

June 2013

Dear Fellow LDNers

Finally we have good weather and it is wonderful to sit outside and hear the birds sing!

As you all know we rely on donations to run the charity and to fund all the things we do to raise awareness of LDN to the medical profession and to people with Autoimmune Disease and Cancers. This all takes money and a lot of time, since we started back in 2004 all the running costs have increase for example the PO Box was £99 and now is £290 a year!

I spoke to a lady the other week that very kindly send a cheque and she said I should highlight our plight in the newsletter. We would like all our members to donate £12 a year of £1 a month (\$1.5, \$18.3) (€1.2,€14) only 14 people mane either regular monthly or annual donations, thank you to each and every one of you! A big thank you to all of you, that take part in sponsored events and fundraise for us. Without help we are limited in what we can do.

In this issue of the newsletter

- * LDN 2013 Conference details
- * BIG Give Raffle
- * Dr Tom Gilhooly
- * MAD Online Jewellery - Special Offers
- * TNI Biotech, Inc
- * Google Adword Grant Award
- * Multiple Sclerosis and Parkinson's Disease Researchers Seek Help with Unconventional Studies *Laurie Mischley, ND*
- * Shopping Online with Giveabit
- * Hailey-Hailey Disease – Ray Bagshaw
- * The Psychiatrists Couch with Dr Mark Shukhman
- * Resveratrol - Pharmacist Stephen Dickson
- * Do These Symptoms Sound Like You? Ellen Smith
- * Hypnosis CD's
- * LDN Research Trust Shop Items
- * Information and Contact Details
- * LDN in Norway and Finland

You can donate in many ways check out <http://ldnurl.info/donate>

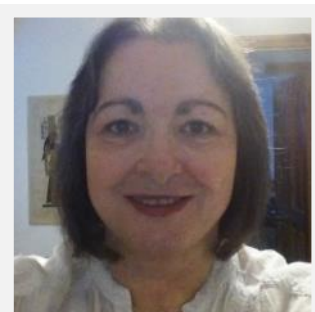
Thank you in advance!

In the newsletter you can find ways of helping us raise funds, with a new online Jewellery Story were we receive 100% of the profits, Online shopping in the UK from 1,200+ top high street store we receive a min. of 3% of your total shop. The GIB Give have a raffle tickets are just £1 each and we received 96p from each ticket sold and you stand the chance of winning £2000, or a lucky holiday for 2 or one other the other many prizes and not forgetting the LDN Research Trust online Shop <http://ldnurl.info/ldnshop>

If you have any spare time and would like to help, to find out more how you can become involved, many hands make light work! Please email linda@ldnrt.org for more details. I would like to thank all of you that already work as volunteers; it means a lot to us.

Wishing you a wonderful Summer,

Linda



LDN 2013 Survey,
please spare 5 minute to take the survey if you haven't already done so, thank you!
<http://fluidsurveys.com/s/LDN-2013/>



LDN Conference 2013

The LDN 2013 AII Conference is a charity event organised by Linda Elsegood Trustee of the LDN Research Trust (UK) and Dr Mark Mandel owner of Mark Drugs in Roselle, IL (US)

The conference reviews, compares and contrasts the most recent data and treatments for a variety of Auto-Immune and Immuno-modulated Conditions.

Visit the Conference website: <http://ldn2013.com> for full details of speakers, discounts on limo travel from airports and hotels etc

Chicago was the best place for the The LDN 2013 AII Conference, being within easy access by plane from the whole of the US and for those travelling from outside the US. The Harper College in Palatine, IL is the ideal venue offering theatre seating and a good space, accessibility for those in wheelchairs and plenty of parking for those driving.

Date: 5th October 2013

Time: 8.30 Registration, 9am – 5pm

Place: Harper College, Palatine Illinois US

Cost: \$80 per head includes: conference, lunch, refreshments and the Friday Night Networking Party.

Early booking is advised to avoid disappointment as spaces are limited.

Would you like to be a sponsor?

We are looking for sponsors for the venue, registration, breaks, drinks, pens, folders, notebooks, DVD's etc

Should you wish to be a sponsor we would like to hear from you!

Please email, Linda linda@ldnrt.org or Mark mark.m@markdrugs.com

Networking Party

The networking party is being held at the Wingate Hotel in the Woodfield Room and the Social Reception Area on Friday 4th October, from 6 pm – 9 pm.

When registering for the conference, please tick the box for the networking party if you wish join us. TNI Biotech, Inc. are fully sponsoring the Networking party.

Please note we are limited to 90 people, so early booking is advised.



Supporters

TNI Biotech, Inc
Mark Drugs



Wojcik Conference Center, Harper College

- * Conveniently located northwest of Chicago, just 20 minutes from O'Hare International Airport
- * Adjacent free parking
- * Wheelchair accessible
- * Boxed Lunch - sandwich (selection), apple, chips, cookie and drink. Vegetarian option available
- * Morning Break - drink
- * Afternoon Break - drink & cookie
- * Drinks available during breaks - Tea, Coffee, Water, Apple Juice
- * Water will be available throughout the day
- * 250 seats available

Please can you post the below link on your websites, blogs, FB Groups and forums. The PDF gives full conference details A word version is available upon request. Thanks You!

www.ldnresearchtrustfiles.co.uk/docs/LDN%20Conference%202013.pdf

Wingate Hotel & Holiday Inn Express Hotel

We have reserved rooms at discount prices for conference attendees.

Discounted Limo travel

Available from the O'Hare and Midway Airports to either Harper College or The Wingate Hotel/ Holiday Inn Express Hotel. Click the Windy City Limousine. Full details <http://ldn2013.com>

Filming of the Conference

The conference will be filmed and will be available to buy on DVD, to pre order your copy email linda@ldnrt.org

The Big Give Charities Raffle 2013

UK Supporters Only

theBigGive.org.uk Charities Raffle 2013
helping your donations go further

FIRST PRIZE
£2,000 Cash or a
Luxury Holiday for Two

SECOND PRIZE
£1,000 Cash

THIRD PRIZE
£500 Cash

RUNNERS UP PRIZES
10 x £50 Cash



Dear Supporter,

The LDN Research Trust is proud to be taking part in the very first Big Give Charities Raffle and we hope you will be keen to support us. For full details of the raffle, and the great prizes on offer please [click here](#).

As we are registered on the Big Give Campaign, we are asking our supporters to support us, as the charity selling the most tickets will be awarded £500!

This £500 would be monumental to us and truly benefit our efforts to provide, support to those with complex and rare conditions.

So how can **you** help us secure this valuable financial support? The answer is simple please buy 10 Tickets (minimum) at £1 each. Then you will have 10 chances to win one of these great prizes.

- ✦ 1st prize - £2,000 cash, or a luxury holiday for two
- ✦ 2nd prize - £1,000 cash
- ✦ 3rd prize - £500 cash
- 10 x runners' up prizes of £50

Not only that but you will be helping us as well as we will receive 96p for each ticket bought, with the other 4p going towards the administration costs. What a great way to support us and to win big!

So buy your tickets on behalf of the LDN Research Trust now, please click

<https://secure.thebiggive.org.uk/charity/view/490> and select 'Buy Raffle Tickets', it's that easy.

Please, remember your support is vital to us and we truly are grateful for every penny we receive, and so are the people we continue to help every day.

So please remember, **"Click to Win"** as soon as you can.

Thank you so much for your support...it makes a difference, and that's what we're to do.

TNI Biotech Utilizing Three-Part Global Initiative For Progress

TNI Biotech is already achieving its goal to benefit patients with chronic and often life-threatening diseases (through the activation and rebalancing of the body's immune system). Recent efforts, however, will allow the company worldwide outreach and increased product development to harness the power of the immune system to improve the treatment of cancer, chronic infections such as HIV/AIDS, and autoimmune diseases such as Crohn's disease, other types of inflammatory bowel disease, and multiple sclerosis (MS). By implementing a three-part program to make huge strides toward drug developments and providing affordable, high-quality medicines in areas where current practices and products are substandard.

The first part of the program is to continually add highly accomplished members to the management and consulting team. Latest among these appointments is Dr. Joseph M. Fortuank, former director and head of Global Chemical Development at Abbott Laboratories Corporation, where he managed more than 350 scientists and technical people. His accomplishments include significant contributions to 15 new chemical entities for the treatment of HIV/AIDS, malaria, cancer, and various cardiovascular and central nervous system indication. He also contributed to roughly 20 new generic drug launches.

"Dr. Fortuank is a strong addition to our team," said Noreen Griffin, CEO and Director of TNI Biotech, Inc. His influence in the pharmaceutical and healthcare sectors offers a tremendous resource to our organization as we focus on various products in development at TNIB."

Also recently added to the TNIB executive team is Terry L. Lierman, who was employed by National Institutes of Health and served as Chair of Board of Advisors at Institute of Human Virology.

He also founded several companies and organizations, including the Children's Research Institute at Children's Hospital National Medical Center, National Coalition for Cancer Research, the National Organization on Fetal Alcohol Syndrome (NOFAS), and the Pancreatic Cancer Action Network (PANCAN).

In a profile on Mr. Lierman, Dr. Robert C. Gallo (pioneer of the field of human retroviruses, discoverer of HTLV-1 and HTLV-2 and co-discoverer of HIV as the cause of AIDS and of the blood test that has saved thousand of lives) said, "Terry has an extraordinary commitment to health care and research, both as an advocate for patients and as the founder of a number of companies and organizations that focus on the advancement of medical science."

A second part of the TNI Biotech strategy is to cultivate its strategic alliances with companies like GB Group Global, led by international health crusader and expert Dr. Gloria B. Herndon. GB Global Group as well as alliances with a Chinese pharmaceutical company and a Nicaraguan facility for manufacture of LDN that should allow for delivery of product by July 1, 2013. The Chinese company will also be involved clinical trials on pancreatic and liver cancer.

Continued TNI Biotech Utilizing Three-Part Global Initiative For Progress

Dr. Herndon of GB Global recently met with top Equatorial officials to help bring improved health care to Equatorial Guineans. Projects under discussion include building a pharmaceutical manufacturing facility in EG, implementing pharmaceutical quality control and policies, and exploring the release of a new LDN against cancer and HIV/AIDS.

The third part of the strategy of TNI Biotech is to continually expand trials and developmental fast tracks to new therapies. As part of an agreement, between TNI BioTech and University of Pennsylvania, Dr. Jill Smith Dr. Ian S. Zagon, Dr. Patricia J. McLaughlin and Moshe Rogosnitzky the company had the right to apply to the Food and Drug Administration (FDA) for the transfer of the Orphan Drug Designation and the Investigative New Drugs (IND's). The Company has now announced that on April 3, 2013, they received acknowledgement from the Department of Health and Human Services confirming the Food and Drug Administration's (FDA) receipt of the change in sponsorship of the investigational new drug application (IND) for Naltrexone HCL and the orphan drug designation for [met5]-enkephalin and the orphan drug designation for the use of LDN in the treatment of pediatric patients with Crohn's Disease.

In March 2013, the Company made a strategic decision to outsource its manufacturing. This decision was made when the joint venture partner was unable to provide a facility that met international standards for manufacturing and canceled the contract. The

Company concurrently entered into discussions with an existing facility in Managua, Nicaragua that has excess capacity. The Company believes that between the facility in Nicaragua and the Qianjiang Pharmaceutical GMP facility located in China, the Company should be able to begin delivering LDN by July 1, 2013.

In May 2013, the Company received confirmation of a Type C meeting with the FDA to discuss the Phase 3 clinical development program for a proposed 505(b)(2) application for Low Dose Naltrexone ("LDN") in the treatment of adults and pediatric patients with Crohn's Disease. The Company is moving forward in developing its other therapies and hopes to set meetings with the FDA shortly to discuss the clinical trials for pancreatic cancer.

The heavily-researched and documented benefits of LDN are known to readers of this newsletter. With the addition of the three components explained here (ongoing recruitment of talented consultants, scientists, and analysts; strategic alliances with powerhouse companies and facilities; and ongoing drug trials and development, TNI Biotech is doubling down on its mission to change the face of healthcare, medicine and global drug affordability and safety with LDN therapy.

LDN Research Trust YouTube Channel

<http://www.youtube.com/user/TheLDNresearchtrust?feature=mhsn>

I am looking to interview, LDN Advocates. The interviews will be carried out over the phone and recorded, it doesn't matter where you are in the world. If you are an advocate, would you be interested in adding your voice to the LDN cause? You can remain anonymous if you prefer or you can write your story and have it read for you.

The interviews will be turned into videos and added to our YouTube channel you can see the play list http://www.youtube.com/view_all_playlists

Please email me linda@ldnrt.org telling me where you live so I can work out the time difference, dates and times you are free plus a telephone number.

I look forward to hearing your LDN story!

Many Thanks Linda



LDN COLLECTION BOXES PLEASE CAN YOU HELP?

We are proud to announce our new collection boxes.

We would like help placing the boxes in Post Offices, shops, pubs, Doctors waiting room in fact anywhere that gives permission for a box to be displayed.

We are looking for people who are willing to take control of displaying boxes, collecting them and banking the money into the LDN Research Trust's Barclay's Bank Account.

Small change adds up and we have managed to purchase 500 of these boxes at a very special rate and if we could find homes for all of them that would be great.

Are you able to help?

Please email contact@ldnresearchtrust.org with your name, address and how many boxes you require.

Thank you in advance. Linda



Are you or have you taken LDN for any condition?

We would love to hear your story, please email contact@ldnresearchtrust.org
We would not use your name without your permission.

Thanks to Cris Kerr from Case Health - Health Success Stories, for all her help, support, sharing stories with us and for compiling the eBooks below.

Those That Suffer Much, Know Much 2010 eBook

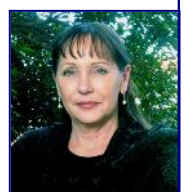
<http://ldnurl.info/ebook2010>

201 Reasons Why You Should Know About LDN eBook

<http://ldnurl.info/thosewhosuffermuchknowmuch2010>



Linda Elsegood



Cris Kerr

LDN in Norway - Frank Melhus



Frank Melhus is working very hard to raise awareness of LDN in Norway, and as you all know from the last newsletter Frank and his fellow Norwegian TV crew made an LDN documentary which is now available with English subtitles.

<http://www.tv2.no/nyheter/vartilleland/unknown-medicine-ldn-gives-hope-to-thousands-of-patients-4037140.html>

Thank you for everything you are doing Frank!

LDN in Finland - Maija Haavisto



LDN awareness in Finland made a tremendous leap when Finnish TV1 broadcast a 48-minute talk show with me, another CFS/ME patient and professor Olli Polo, who thanks to my initiative has been prescribing LDN for CFS/ME patients for six years now and it's main treatment he uses. The show was watched by almost 400,000 people, which is a lot in Finland. Olli Polo is a well-known sleep researcher and no one would describe him as an alternative medicine doctor, so it lends great credibility to LDN, at least as a CFS/ME treatment.

Maija maintains the only Finnish website and forum about CFS/ME

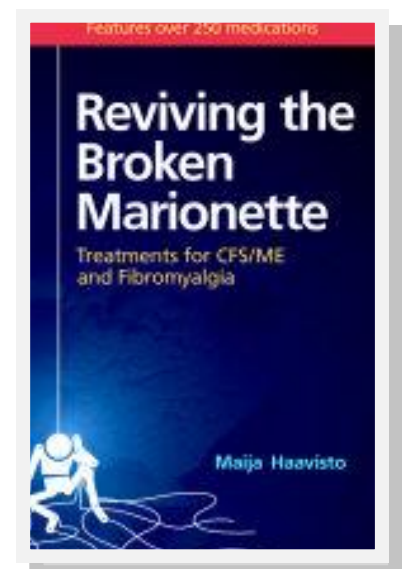
(<http://cfs.gehennom.org>). She has websites about LDN in both Finnish

(<http://ldn.gehennom.org>) and English

(<http://www.fiikus.net/?ldn>), which contain a large collection of scientific references related to LDN and its mode of action.

Maija'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.



Earthing - The Greatest Health Breakthrough Ever !

Dr Tom Gilhooly

The claim on the cover of the book "Earthing" by Clint Ober is that this is the greatest health breakthrough of all time! Quite a claim and one that is both intriguing and a bit off-putting. I was told about the book almost a year ago but it took a good six months before I got round to reading it. If this was such an important health breakthrough then surely I would have heard about it!

I was not expecting too much when I eventually got round to reading the book over a new-year holiday in Tenerife. How wrong I was! From the very first few pages you realise that this is indeed a new piece of information which is both profound and important.

The source of this new knowledge is equally surprising. Clint Ober was a cable TV installer; actually he owned a company that installed TVs. He knew that if a TV was not "earthed" by a cable leading to the ground, it would be severely affected by static. Although this information was interesting it was not enough to impact on anyone's health. Circumstances changed for Clint Ober after he became quite severely unwell with a liver complaint. This brush with death made him re-evaluate his life. He realised he had a higher purpose than selling and installing TVs, no matter how lucrative that had turned out to be. He took off across America looking for his "higher purpose" and after a couple of years of frustration he had his creative spark!

As he watching people walking down the street he suddenly realised that because of their insulating footwear, shoes and training shoes, they were not "earthed" and so must carry a static charge. He was actually able to measure this as an average of 350 volts, which reverts to zero as soon as skin contacts the earth.

Interesting as this was, did it have any implications for health? Remarkably, he found that it did. Having a minimum of 30 minutes per day in direct contact with earth, grass, sand or even concrete, seemed to have an anti inflammatory effect. People claimed to have less pain in arthritic joints, reported feeling calmer and sleeping better. Getting people to try "earthing" was not the difficult part. For many it made sense and felt natural. The wonderful feeling of walking barefoot on a sandy beach or on wet grass could be partly explained by the "earthing effect".

Clint speculated that it was the passage of negatively charged electrons from the earth into the body via skin contact that imparted the anti inflammatory effect. This was probably the "chi" that traditional chinese medicine

refers to. The really difficult part for Clint Ober was to persuade a very sceptical medical profession that there was a health value in this free and easy activity. In an age where drugs are king, this was not easy. He was determined however, and with great persistence eventually managed to convince some doctors and researchers of the potential value of "earthing". These included the influential American cardiologist Dr Stephen Sinatra, who co authors the book "Earthing". There have now been several scientific papers published to support the health benefits for "earthing" and more are planned. It is fair to say that supporters for this among the medical profession are few and far between, but the patients seem to like it. Having a natural, free and easy activity that has few potential side effects (frostbite in Scotland!) makes sense to many. I have actively promoted "earthing" to my patients and have been surprised and delighted by the positive response.

I have been in email contact with Clint Ober and discussed possible collaborative research on this subject. He states that the condition which responds best is Chronic Fatigue Syndrome but that there are benefits in MS, Arthritis and many other conditions.

For those who cannot or do not wish to "earth" naturally, there are a variety of earthing products available, including sheets for the bed which are connected by the mains electricity sockets to earth. These allow you to "earth" while asleep, and although I have not had enough experience of these to recommend them as yet, I can see no reason why this would not work. "Earthing" mats can be used to counter the electromagnetic fields built up by electrical devices which may have harmful health effects. I now use one in my surgery as a mouse mat to reduce the effect of using a powerful computer for a large part of my day. I have also taken every opportunity to "earth" naturally and definitely feel there is a pleasant calming effect from doing so.

I would strongly recommend reading "Earthing" by Clint Ober and looking into adding a bit of natural barefoot contact to your health regime. There are a number of "earthing" web sites and information online, some of which are listed below. Along with omega 3, antioxidants and a healthy diet, I can see this becoming a standard part of our healthy lifestyles in the future. Why wait?

References on page 8

Earthing - The Greatest Health Breakthrough Ever !

Dr Tom Gilhooly

References

1. Earthing - Clint Ober, Stephen Sinatra MD, Martin Zucker - Basic Health publications
2. Gaetan Chevalier, PhD,¹ Stephen T. Sinatra, James L. Oschman, PhD,³ and Richard M. Delany Earthing (Grounding) the Human Body Reduces Blood Viscosity—a Major Factor in Cardiovascular Disease THE JOURNAL OF ALTERNATIVE AND COMPLEMENTARY MEDICINE Volume 19, Number 2, 2013, pp. 102–110
3. Ga  tan Chevalier, Stephen T. Sinatra, James L. Oschman, Karol Sokal, Pawel Sokal Earthing: Health Implications of Reconnecting the Human Body to the Earth's Surface Electrons Journal of Environmental and Public Health Volume 2012 (2012), Article ID 291541, 8 pages doi:10.1155/2012/291541
4. Ga  tan Chevalier, PhD; Stephen T. Sinatra, Emotional Stress, Heart Rate Variability, Grounding, and Improved Autonomic Tone: Clinical Applications Integrative Medicine • Vol. 10, No. 3 • Jun/Jul 2011
5. Dick Brown, Gaetan Chevalier, Michael Hill, Pilot Study on the Effect of Grounding on Delayed-Onset Muscle Soreness THE JOURNAL OF ALTERNATIVE AND COMPLEMENTARY MEDICINE Volume 16, Number 3, 2010, pp. 265–273
6. Gaetan Chevalier Changes in Pulse Rate, Respiratory Rate, Blood Oxygenation, Perfusion Index, Skin Conductance, and Their Variability Induced During and After Grounding Human Subjects for 40 Minutes THE JOURNAL OF ALTERNATIVE AND COMPLEMENTARY MEDICINE Volume 16, Number 1, 2010, pp. 1–7
7. Applewhite R. “The effectiveness of a conductive patch and a conductive bed pad in reducing induced human body voltage via the application of earth ground.” European Biology and Bioelectromagnetics 2005; 1: 23–40
8. M Ghaly D Teplitz, The Biologic Effects of Grounding the Human Body During Sleep as Measured by Cortisol Levels and Subjective Reporting of Sleep, Pain, and Stress THE JOURNAL OF ALTERNATIVE AND COMPLEMENTARY MEDICINE Volume 10, Number 5, 2004, pp. 767–776



The LDN Research Trust is proud to offer online Jewellery from MAD as an ongoing Charity Fundraiser!

Support the LDN Research Trust in a completely new way!

We are delighted to announce a brand new way to support us and treat yourself at the same time!

We're working with M.A.D. (Make a Difference). M.A.D. is a brand new online store selling beautiful jewellery to suit all tastes, ages and occasions. But there's one big difference...

When you buy jewellery from M.A.D. in our name 100% of the profits are donated directly to the LDN Research Trust

There's absolutely no cost to us or to you. Just gorgeous fashionable jewellery sold to help us continue our work.

Whether you're looking to buy a special gift, accessorize next season's wardrobe or just treat yourself to a little something, taking your custom to M.A.D. turns your purchase into a donation at the same time! There are thousands of products to choose from – including exclusive ranges that you can only purchase in the UK through M.A.D.

You have a choice of rings, bracelets, necklaces in either Silver or Gold, You can also buy Diamonds!

Price start at £4.26 for Silver Earrings, ring & bracelet size gauges sent upon request. Satisfaction is guaranteed. 14 days return is offered on all items, except earring due to health & safety



All day Jewellery Fundraiser at my home in Buxton Norfolk UK

Everyone is welcome at my home for a Jewellery party to raise funds for the LDN Research Trust on **Saturday 22nd June**. To accommodate as many people as possible I will be holding 3 parties in the one day. **10am - 11.30am** ~~ **2.30pm - 4pm** ~~ **8pm - 9pm** We will have refreshments, raffle and Tombola, LDN Goods and Special Offers from MAD, see next page.

I will also have a Charity stand at the Castle Mall in Norwich on **Saturday 6th July**, please come and say hello if you are able to get there.

For full information please email me linda@ldnrt.org, I hope you are able to support us, even if you are too far away you can help online. Thank you in advance, Linda



**Buy Jewellery online and we receive
100% of the profits!**

<http://www.choosemad.com/ldnrt>

Check out the Gifts for Fathers Day.

Special Introductory Offer for our Members Worldwide

**Pendant and Earing Set in a
Presentation Gift Box**

£39.99 inc P&P in the UK

Or buy 3 for just £100 inc P&P in UK

High Street Price £74.99 each!

**Why not treat yourself or a loved
one today!**

**These sets are ideal Birthday or
Christmas Presents, take advantage
of this offer while stocks last!**

Choose M.A.D.

**Buy this beautiful pendant
& necklace set for the
special price of £39.99!**

MAD
MAKE A DIFFERENCE

All profits go to the
LDN Research Trust.



Fashionable jewellery, profits to charity, making a difference to YOUR favourite cause

**Available in a
Range of colours**



FREE competition, open to all our members Worldwide

**Two lucky winners will receive a Beautiful Stylish Crystal Ball
Pendant Necklaces and Stud Earing Set (colour of your choice) in a
Presentation Gift Box.**

Here is what you have to do:

Visit the LDN Research Trust Pages <http://www.choosemad.com/ldnrt>

Find the necklace on the right, and the product ID.

Email the product ID with your name and address to linda@ldnrt.org

The correct entries will be entered into a draw which will take place on 12th July 2013



**Sterling silver butterfly
pendant on a snake
chain**

<http://www.choosemad.com/ldnrt>

Please take 5 minutes to take part in a Jewellery Survey

Link to be added

**To find learn about MAD, Special Offers and the
Competition please listen to our YouTube Video**

Link to be added

Google Adword Grant Awarded



We are trilled to announce last month we were awarded a Google Adword Grant!



Better still Ray Bagshaw is going to be the account manager for us.

Welcome aboard Ray, we are very pleased to have you with us.



LDN Research Trust Links Where to find us!

LDN RT Main website:	http://ldnurl.info/ldnrt
LDN RT Forum:	http://ldnurl.info/forum
LDN RT Chat Room:	http://ldnurl.info/chat
LDN RT Facebook	http://ldnurl.info/facebook
LDN RT on Twitter:	http://ldnurl.info/twitter
LDN RT YouTube Channel:	http://ldnurl.info/youtube
LDN RT YouTube Play List:	http://www.youtube.com/user/TheLDNresearchtrust/videos?view=1
LDN RT Shop:	http://ldnurl.info/ldnshop
To Donate:	http://ldnurl.info/donate
LDN Aware Website:	http://www.ldnaware.org/

All ideas and suggestions are welcome to raise awareness and funds for LDN.

Multiple Sclerosis and Parkinson's Disease Researchers Seek Help with Unconventional Studies

Laurie Mischley, ND

Medical researchers have struggled for years to understand multiple sclerosis (MS), a nervous-system disorder with no known cause. An unpredictable disease, MS causes severe degenerative symptoms in some patients while others remain largely unaffected.

At the heart of the investigation lies a crucial question: Why do some MS patients have a benign disease that does not worsen over time? And what do diet, lifestyle and integrative medicine have to do with their success?

"When people are diagnosed with MS, they're told the disease is irreversible and progressive," says lead investigator [Laurie Mischley, ND](#), a clinical research assistant professor at the [Bastyr University Research Institute](#). "But it's just not true. We know from years of research that not everyone's disease progresses.

"We're trying to find out from people who are doing really well: What are they doing differently?"



Laurie said "I am a scientist, not an advocate of anything other than trying to figure out what works and what doesn't. I'm conducting research on both multiple sclerosis and Parkinson's disease, and both studies include questions about individuals using LDN. The purpose of the studies is to determine which therapies are associated with the best outcomes. The more folks you

can get to enrol in these studies, the more data I can collect and disseminate. I have an open mind and would very much like to learn that the community has found something that really works". (I have patients who insist it does!)

Please direct any individuals with MS or PD to the following sites, so that I can help shed light on the LDN debate! (anyone in the world may participate!)

Thank you for your support
Be well,
Laurie Mischley, ND

Multiple Sclerosis Study Link
<http://www.bastyr.edu/news/general-news-home-page/2013/03/multiple-sclerosis-researchers-seek-help-unconventional-studies>

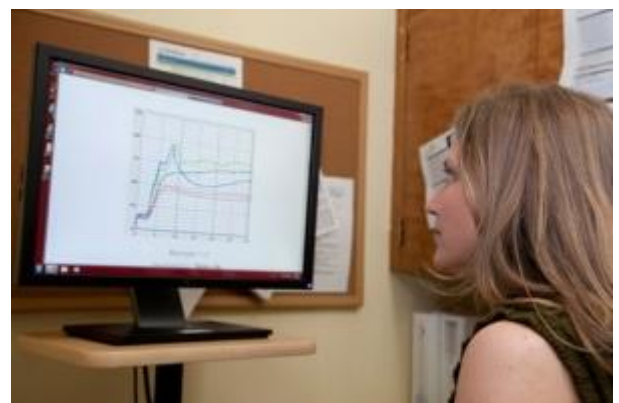
Parkinson's Disease is often said to be an incurable, progressive, and degenerative disease. It is our hypothesis that some of you do not, or will not, have a progressive disease. The goal of this PD study is to collect as much data as possible over a five-year period with the hope of finding dietary and lifestyle factors associated with a slower disease progression.

We are seeking "Positive Deviants".

"Positive Deviance is based on the observation that in every community there are certain individuals or groups (the positive deviants), whose uncommon but successful behaviors or strategies enable them to find better solutions to a problem than their peers. These individuals or groups have access to exactly the same resources and face the same challenges and obstacles as their peers.

The PD approach is a strength-based, problem-solving approach for behavior and social change. The approach enables the community to discover existing solutions to complex problems within the community."

Parkinsons Disease Study Link
<http://www.bastyr.edu/research/studies/complementary-alternative-medicine-care-parkinsons-disease-cam-care-pd>



New Shopping Online Fundraising For Our UK Supporters



Did you know that if you shop online, you can raise money for the LDN Research Trust at no extra cost to you!

We have registered with www.givingabit.com who have partnered with **over 1,200 shops** that will pay us a donation every time a purchase is made. It will not cost you a penny more and it is free to sign up. In fact you could even save money as there are thousands of discount codes too! You still buy directly from your favourite shops, including Amazon, Play.com, Sainsbury's, John Lewis, Vodafone and many more – you just visit them through the givingabit.com website to create a donation for us!

How can they do this? It is entirely funded by the retailers that are on givingabit.com. They're happy to make a donation, as it is their way of thanking you for making a purchase from their online shop when you visit them from givingabit.com

On average, 3% of whatever you spend is given to us as a donation, but remember, this is at no extra cost to you. Also, they are partnered with many home & car insurers, as well as

mobile phone companies, which could create up to a £50 donation for the LDN Research Trust at no extra cost to you! Booking a holiday? They are partnered with holiday specialists such as Kuoni, Walt Disney World, Butlins & Expedia to name but a few.

There are daily Voucher codes, sales and offers!

All you need to do is go to Giveabit and sign up. Once you have signed up, click on 'Find a Charity or Community' from your Quick links box, and choose the LDN Research Trust. It's a free way of donating to us! Once you have signed up, every time you shop we will get a donation and you can keep track of how much you have spent and how much you we receive by clicking the quick link Your Giveabit History . Giveabit will also send you a confirmation email after you shopped online.

Thank you for your continued support! Oh, and happy shopping!

Linda

Ray's Hailey-Hailey Disease & LDN Story

Hailey-Hailey Disease (HHD) is an extremely rare hereditary condition, which arises from a defect in Chromosome 3. It affects the Golgi pump, which prevents the skin's ability to bind together. This causes bleeding, severe pain and blisters, which are prone to infection. The main areas affected are where the skin folds; groin, under-arm, chest/breast area, elbow crease, and genital area. There is no cure, and sufferers are often embarrassed by the symptoms and the effect on their quality of life.



GP, I managed to secure an appointment with consultant at the Queen Elizabeth Hospital Birmingham.

This lady took one look at me, and wanted an immediate biopsy of my groin, along with relevant blood tests. She discussed her initial feelings and two weeks later diagnosed me with HHD. Knowing what it was, I began researching it fully on the internet. Days and weeks went by but I knew what I was facing; no cure, only a slight

hope of remission, and the best chance for me was to have laser treatment to burn skin off all the affected areas.

I have had this disease on and off for over 15 years, mainly around my neck and chin. It has been proposed to be eczema, non-specific infection, jock itch, dermatitis, barber's rash, sweat rash, and general allergy, but no one took any interest to diagnose it. I was given over 45 different drugs and steroid creams, some of which were so potent they could not be used for more than 7 days. I suffered side effects such as kidney pain, nausea, increased blood pressure, thinning of my skin and changes to pigmentation.

In 2010, I had it on both sides of my groin, raw, bleeding and infected. I asked to see a consultant, but rather than wait I paid. He took one look and said "that looks painful", giving me more antibiotics and steroids and assuring me it would be clear in a couple of weeks.

This situation carried on for two years until I was losing the will to live. I could not maintain my career as a teacher, due to decreased mobility, pain, and constant bleeding from the wounds. Driving was intolerable; I could not wear normal clothes, sit or stand for any length of time, and was suffering sleep deprivation due to the pain. I was prescribed opioid painkillers given like smarties, but no medication could dull the pain for more than an hour or two.

I made one final effort in 2012 and insisted that I was given an appointment to see a dermatologist. Although I had to make a strong representation to my

However, when my consultant requested a consultation with a Laser Specialist to my Clinical Commissioning Group (CCG), they refused to fund the procedure or the consultation. I was devastated by this news, with nowhere to go and no one to talk to. Although I complained to my CCG, they simply refused to answer me. I then went deeper and found an on-line help group Hailey-Hailey Disease New Approaches. From them and with the help of newfound friends who understood, I discovered Dr Bernard Bihari and his work on LDN. Shortly after reading about the late Doctor and his pioneering work, I found another great friend and mentor Linda from LDN Research Trust.

Despite my research and the evidence I produced (my consultant was in favour of me trialling LDN), the CCG again refused to fund an off-label drug, even at a cost of £1.00 per day. I took matters into my own hands and purchased LDN from abroad. Monitoring myself daily with BP readings and examinations, I prepared primary evidence based on my own case.

When I saw my consultant after 6 weeks of LDN, she was amazed at the transformation and asked if she could use me as a case study; the change was that dramatic. My chest had cleared completely, all open sores had gone, under my arms was as normal. I still have severe

Listen to Ray on our YouTube Channel: [to be added later](#)

Continued – Ray’s Hailey-Hailey Disease & LDN Story

scarring in my groins, but the pain, blisters and everything else has gone. After two months on LDN I am still pain free. I have had some outbreaks but they are minor, and it is still early days. During the last 3 months I have suffered no side effects from LDN whatsoever. I no longer have to use steroid creams or take strong painkillers, and my body is free from medical toxins for the first time in many years.

I am getting my life back. My confidence has returned, I have mobility and a chance to live again. There is still a battle with the bureaucracy of the NHS, and I am still waiting for a response to the numerous letters and e-mails I have written after 4 months, from the Commissioning Officer who continues to ignore my plea.

I have a fight on my hands, and a quest to have LDN prescribed not just for HHD sufferers and myself but also for other people with various conditions. LDN works, and the medical profession need to embrace new ideas, not

simply fall back on expensive drugs with potentially life-threatening side effects.

My salvation came from LDN, but along the way through my help group and the LDN Trust I found hope, understanding and compassion, which was sadly lacking from the medical profession. I have met some of the kindest and most genuine people in my life. If there is one positive thing which has come from my disease, it is my restored faith in the existence of good, caring and compassionate human beings in this world.

I offer one piece of advice, there are good people out there who will support you and offer advice in a genuine way. Helping oneself is the key to helping others.

Good Luck Everyone

Ray

Before



Ray’s Hailey-Hailey Disease New Approaches Group Survey Report

<http://www.ldnresearchtrustfiles.co.uk/docs/Group%20Survey%20Report.pdf>

Link for YouTube once live

1 Month on LDN



1 Month on LDN



1 Month on LDN



2 Months on LDN



2 Months on LDN



2 Months on LDN





PLEASE can you help?



Times are tough for all of us and raising funds is very difficult. Everyone one at the LDN Research Trust works as a volunteer, no one gets paid and we receive no funding from anyone. We do however have running costs which have to be paid for and we really could use YOUR help!

**Can you spare £1, \$1 or 1 Euro a month
or an annual donation.**

To help support the LDN Research Trust?



Many people said they are embarrassed to make such a small donation, please don't. Every little really does help!

If you would like to make a donation please visit: <http://ldnurl.info/donate>

Most people could afford £1, \$1 or 1 Euro a month, please consider helping us today.

**Your help will make a difference.
Thank you for your support**

Selling Goods on eBay



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

Now is a good time to have a good clean and get rid of all your unwanted items and you can donate a percentage of what you raise to the LDN Research Trust.

We are very grateful to all of you that have made donations already via eBay, your help and support is truly appreciated



If you have free time and would like to help please get in touch with us regardless where in the world you live, even if you can only spare an hour a week it would help.

We are looking for people who can: search the internet, help host the chat room (if talking to other people is your thing, this would be fun!) help with marketing, press releases and contacting the media.

If you have any free time and would like to get involved in someway please email contact@ldnresearchtrust.org



The Psychiatrists Couch

with

Dr Mark Shukhman

Question: Can LDN be used to treat bulimia?

Yes! The following needs to be considered, however:

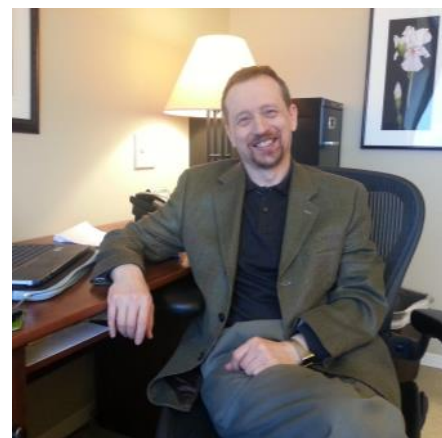
The word bulimia, if used colloquially, can mean anything from increased craving for food and overeating to binge eating, and subsequently feeling so remorseful that it leads to vomiting or over-exercising, in the hope of not gaining weight.

LDN cannot solve this problem alone, but can definitely become a crucial part of a comprehensive treatment plan.

LDN can block endorphins that are increased in response to overeating. Blocking the endorphins helps extinguish a behavior that perpetuates bingeing. Essentially, it is similar to not giving treats to a dancing circus bear. Eventually, there will be no initiative to dance, and the learned behavior will stop. Giving LDN will not affect a current episode of bingeing, but may decrease the inner tension that leads to binge eating in the future. Do not expect this to happen right away or without other issues being addressed; bulimia is normally accompanied by other medical and psychological problems. However, this element might make the crucial difference between knowing what you should do, while having no control over your behavior and being able to control your urges.

I would like to point out an unusual usage of LDN in this case. Normally, low dose naltrexone is taken to increase endorphins. In this case, however, our goal is to block endorphins at strategic times of a routine behavior.

The same strategy, with modifications, can be used for other behavioral cases and addictions. It has been described in application to alcohol addiction by Dr. John David Sinclair. Inspired by his ideas, I modified his method to incorporate LDN into a pharmacological and behavioral modification treatment. We have also used a similar model to help patients change self-dystonic sexual behaviors, as well as addiction to the internet and gambling. I believe with certain modifications it can be applied to any "bad habit" that needs to be changed.



Mark Shukhman MD

Mark Shukhman MD is a psychiatrist in private practice in suburbs of Chicago. Prior to becoming an MD, his interests included alternative medicine and mathematics. Dr. Shukhman's practice is focused on such problems as mood, anxiety, sleep, sex, appetite control, memory problems, chronic pain and addiction to opioids and alcohol. Dr. Shukhman is frequently consulted on psycho-somatic problems and psychiatric symptoms, accompanying general medical conditions. Treatment approach is based on neuropsychiatric interpretation of symptomatology and usually consists of combination of medications with vitamins, supplements and reflexotherapy. LDN is a part of psychopharmacological armamentarium for treatment of mood disorders, eating disorders and addictions.

Dr. Shukman teaches, including "doctor teaching other doctors" He was on the faculty of a board preparation course, advisory panels, multiple grand rounds etc. He served as a primary investigator for a several pharmaceutical research studies.

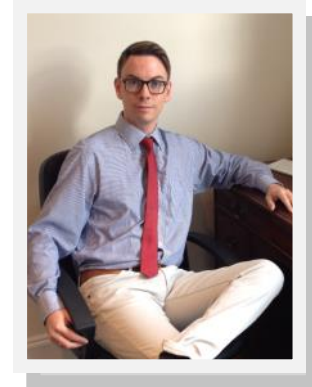
Dr Mark Shukhman welcomes any questions.

He will be having a regular column in the

newsletter. Any questions you wish to ask will be used anonymously. Please email

linda@ldnrt.org. All data will be held securely.

Resveratrol - Pharmacist Stephen Dickson



Recently published data, showing positive effects on autoimmune diseases – and specifically a very positive effect on animal Optic Neuritis - the animal model of MS used to test potential drug therapies against.

We have links on <http://www.dicksonchemist.co.uk/Home/Default.aspx> - follow the tab on the top to RESVERATROL.

Who should try resveratrol? Anyone with:

1. CogFog or diagnosed with CCSVI could potentially benefit from Resveratrol - as it has been show to increase brain blood flow significantly.
 2. Autoimmune disease, especially MS - due to the positive study in animals with Optic Neuritis.
 3. Anyone who has a family history of diabetes - as prevention.
 4. Anyone with coronary heart disease.
 5. Anyone who wants to take something that has been shown to make animals live a bit longer :-). (It is being investigated by Glaxo as a life-extension drug - with amazing results in animals - see video on our website!)
- Potentially anyone with metastatic cancer may benefit - but you must contact us first to let us do the relevant research for your specific indication.

Warnings:

Do not use if you have breast, prostate or hormonal responsive cancer - it may stop your cancer medications from working properly. (However, it has been shown to be effective in hormone treatment resistant prostate cancer)

Call 0141 647 8032 or email homedeliverypharmacy@yahoo.co.uk with your requirements, phone number, and we will call you back. Please note, our telephone can be quite busy, but we have added a helpful messaging service - you can press * and leave us a voicemail, which we check regularly and will call you back.

The price is £17.99 - including P&P. We will donate £1 to the LDN Research Trust for every pack sold.

Thanks to John Donnelly for his help and support, John has a world database where you can add your LDN story and read what others have to say.

<http://www.ldndatabase.com/>



Do These Symptoms Sound Like You?

Ellen Smith

We are born into our bodies and that is our norm, thus it is shocking when you realize your body is not acting the way it was meant to be. For many years, life seemed pretty normal. But, looking back, I was mentioning things to others and now realize they were very strange – like in high school having my palms of my hands turn black and blue after clapping at a dance and also asking which way to put my elbows while on the parallel bars in gymnastics. But, I lived my life as an active person, not realizing I was born with a rare condition called Ehlers Danlos Syndrome, which was causing my collagen to be deformed. Thus, my ligaments and tendons are like overstretched elastic bands. This in turn allows joints to get too loose and causes painful subluxations, meaning partial dislocations.

Many others with this condition are like me and don't get diagnosed properly due to its rareness. It took me fifty-two years before a doctor recognized the symptoms and suggested what she thought was the problem. I had been sent to her due to a repeat bladder prolapse just two years after having the surgery to correct the sudden problem. She sent me off to a geneticist to confirm her suspicion before she would operate on me. I was grateful that she finally helped to put the pieces of the puzzle together for me. However, I was shocked to learn that at this time, it is an incurable condition.

So, what is one's life with EDS like? You have to spend your life being cautious with your every move. For instance, due to our laxity, a simple hug can cause the ribs and spine to move and sub lux. The incidents of the body shifting increases with age, as the pain does. Three things are very important to get evaluated with this condition. First of all, we are prone to having a tethered cord, meaning the cord could still be pulling down on the spine. If not corrected, this will potentially cause permanent kidney damage. The next thing to check for is instability of the neck. We need to wear neck collars in the car to be safe due to this and some will require stabilization of the neck to regain strength. The other thing you need to check for is Chiari I malformation,



where the brain tissue protrudes into your spinal canal. This can be surgically corrected and would alleviate the headaches one has to endure with this condition. Also, many of us also deal with severe osteoporosis.

It is important to learn how to properly care for yourself with this condition. For instance, you should not lift more than five pounds or it would cause more pain in the body, straining the ligaments and tendons. The core needs to be strengthened since the muscles are responsible for not only their job, but are also on overload taking over the job of the ligaments and tendons. Many with this condition also tend to have issues with digestion, with numerous food

reactions and issues with metabolizing drugs. Celiac disease is not uncommon for many of us to face. A manual therapist is a wonderful person to turn to for help for they can safely get you subluxations corrected. Also, if things persist, find a surgeon that understands the condition and is willing to use cadaver tendons to secure your joints.

Life with EDS is a constant challenge. Please help the next person you meet. Someday we dream of not only a cure but finding an understanding network of doctors to help us out. It is a lonely journey if you don't reach out to others.

You have any questions, feel free to contact me:

Ellen lenox smith
Ellen.smith2@gmail.com
 401-474-0115



Help fundraise with Everyclick, search engine.

When searching the internet you can help earn us money at no charge to you, regardless where you live in the world.

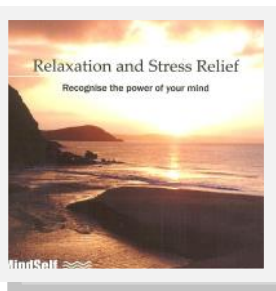
Membership is free & easy and every search helps raise funds. <http://ldnurl.info/search>
Save the link as a favourite, use it each time you search the internet and funds will soon add up.



LDN Research Hypnosis CD's

Ted Heaths Relaxation and Stress Relief CD suitable for all

- ◆ Discover a wonderful feeling of pure relaxation.
- ◆ Within that relaxation:
Produce positive thoughts
- ◆ Remove fears and Anxieties
- ◆ Gain a heightened awareness of your own mind and its power
- ◆ Use the power of your mind to alleviate stress
- ◆ Recognise the power of your mind to overcome Adversity
- ◆ Awake refreshed and alert.



Price: £10

Hypnosis for MS CD from Sharon McKay

will help people to stay relaxed, calm and focussed, and can also help with the following:

- ◆ Promoting your body's own natural healing force.
- ◆ Help you to feel loved, wanted and respected.
- ◆ Strengthen your sense of purpose and meaning on this earth.
- ◆ Inspire you to remain positive in the face of adversity.
- ◆ Help you to reassess your life and goals in a positive way.
- ◆ Help you to deal with other peoples' reactions in a positive way.
- ◆ Reinforce your sense of pride and dignity.
- ◆ Improve your self esteem, and elevate your mood.
- ◆ Boost your confidence and self belief.
- ◆ Help to get rid of fear, and manage each day as it comes.
- ◆ Improve your sense of well-being
- ◆ It can also improve sleep, and sometimes help with pain.

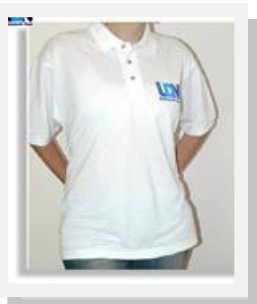


For full Details
<http://ldnurl.info/ldnshop>

Price Was: £10

Now only £3

Fundraising Items



White Polo Shirts in 5 sizes ideal
£10



Ribbons

.75p each



Key Rings

£2 each



LDN Mascot Lambs

£2 each



LDN Car Stickers
£1 each



Wristbands in 2 sizes
£1.75



LDN Round Button Badges
with a pin on the back.
2 sizes. 95p and £1.25p



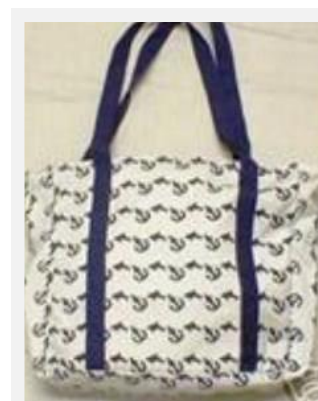
Silver coloured metal pin
badges.
£2 each



LDN DVD's £10 each



Leather Disable Badge Wallet
£13.50



Canvas Beach/Shopping Bag
£4.00

Check out our range of greeting cards in the shop.

100% goes to the LDN Research Trust on most cards

We would greatly appreciate your support promoting these items.

All these Items can be found in our website shop:

<http://ldnurl.info/ldnshop>



For information how to obtain
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

LDN Research Trust

PO BOX 1083, Buxton, NORWICH , NR10 5WY UK

Email: contact@ldnresearchtrust.org

Web Site: www.ldnresearchtrust.org

Trustees: Linda Elsegood, Alex Parker, Neil Lucas

Medical Advisers:

Dr Bob Lawrence MRCS; LRCP

Dr Tom Gilhooly MBChB; MRCP

Stephen Dickson BSC(hons) MRPharmS

Newsletter Editor Linda Elsegood - Sub Editor Sophie Marrion

Web Master - Lee Reynolds

Forum Manager - Alan Browne Senior Moderator - Derek

Graphic Designer - Graham Parker

Survey Form - Mark Lane

Facebook Administrator - Helen O'Neil - Alf

Manager of Google Adwords - Ray Bagshaw

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 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!!

<http://ldnurl.info/mycharity>

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.

<http://ldnurl.info/gift-aid-form>

**To Make a Donation Direct into our Bank Account
Or
To setup a regular monthly payment**

Barclay's Bank PLC

Sort Code: 20-03-26

Bank Account No: 60515213

PayPal

PayPal Donation from anywhere in the world, although they charge us a fee to accept payments.....

<http://ldnurl.info/donate> and then the PayPal Button