few good people out there who have the time, and would be willing to transcribe some of these interviews? If several of you can help by transcribing just one interview each, it will be a great help.

Please email me your name, phone number and email address and I will pass them on to Julia. She will take it from there. (By the way, when you are on Mary's blogtalkradio site, do listen to Julia's interview with Mary.)

Thanks so much, in advance, for any help you can give to this project. We feel confident that having educational materials to share with the media -- and with the public -- during International LDN Awareness Week will go a long way toward getting the word out to the world about this wonderful treatment. **(And of course, credit will be given in the ebook to each and every person who helps with the transcriptions!)** We hope that several of you will be able to volunteer.



NEWS: Julia is in the process of writing a book about **"four inexpensive, lifesaving treatments that could change healthcare."** Of course, LDN is one of these treatments. (The others are intravenous alpha lipoic acid, the ketogenic diet, and Silverlon. You may read about them at

www.honestmedicine.com/2008/05/four-lifesaving.html.

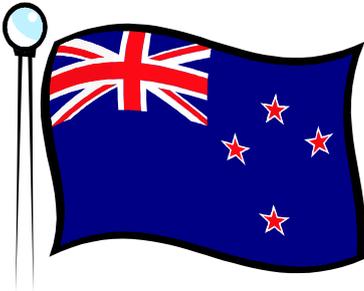
International Awareness Week Testimonials

Your help is urgently needed!

Please help and support us, we need you to e-mail us with your LDN story. It doesn't matter how long your text is, or whether spelling or grammar is not your 'thing', because it will be edited for inclusion in an Awareness Week eBook which is being compiled by Cris Kerr.

We would like to hear from you as soon as possible, wherever in the world we live.

Autoimmune Disease vs LDN – Nettie



My two-year nightmare began in August 2006 when I woke up with severe cramping in my abdomen, vomiting and diarrhea. 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. It was performed a few days before Christmas.

The gastroenterologist found a large polyp, and told 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, but I had to have it removed surgically because it was impossible to remove by colonoscopy without the risk of perforating the bowel.

The surgery in February 2007 was straightforward, 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 sleeping. 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 prescription 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".

Then she prescribed Lexapro followed by Paxil. The tremors didn't return, but I continued to lose weight.

I felt progressively unwell and developed electric shock symptoms and numbness in one foot. Saw yet another doctor who increased the Paxil and added Naproxen. Two days later I called back into the clinic to have my B/P re-checked. It was 170/120 and shouldn't have gone up that much in two days. I saw doctor number 4, and at last I was viewed as someone who was sick.

The Neurologist seemed concerned and he told me I had Peripheral Neuropathy of which there could be 100 causes. He ordered a bunch of tests

and said he would see me in a month for the results. On October 30th while at work, I developed shooting pains in my jaw while eating grapes, and then the whole left side of my face went numb. Panic ensued, and my husband came to take me to the ER.

A CT scan revealed nothing, but the Neurologist assured me that the MRI he had ordered was bound to tell him something. I couldn't return to work in the meantime as I had to drive half an hour each way. 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. I went straight to my GP and asked that I be taken off them.

He assured me there would be no withdrawal affects from the Paxil since I was on the lowest dose. He put me on a decreasing dose of Temazepam to wean me off. All I could do was wait to see the Neurologist on the 19th.

We would like to thank
Cris Kerr

Case Health - Health
Success Stories, for
sharing with us.

Continued Autoimmune Disease vs LDN – Nettie

What an anti-climax. Tests revealed nothing, he said, and he recommended taking a wait and see approach. 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 shocks down both arms when I turned my head. I knew this could be an MS symptom, so I had to have the spinal tap to be sure. Results? Nothing.

So where did all this leave me? What did I have? Where would I turn? You guessed it - the internet.

To cut a long story short I dealt with each symptom separately. I wasted a lot of time waiting for appointments to see specialists. I became convinced early on that I had developed a thyroid condition. I was also convinced that I was suffering from some sort of autoimmune disease(s). In 2008 I found a chiropractor who researched everything I was telling him. He did reduce a lot of my pain but then I reached a plateau. I lost my job and my health insurance and stopped seeing him. The third Neurologist I saw diagnosed a goitre, Hashimoto's thyroiditis and low levels of Vitamin D. I was relieved 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, and get more exercise.

Now I am not overweight, and I was simply not capable of exercising - muscle pain, weakness and fatigue made it impossible to do much.

It was time to speak up and take charge of my own health. I read about LDN and 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. I told him I wanted a prescription for LDN, and if he wouldn't write it for me I would still get it. He simply said, 'I know you have done your research - just give me some information on LDN for your file'. I had my Rx the next day.

I took my first dose, gradually increasing to 3mg. I felt an immediate improvement in energy, the pain and an overwhelming sense of hope for the first time in more than a year. I tried increasing to 4.5mg but my leg muscles became stiffer so I dropped it again. I had an appointment to see a gastroenterologist, and when I 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 pre-cancerous polyps, and

microscopic colitis. This was the only disease left that I could find that explained my unending diarrhea. 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.

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, and the doctor wrote a prescription for Asacol.

Between LDN and the diet, I was cured. I say cured because if I stick to my diet I have no issues whatsoever!

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, and to demand what I believe is right. No-one knows your body like you do. 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.

I hope this helps someone,
Nettie, NZ



Are you or have you taken LDN for any condition?
We would love to hear your story.

MY 2 LITTLE PILLS are called LDN

Kristie Sullivan in Tennessee

. Imagine being the sick child in the family. Tonsils removed at age 6. Liquid nerve medicine because of tummy aches. Always getting a virus!

Imagine as a teen not eating pizza because of stomach pains and all other pains are called growing pains even though you only grew to 4ft 11 ½ inches tall. Then as an adult you hurt with muscle spasms and doctors say “You did too much” or “Maybe you’re depressed” when you want to sleep so much.

Gall bladder removal, cystitis, hysterectomy and always having “Inner Ear Infections” and losing balance for weeks. Your eye-ball hurts so bad at times you wish you could just take it out for awhile. Your vision comes and goes and the docs say it’s low blood sugar. And you wonder why your mom and grandma have so much energy and you don’t!

Then at age 46 your feet decide to go to sleep! The next day your leg goes to sleep and hurts so bad you can’t sit, stand or lie down. You have to keep moving to make the pain tolerable, only you stumble and can’t keep your balance again! So you decide to go to your doctor even though it’s probably in your head anyway. And think “this is a fine time for my inner ear problem to act up!”

Again the doctor says

“You probably pulled something in your back, or hit your leg..if it doesn’t leave in 6 weeks come back”, which leaves you begging him for at least some pain medicine so you can sleep! You go home to sleep and then awaken to a major decision. “I’m getting another doctor!!!” You call a doctor who a friend recommends, and they see you. That doctor is very concerned and pats you and says “we’re gonna fix your problem. It’s not in your head!” In a week and a half you have tests that confirm multiple sclerosis. (Which was the easiest diagnosis the neuro ever made, due to so many lesions on the MRI.) The spinal wasn’t needed but it was done too.

I was so thankful to hear it was M.S. 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, then switched to Rebif, then to Betaseron shots. I was tested because for some reason my MS was progressing too fast, and I had Solumedrol I.V. every 4 months for exacerbations. When tysabri and other new meds were mentioned I said no because I was not ready to take the risks involved.

Then I discovered

LDN (Low Dose Naltrexone). I found it searching on the internet. Since I worked in a cardiac unit years ago I understood to take care, but this intrigued me and made sense. After studying it for 2 months I asked my neurologist to check it out to see what she thought. She wanted to make sure it was safe for me, and studied it too. After 4 months she said I’m ready to try the LDN for you if you still want to try it. YES! After all at this stage 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, and that doctor was so impressed he put a pancreatic cancer patient on it!

Now my doctor calls LDN “Kristie’s Medicine” and says she is getting known as the LDN Doctor here in Tennessee. She gets calls almost daily from new patients who want to try it.

I’ve been on it a year now and I have not had a single exacerbation! No balance problems, and my cane and walker are put away! Everyone from my family, my friends, my doctors, pharmacists and me are amazed at how well I’m doing. LDN should never be hidden from patients.

I advertise it anywhere and everywhere I can!

Kristie Sullivan



LDN Prescribing and Prescribers - Dr Tom Gilhooly

One of the great challenges we face in increasing the availability of LDN is to persuade my fellow medical professionals of the value of prescribing this drug. The usual objection is that LDN is "off licence" and therefore its use is not allowed! This is not the case however, as the prescribing of "off licence" medication is enshrined as a right of any medical practitioner. It is true that the responsibility for this prescribing is jointly shared between the prescribing doctor and the dispensing pharmacist, but "off licence" prescribing is a daily occurrence for most doctors in the U.K. Another objection is that the medical indemnity organizations will not cover this activity, but in most cases this has been an assumption rather than fact. When the situation is explained to the medical indemnity insurers, that we intend using a fraction of a dose of a medication already known to be safe, and which has been available for 25 years, they have little concern about this. A good analogy is with aspirin, which is a well-established painkiller and anti-inflammatory (although with significant side effects). When it became apparent that this drug was also useful in smaller doses as a blood-thinning agent, there were few doctors who were reluctant to prescribe it, regardless of the licence situation. The key point is that they were familiar with the drug in its standard dose and so felt confident with prescribing the low dose version, as common sense would dictate it would have fewer side effects. Naltrexone is not a drug which most doctors have had any experience of, even those who have used substitute opiate medication such as methadone. In my capacity as clinical director of two drug services and medical officer to four drug

rehabilitation centres, I was fortunate enough to be familiar with naltrexone so was not concerned about the prescribing of low doses.

In my NHS practice we have over 40 patients on LDN for a variety of reasons. The drug is prescribed like any other, patients do not pay for the prescription and it is on the computer as a repeat medication in the majority of patients who are now established on a stable dose. This is clearly a model for future LDN prescribing, but even in our practice, when I am not available, the other two doctors will not take responsibility and sign prescriptions. I am confident this will change as they see the benefits to patients but at present it means that I have to put in a lot of preparation work to ensure the prescriptions are up to date if I want to take time off. Recruiting other doctors to work in The Essential Health Clinic has also been a challenge. One doctor was happy to work there but not to prescribe LDN and as this is such a large part of the work, it meant he was not seeing many patients! The ironic thing is that it is the doctors who are missing out. Seldom, if ever, have I prescribed a drug where the feedback was so overwhelmingly positive. We managed to recruit one doctor who, after a great deal of deliberation and due diligence agreed to prescribe LDN. He concentrated on patients with psoriasis, and although several patients have given up the treatment mainly due to financial constraints, he has been amazed at the effect of LDN in this condition. He asked me how many patients who were still attending did I think had a skin clearance? This is an incredibly difficult thing to achieve in psoriasis and as the skin is visible, any persisting lesions could suggest treatment failure

even though the inflammation was greatly reduced. The gold standard in Psoriasis research is 75% clearance and many clinicians consider this to be far too high, with 50% a more achievable target. I suggested that perhaps 50% of those still attending the clinic may have had a total clearance, bearing in mind that those still attending are more likely to be having success. I was astonished that when he told me that all 100% were clear. Although this was only 7 or 8 patients, in the doctor's words 'everyone has had their lives transformed'. One patient who attended that evening had been clear of psoriasis for the first time in 51 years. You can imagine how good the patients felt and I could see how good the doctor felt! He is now branching into using LDN in Crohn's disease, chronic fatigue and MS as his confidence has grown.

The need for training and support of doctors is huge but could increase the availability of LDN, and patient and doctor satisfaction. Prescribing LDN is not difficult, but it does have its challenges. I am firmly of the opinion that it should only be carried out after a face-to-face consultation with a trained and experienced clinician. I know this is a high standard, but the reputation of LDN has already been damaged by poor prescribing practices in the past. One of the challenges of the LDN Research Trust and others in the field is to provide this training and support for doctors, in addition to making the drug more widely available, preferably on the NHS, so that cost factors are not an issue and LDN can be collected during a routine visit with a GP. The prize is better health for patients and greatly increased job satisfaction for doctors; something worth striving for, and alongside the research agenda one we urgently need to address.



Mary Bradley talks about LDN and her new radio show

[Link to Mary's Radio Show www.blogtalkradio.com/mary-boyle-bradley](http://www.blogtalkradio.com/mary-boyle-bradley)



In 2002, when my husband's Primary Progressive Multiple Sclerosis was progressing at a rapid rate, I never imagined that the nightmare would end happily. Our doctors had prepared us for the worst and we believed them. Then we found Low Dose Naltrexone (LDN): a cheap, generic, out of patent pill, taken orally, with no side effects, stopped the progression of Noel's MS in September 2002 and since then he has not experienced any brand new MS symptoms. It is difficult for Noel to walk so some people cannot see the miracle we received. I am very familiar with the "you poor dear, you are totally crazy," look that people try their very best to hide but can't. Such people truly don't understand the nightmare we survived. Noel is the perfect poster child for LDN, because LDN stopped the progression of MS in the nick of time.

What if we had found it sooner? Such thinking can make a person crazy, but if had, his MS would be invisible today. People need to hear about LDN as soon as they receive an autoimmune diagnosis. It is a tragedy that it is not used as a first line of defense. We should be ashamed of ourselves for the way our health care system is monopolized by profit-making companies. How on earth did we let that happen? Nobody should profit from sick people, but I cannot think of a bigger business than drugs. It is the most depressing reflection of

humanity that society accepts that profit must come first when contemplating the relative merits of investigating potential uses for drugs. There is no actual bad guy, by the way. There is nobody I can call up and scream at. The problem is woven so deeply throughout our healthcare system that when a pharmaceutical company refuses to run the trials we desperately need on Naltrexone, they do not become bad guys. They are in fact, very smart businessmen. Naltrexone is a cheap, generic drug. Nobody will investigate new uses for the drug, because after they spend millions proving it's effectiveness, anybody can manufacture and sell it for pennies. It makes no business sense to invest in Naltrexone.

I am starting to conclude that it will be up to the Government to help us. I like to think that the only reason they haven't stepped up to the plate already is because they simply don't believe us. After all, it is pretty difficult to believe. It was hard for me to believe it, and I am an optimist by nature and had my back against the wall. If I am totally honest, I believe that some governments are in bed with the pharmaceutical companies, but not all of them. Good guys still exist. I am certain of that. There is so much evidence of the effectiveness and safety of Low Dose Naltrexone, it should not be classified as anecdotal anymore. LDN really and truly is the greatest medical discovery since

Penicillin. Dr. Phil Boyle was the first person to use that phrase, and he was right. We have more than enough proof that LDN works, but we haven't presented the information convincingly enough to a reputable government to convince them to help us.

When enough names sign the UK petition, it should be presented to the government along with a state of the art business proposal. We have learned by now that an emotional plea will not work. I confess that it is difficult not to get emotional, especially when we know people are dying and will die because we cannot be heard. I buried two friends with MS last year. Both started progressing at the same time and rate as Noel in September 2002, but I could not convince them to take LDN. Of course they didn't die from MS, but we all know they would still be alive today if their MS was controlled. It is the raw emotion and the pure passion of the LDN community that has got us this far, but I am starting to conclude that we need to be more professional and businesslike, almost robotic, in order to get LDN to the masses. When approaching the UK government, the bottom line we must present to them has to be how much money they will save. We have to know that even they will consider saving lives a bonus. I think we should play their game, and I think we should decide to win it. Between us, we have enough talent, passion and brains to win this.

Continued - Mary Bradley talks about LDN and her new radio show

Between us, we have enough talent, passion and brains to win this. And we will win, today, tomorrow, or the next day, for no reason other than we are right. This is the right thing to do and it is our duty to do it. To quote Margaret Mead: "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has."

To be honest, when Noel's MS stopped and our nightmare ended, part of me wanted to forget that he ever had MS and get on with our lives. It feels as if we are living with an injury of old now as opposed to a progressive degenerative disease, and, believe me, there is nothing better than release from the onslaught of a progressive, degenerative disease. I even stopped worrying about my kids getting MS or any autoimmune disease because we know about LDN. But, truth be told, I wanted to forget about it all more than anything-if we found LDN, anybody could. But it bothered me that I knew people would leave it until they were desperate, like we did. It bothered me enough to write the book "Up the Creek with a Paddle." I thought that writing the book would help me sleep better, and it did. I thought it would allow me to forget about LDN and get on with my life. I am very proud that my book has helped thousands of people understand and find LDN sooner, but it was not enough because

I still could not forget about it. Nobody in the LDN community can! How does one move on from a miracle that should be granted to everyone? In my case, I started an online radio show.

I will never forget Noel's face when he came from work one day and asked me what I did for the day and I told him that I started a radio show. Then I told him that I called it 'The Mary Bradley Show'. He gasped and asked "who the heck does that, Mary?" Noel always makes me laugh out loud. I explained to him that I wanted to put my name on the show because so many people in the LDN community were hiding behind fake names. So many people were afraid. I am not afraid, and am willing to stake my entire reputation on the efficacy of LDN. Somehow, putting my name on it made it feel more legitimate. All I can say is that it felt right and I live by following my gut instinct. I had no idea that the show would become so popular so fast. I did know that the LDN harvest was ready to reap though, and I also knew that if people could hear our united voices and passion somehow something big would happen. I don't know exactly what that is yet or how it will work, but I know that something great will happen because of all of us banding together. It is an honour for me to interview people in the LDN community, and bring them to life on air for the world to hear. It is powerful. I am learning a great deal and right now I

believe the way forward is through the government. A not-for-profit patient driven campaign will never raise the money we need for trials during my lifetime.

People have spoken about trying to change the patent laws to provide financial incentives for pharmaceutical companies who find new uses for old drugs, but part of me now believes that such an action would be feeding an already deeply flawed system. Changing the patent laws is almost like we are saying that it is OK for these guys to make a huge profit from sick people. It is not OK. We have all learned the hard way that it is inherently wrong.

I have some pretty amazing guests lined up to speak on my radio show and am excited about that. Call in anytime using 001 646 200 40 47. The show airs every Tuesday at 1PM Eastern Time or 6PM UK time.

Noel, the kids and I are thoroughly enjoying summer here in New Jersey, and more thankful than most for every day together. I am in the process of finishing up my second book. It is called "Mom's Final Lesson: How to Die Right." It captures her final year with cancer and everything we learned about the disease. I am actively looking for a literary agent, so if you know any let me know!

This year we will vacation in Florida for two weeks in August and next year I intend to take the kids to Ireland for over a month and have Noel join us for the last week or so. Thanks to LDN, life could not be any better.



Members Discount on Award winning Wheelchair accessible Holiday's in Blackpool and St Annes



The Bond Hotel Group aims to offer affordable value holidays for people with special needs and their carers. Although in principal we cater for people with disabilities (i.e. 40 disabled, 60 carers), this creates a lively and fantastic atmosphere thus not giving the impression of a totally disabled hotel.



The Bond Hotel Blackpool is an award winning fully accessible Hotel providing accessible accommodation for all, The majority of the 65 en suite bedrooms are fully adapted and suitable for wheelchair users and people with special needs; with wheel-in shower rooms, electric raiser beds, hoists and ground floor rooms every need can be catered for.



The Bond Hotel St. Annes has 26 bedrooms, most with en-suite. This hotel offers an up-market



alternative to our Blackpool hotel, with designer suites and bedrooms most with disabled access with large walk in showers along with high-tech overhead tracking hoists. There is also a hydrotherapy pool which is free of charge to all residents. The hotel overlooks the picturesque beach; it was planned and rebuilt for the sole purpose of offering people the chance of a stress-free seaside holiday in the pretty town of St. Annes-on-Sea.

Both hotels have spacious restaurants offering full English breakfast each morning, as well as a delicious 3 course evening meal. Food is also available during the day.

There is a full entertainments programme in both hotels every night with cabaret, bingo and raffles.

Transport can be provided, with accessible minibuses providing a pick up and return service from your home. They also arrange day trips to Blackpool Zoo, Fleetwood Market and The Lake District.

Holiday homes are also available sleeping up to six persons, fully adapted and equipped with ramps, enlarged corridors and wheel-in showers. They are situated on a site close to Blackpool, with full disabled facilities.

A special offer is available to all members; quote LDN Research Trust and receive a £20.00 discount off any holiday

Call today on **01253 341218** to discuss your holiday needs, then relax and look forward to a friendly and entertaining holiday in Blackpool. Why not visit our website at

www.bondhotel.co.uk



London Walks - John Mahoney

Recently my guide friends at London Walks have not only been walking and talking - but scribbling as well. The book: 'London Walks - London Stories' features 23 of the most interesting walks out of a total repertoire of over 100 walks each week.

The Original London Walks is the oldest London walking company. Founded by a visiting Aussie tourist who stayed on a while, it's now run by an Anglo-American husband and wife team. Mary is a former ballet dancer; David's the American who came over to study and has stayed on for more than 30 years. He's a literary historian and scholar who specialises in Shakespeare and Dickens who fell totally in love with London, its history and heartbeat. With four stories he's the major contributor to the book although there are 15 other guide-authors, each writing on his or her special interest walk. Most London Walks' guides are blue badge qualified as well as being actors, writers, historians etc.

For me London Walks proved to be the ideal retirement diversion - interesting people and places, cash-in-hand, and, as most of the walks last around 2 hours, good exercise. Moreover as many are pub walks it was the only job I ever had where I was paid for going into the pubs. Then

sadly the first signs of PPMS started to appear. I began to trip over more and more often, and by the end of a walk, after saying goodbye to the group, I often had to sit down while the strength came back into my legs and I was able to walk back to where I'd left the car. Some actor guides suggested I use a walking stick and make the best of the situation by treating it as a theatrical prop. This worked for a while but as many of you will know, PPMS has its way in the end.

In all I guided 12 different walks. Each time I was asked to do a new one, I had to recce the location - as well as the historic building - situation. Then one Sunday afternoon the right leg refused to do its duty half way up Highgate Hill. There was nothing I could do except apologise and refund the money. What started as a very good wheeze was over. There were some amusing memories though, starting with the very first assignment when David phoned to cheekily ask "If I could manage 9 Danish nurses in a private party!". There were other wry smiles like the American (from Harvard, no less) who took one look at Big Ben and asked if it was the Tower of London. Or the lady who really did ask if there were nightingales in Berkeley Square. Or on the Jack-the-Ripper horror beat, when I was striding out like a pocket sized Moses, leading a 35 strong group of girls from Kentucky down a particu-

larly rough looking street in Whitechapel. Suddenly one piped up with: "Hey Mister, is there someplace round here where a girl can buy some Mace?". There was also the Los Angeles movie buff who had lived with the ashes of his favourite filmstar for several years before having them scattered at the Golders Green crematorium!

Rain or shine the walks go 365 days a year. There's even a walk on Christmas Day, starting from the Christmas tree in Trafalgar Square, very popular with tourists holed up in Central London hotels. The guides aim to be informative and entertaining. The walks are especially suitable for birthdays and anniversaries but not just for tourists. There's a large number of Londoners eager to learn more about their city. Finally if you meet your future wife or husband on a walk, you get the added gift of free London Walks for life! Now there's romantic for you!

[\[www.walks.com\]](http://www.walks.com)



My MS story - Christian, son of an MS Sufferer



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.

My mother was diagnosed with relapsing-remitting MS in 1995, and over the first 10 years had many relapses until the MS is now 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 business-woman, 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, and fidgety leg (uncontrolled muscle spasms) but the main result is loss of dignity. Remember these are her main symptoms, but she is affected by a whole host of other MS symptoms and these, as her son, 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, 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, from my point of view seeing your mother being slowly ravaged by this horrible illness is impossible to describe.

LDN:

A fellow MS sufferer first talked about LDN and the effects it had on him about 12 months ago. 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, but this proved fruitless.

With the help of the LDN research trust, we found a very sympathetic consultant in London who is experienced at 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 written at the end of week two where she is still on 3mg.

Initially she was understandably very nervous about starting LDN, as anyone is with a new medical regime. Her response to the LDN was almost instantaneous; the main symptom that has been relieved is fatigue. Other symptoms are more manageable because her fatigue has been greatly reduced:

Sleep has improved with her fidgety leg bothering her less.

The walking has improved (she does not

stumble because she is exhausted).

As her walking improved, 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 could wear off over time. We hope not, because the changes over two weeks have been outstanding. However, not every day is a magical day, she still suffers from fatigue and the symptoms of MS are always there.

I am there when needed to help both my parents live as normal a life as possible.

As a side activity, my holiday this year is a banger car rally of 2400 miles around Europe. The contestants are encouraged to raise funds for their chosen charity, and as LDN has had such an effect and the LDN Research Trust have been so helpful and forthcoming, I will raise funds for them. I may not raise a large amount of money but I know it will be greatly appreciated. I will undertake the rally in September 2009.

In conclusion, I understand the views and hesitation of the consultant, because the BMA has to use evidential medicine. This is to stop 'fad' medicine and the Shipmans of this world. LDN is the reverse of this. What is currently needed is a full double-blind trial of LDN. If the results back up the current experiences felt by the majority of people taking LDN, this will give the BMA another weapon in their armoury of the treatment of MS.

Christian's Fund Raising Event!



The meeting point and start of the rally is St Omer in France, just a few miles south of Calais. Teams will be required to meet here after making the journey across or under the English Channel.

First stop after leaving St Omer is Koblenz in Germany. With an optional stop off at the Nurburgring, this an unbelievable experience - but not for the faint hearted!. It is virtually all motorway driving, travelling through Belgium and Netherlands on route.

Koblenz is situated in the picturesque landscape of the Rhine and Mosel and is surrounded by 4 low mountain ranges. It is one of Germany's major tourist centres.

From Koblenz, we travel down the Rhine gorge towards Bingen, to experience the finest scenery along the whole of the Rhine. Along this stretch you will find there are more castles than anywhere else in the world. We then leave the Rhine and head off to our next stop, St Gallen in Switzerland situated half-way between Lake Constance and the Appenzell Alps. There is an optional visit to the Porsche museum at Stuttgart on

route.

From St Gallen we head south to Davos for the start of the 'World's best driving road' as featured on Top Gear. The route takes us across the Stelvio pass which at 2757 metres is the second highest paved mountain road in the Alps and regarded by motorists as one of the most challenging roads in the world, it has a total of 60 hairpin bends. We then make our way to our next stop, Merano 'city of flowers' in Italy.

We then move on again, the route taking us through a beautiful Alpine valley, skirting the Triglav National Park in Slovenia onto our stay in Bled, the famous Lake Bled formed from a Glacier and is overlooked by the iconic Bled Castle. On route there is an optional visit to 'Tre Cime di Lavaredo',



the three enormous free-standing limestone towers which are amongst the most beautiful and recognizable mountains in the World.

The penultimate stop is Olomouc, in the Czech Republic. Here in the historic old town you will find a multitude of fabulous old buildings and monuments, second only to Prague.

The final day. We now head off through the Tatra Mountains to Krakow, Poland's most visited tourist destination. As a city, it has one of the most wonderfully preserved old-town complexes in Europe. There is an optional visit to Auschwitz on route.

It is now time to get rid of the cars and have some fun. There's an excellent nightlife scene and the salt mines of Wieliczka which are not too far away are well worth a visit.

Christian is paying all his own expenses and every penny donated via My Charity Page will be given to us.

To sponsor Christian please click the below link, payments are made securely.

www.mycharitypage.com/rally09

Check out Christians website for full details

www.cundall.org

We all wish you Good Luck Christian and hope you have a great time!



Fund Raising News

Help fundraise with Everyclick, search engine.

Membership is free & easy and every search helps raise funds.

<http://charities.everyclick.com/info.xq?id=578&name=LDN-Research-Trust>



Welcome to the Potions & Possibilities collection, a superb collection of premium quality aromatherapy and natural health products; all developed and produced in England by trained and qualified aromatherapist, Julie Foster.

All of the range, whether essential oils, therapeutic bath & beauty products or exquisitely hand-packaged gift collections are a reflection of the energy Julie brings to her business.

By click the link <http://www.potions.co.uk/index.php?a=ldnrt> we get a commission on the goods you buy. Make sure to add it to your favourites.



LDN Research Trust Polo Shirts



These unisex loose fitting polo shirts are of a high quality and will stay in shape wash after wash, the colour will not run, smudge or fade.

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Made from 100% polyester

Chest Sizes:
Small 38"
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Postage and Packing:
UK £1.50
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For Full details: www.ldnresearchtrust.org/default.asp?page_id=127

Selling Goods on ebay?

You can donate a percentage to the LDN Research Trust when listing your items.
Every little helps!



Help Raise Funds by Recycling your Old Mobile Phones

LDN Research trust has joined forces with Weee Recycle Mobiles to offer a new fund raising scheme. For every phone donated Weee Recycle Mobiles will pay us between £2 - £30, depending on the make and model.



Post your old mobile phones (no chargers please) to:

Freepost Weee Recycle Mobiles

Make sure you add LDN Research Trust on the envelope.

By recycling we will be helping the environment. The number of phones being dumped on landfill sites is becoming a huge problem in the UK and requires our immediate attention. The phones donated will be reused or recycled and then resold. Many will be shipped to developing countries where the price for mobile phones is still high. There are nearly 60 million unwanted phones in the UK alone, and we are hoping everyone can take part so that this will be a successful partnership.

Before you send your phone please ensure you remove your sim card, as you will not be able to get it back (sim cards are recycled too!)

Help Raise funds by Recycling your Old Ink Cartridges



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Cartridges for recycling are:

Dell all makes
 HP all makes
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 Canon CL40, CL50, PG41, PG51



Please send your cartridges to:

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Putting our code: R01174, on the envelope.

Or you can print off the freepost address from:

<http://www.ldnresearchtrust.org/forums/index.php?act=attach&type=post&id=22>

Or email contact@ldnresearchtrust.org and we will send you pre printed envelope.

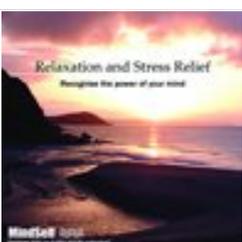
Shop online and we get a commission

Check out the High Sheet Shops and Major Retailers, for every sale we get a commission.

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Remember each time to use our link every time you shop online.

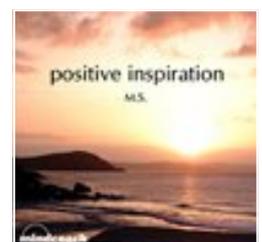
There are always Special Offers and often Free Deliver from some of the shops, not forgetting the Sales!!



LDN Research Hypnosis CD's

For full Details

www.ldnresearchtrust.org/ldnresearch/static/hypnosis_cd_s.asp





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LDN in the UK or for
general LDN information call:

0844 41 45 295

Local rate number

Outside of the UK please email,
we have managed to help
people worldwide obtain LDN

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The LDN Research Trust is a non-profit-making Registered Charity, and all helpers are volunteers.

However, we are no different from other charities, in that there are unfunded elements which do ultimately cost us money to maintain and operate.

To help us continue our work with people who have Multiple Sclerosis and other conditions that LDN helps with, we would appreciate help with fund-raising, either in cash or in kind. You can be sure that all contributions are greatly appreciated, however small.

How to make a Donation

To Make a Donation from anywhere in the world using MyCharitypage.com. This is our preferred method as there are no fees plus if you are a UK tax payer they claim the gift aid back for us!!
www.mycharitypage.com/LDNResearchTrust

**To Make a Donation Direct into our Bank Account
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Gift Aid

If you pay UK Income Tax - like tax on your pension if you are retired, or Capital Gains Tax, or tax on the interest from your savings - then every donation you make, or have made since 6th April 2000, could be worth almost a third more, without any cost to you.

If you want to help the LDN Research Trust to maximise the impact you make through your donations, all you have to do is complete a gift aid form. www.ldnresearchtrust.org/giftaid.asp

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