

Lucy Solomon's Overview of the 1st European Conference April 25th 2009 in Glasgow



I am Lucy, I'm 42 and I live in Brighton. Thankfully I've just recovered from a nasty bout of ovarian cancer; my recovery is without doubt partly due to LDN. When I was poorly the doctor who prescribed LDN (and other off patent prescription drugs not traditionally used for the treatment of cancer) told me that when I was well I should shout about my treatment from the rooftops.....this is my first shout!

I am the kind of woman who is not confident enough to blag it so I thought that if I was going to tell everyone how wonderful LDN was I had better have a good understanding of the drug and all its potential uses. So I found myself at the first UK LDN conference. I went expecting to find myself one of the few non medics there but I was pleasantly surprised by the number of people there who were taking the drug or considering taking the drug and who were not remotely medical.

The day provided 2 testimonials from people with MS which gave me an insight in to this awful disease and the magnitude of what LDN can do for them. I have to say I was overwhelmed at the fantastic response both of them described. Their stories were moving, sad,

funny and ultimately inspirational.

There were a range of expert medics at the conference. An excellent presentation from a pharmacist provided the audience with the technical side of sourcing and compounding the drug and interesting stories about problems with regulatory bodies. There were doctors telling stories of patients who had been treated for a range of autoimmune disorders, some of them were incredible, some sad, all interesting. Obviously for me, because of my personal situation, the most relevant information centred on the use of LDN for cancer patients. Having said that the presentations on the use of LDN for MS and for fertility treatment were informative and enlightening.

The questions and answer session at the end of the day provided those of us in the audience the opportunity to tell our stories and ask questions of the expert panel. This particular session was almost certainly the most useful of the day for me. The doctor who treated me told my story and I saw several people (including an eminent doctor from the US) taking notes on my treatment plan. I heard other stories and took notes myself for someone I love who has cancer and for a friend who has recently been diagnosed with MS. Everyone was doing the same and I am sure I am just one of many who walked away knowing that I was now potentially able to help someone less fortunate than I.

As well as the presentations there were several opportunities throughout the day for everyone to mingle and meet others at the conference. During my career as a university researcher I have attended far too

many conferences and the social time is always the worst part of the day. Trying to find common territory to discuss with strangers in a generally unwelcoming environment is always a challenge! The LDN conference was like a breath of fresh air from the traditional conference in that there were so many interesting people there that I was like a headless chicken....I didn't know who to talk to first. The physical environment was nice and we all had something in common that we could have talked about for ages! Each coffee session and lunch was spent chatting with intelligent, insightful, interesting people from all walks of life.

I met doctors who were using LDN successfully to treat MS patients (one of them had 200 on his books!). I met people with MS who had been taking LDN and were passionate about ensuring that clinical trials on the drug happen as soon as possible to ensure their peers were given the best possible chance to manage their disease and live their lives to the full. I met cancer patients who, like me, truly believe that LDN has played a pivotal role in helping them beat their disease and want to tell the world that the big C has an enemy in LDN. I met people who were there to gather information for their loved ones who were struggling with MS or cancer. These were the people I felt for most because they were all going home to spread the LDN word and keep their fingers crossed that they could convince friends and family to give it a try.

If I had to summarise the day I would say that it was enjoyable, interesting, uplifting and that I am very much looking forward to April 2010

My Cancer Story - Celia

.My name is Celia, and I live in Scotland--not exactly a spring chicken--but hey--I'm working on it!!

May of 2006 gave me shocking news: I had a chest full of cancerous lymph nodes. Tears and grief overwhelmed me, grief for the life I would never have, and for those I would leave behind. The primary tumour was never found, but I was treated as 'lung' and thus received palliative care only--eight doses of chemo, followed by 12 doses of radiation. It was expected I had 6 to 12 months of living left to do.

I also had the following conditions: mild lupus, IBS (so bad sometimes I did not dare go out), intestinal diverticula, COPD, thyroid problems (had a partial thyroidectomy years ago), osteoarthritis, high blood pressure, high cholesterol, and chronic fatigue.

After my conventional treatment, the oncologist was amazed when I went into remission. He assured me this would not last, that I had less than 1% of making it. Far be it from me to accept that!

No further treatment was implemented after that initial work. It was a case of watch and wait--but I was unwilling to do either. Instead, I went in search of anything that might help me.

I went on the usual supplements, changed my diet, and now eat

mainly eggs and fish, vegetables and fruit--and no red meat. I have also discovered a penchant for the darkest chocolate I can find, at least 85 to 86% cocoa. I read about vitamin B17 and I started taking this almost every day in kernel form.

In January of 2007, I had a very bad exacerbation of COPD, which landed me in the hospital. I came out on oxygen and steroids.

I searched the Internet, and came across Low Dose Naltrexone (LDN). I had never heard of it before, but it seemed like a miracle drug. I fought for it, got it on the NHS, and so it costs me nothing.

I got my first bottle but did not dare take it, as I was on steroids regularly for my chest, and had to have my hip replaced and was thus also on painkillers. Steroids and painkillers should not be taken concurrently with LDN. Each night, I looked at the bottle, and each night I thought, 'Shall it be now?' As soon as my hip pain began to diminish, and I could come off the steroids (it was day ten), I took my first dose of LDN. I don't know why, but I was frightened of it!

My first feelings on LDN were as though I was on a bit of a high. I had some disturbed nights, but not too many strange dreams (which happens with some people). I have now deter-



This is me, nearly three years after diagnosis, when I was told I only had 6 - 12 months!

mined when it is best for me to take it.

Very soon after starting the LDN, I found I did not need the oxygen for my COPD; I only need to nebulise now maybe once a day, if that; and today I walked the furthest I have been able to for what seems like ages. It was a miracle, and I still can't believe I did it! One thing I also noticed early on was that I was not spending half my life in the loo. I had been referred for another sigmoidoscopy late in 2007 after my hip operation, but I cancelled it.

To this day, I haven't had the bowel problem like I did before LDN. All my bowel problems went away, 'dire rear' and rectal bleeding, so I cancelled the sigmoidoscopy as I was sick of being poked about and was asymptomatic which was, and is wonderful!!

My energy began to return. I had had chronic fatigue for many years, but slowly am getting more energetic. I was fit enough to have a hip replacement about six months ago. Oh, the relief!!

My last x-ray showed no signs of the cancer which was supposed to have killed me over a year ago, and my last CT scan revealed that my aneurism had ceased growing. My blood pressure is now normal (after being too high for a few years), and I have come off my BP medications. My lupus does not bother me at all. I have a good appetite and am gaining weight.

Celia's UPDATE July 2008 – 1 year + on LDN

At the time of this writing, I have been on LDN for about seven months. I feel quite good, all things considered, and I recommend LDN to everyone!

The chronic fatigue is also much, much better, I have more energy, and there is no sign of lupus. Although I was already in remission from the cancer, the LDN stopped my horrific bowel problem. That's now history!! Don't know if the LDN lowered my BP but something did! My COPD, which was made worse by chest radiation, is also much better than it was. On July 25 I stopped using the nebuliser and instead use Spiriva once daily through my inhaler. Multiple adverse health problems, including cancer, have all been helped by LDN.

A brief update from my early August 2008 appointment with my Oncologist follows: When I saw my Oncologist, he was surprised at how well I looked. He said he thought there should have been 'something' showing up by now. I told him I will not die from this blasted disease ... well I will die, but not from that! He said the way I'm going on he wouldn't be surprised!!! As far as he was concerned, I need no further testing at this time. I'm asymptomatic and there is no sign whatsoever of the earlier enlarged lymph nodes - he said - amazingly - absolutely nothing!!!! I said

maybe it's the Iscador and LDN, and he conceded. I don't have to see him again for four months. All of the nurses commented on how well I looked. Maybe LDN is also the elixir of youth - ha ha, gimme more of that!!!!

My Onco thinks my GP is being very good to me supplying the LDN and Iscador. If they stop giving it to me, I'll go ordering on the net I will not stop taking LDN for anyone. So, it seems I am doing well so far, and that's what I wish for us all

If this story helps even one person, then it has been well worth the effort.

Update – December 2008 – over 12 months on LDN

I have lung cancer and also a 'growth' on my adrenal gland. The doctors don't know whether the growth is cancerous or not, as it's done nothing but sit there unchanged since my diagnosis in 2006.

A few months ago (August 2008), I was admitted to hospital for a couple of days as I had, on two occasions, been coughing up blood. As a precaution the attending physician ordered a scan. There were no changes on this re my cancer from the one I had had before my hip surgery a year ago! Diagnosis - a chest infection....



December 11th 2008, saw my oncologist, he was surprised that I had put on weight. As I have been having some upper back pain he has ordered a full body bone scan for 8th January 2009. He saw no reason to do a CT as I am still asymptomatic, he says I am doing amazingly well!!:-))

I have been on LDN for just over a year - to heck with it all - I went for it and as far as I know am OK.

Update — 8th January 2009, full body bone scan re back pain, result obtained on the 15th January - NED. The oncologist remains amazed that I am still apparently in remission. There was no evidence of the enlarged lymph nodes, he could not palpate any of these at all, and he seems bemused! It is now nearly three years since I was given 6 - 12 months.....

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

First European LDN Conference Report

Dr Tom Gilhooly

The first European Conference on Low Dose Naltrexone was held in Glasgow University on the 25th April 2009. It brought together some of the world's most prominent clinicians involved with LDN prescribing to discuss this exciting treatment for immune related disorders. The delegates came from as far away as Japan, India and South Africa, keen to learn more about LDN and its many uses.

The conference was opened by Linda Elsegood from the LDN research Trust who outlined her own experience with MS and the great response she had to LDN. This very positive response led to her setting up the charity dedicated to supporting and encouraging research into LDN in the UK. Linda announced that the charity has raised £22,000 to date, although it has yet to find a research project to support.

Dr Tom Gilhooly gave an outline of the research on LDN published to date including animal and human studies. The first publication on low dose naltrexone was an animal study by Prof Ian Zagon from Penn State Univer-

sity in 1981. He is still active in LDN research and is currently preparing for publication of some very exciting animal research on MS which confirms the efficacy of LDN in the animal model. Significantly this study was funded by the MS Society of America, giving a clear message to the only accredited funders in the UK. Five disease areas have been subject to publications on LDN in human studies. The most recent was a ten patient pilot study on fibromyalgia published in Pain Medicine in April 2009. This showed significant improvements in pain and mental health in six out of ten patients. The study of primary progressive multiple sclerosis by Maria Gironi from Milan was published in 2008, showing a reduction in spasticity and minimal side effects. The patient-funded MS study from University of California by Dr Bruce Cree showed improvements in quality of life but has not yet been published. The very impressive Crohn's disease pilot study from Penn State was outlined, as well a study showing improvements in quality of life among patients with

haematological cancers. A study in irritable bowel syndrome has also been published showing positive effects of LDN.

Pharmacist Stephen Dickson gave a very interesting outline of the challenges he has faced in trying to supply LDN to patients in the UK. The saga of LDN capsules being impounded and then destroyed by Customs, as the MHRA decided that foreign imports were no longer allowed was shared with a very interested audience. Despite the difficulties in dealing with the various regulatory bodies, he is committed to delivering this service to patients throughout the UK.

Dr Burt Berkson delivered a brilliant lecture on his treatment of cancer with LDN and intravenous alpha lipoic acid. Dr Berkson has published several remarkable case studies and he illustrates the results of treatment with PET and CT scan images which show the effect of this treatment on even very advanced cancers. He recently presented these cases to the National Institute of Cancer in America to great acclaim and is planning more extensive research soon.



Continued First European LDN Conference Report

Dr Tom Gilhooly

Mr Joseph Wouk gave an impassioned performance where he described his own LDN experience, which has resulted in almost complete disappearance of his symptoms. Joe has written a book about his experience called Google LDN which is available from Amazon and also online. Joe finished off his talk with a video of Pink Floyd which completed his presentation of "Saving Lives, One at a time".

Dr Phil Boyle from the Galway Fertility Centre, described the incredible fertility work that is carried out at this centre which included LDN in many cases. Although predominantly a fertility clinic, Phil has had requests for LDN from many patients with MS and other autoimmune conditions. He reassured the audience that LDN is safe in pregnancy, having had fifty healthy babies born to mothers who took LDN throughout the pregnancy. Not only that but he feels LDN greatly improves pregnancy outcomes and reduces risk of prematurity. LDN is also useful in treating endometriosis and polycystic ovarian

disease. Dr Boyle made the point that LDN works best when given alongside appropriate nutritional support including vitamin D and omega 3.

Dr Tom Gilhooly then outlined the progress with the Tyscore assay which measures immune activity; it has now reached the stage where it is ready to be validated against other standard measures of oxidative stress. He also updated the conference with progress of funding applications for the LDN MS study and on a new study on Autism which will be a joint effort between the Autism Treatment Trust and The Essential Health Clinic.

The conference concluded with an expert panel discussion where Dr Bert Berkson, Dr Bob Lawrence, Dr Pat Crowley and Skip Lenz (a pharmacist from Florida) answered questions on LDN from the audience. There was a lively discussion and numerous interesting points were raised, including timing of LDN dosage. The tradition of always dosing at night was called into question by both Stephen Dickson and Dr Tom Gilhooly, who

find no difference in clinical outcomes with morning dosing, but better compliance and fewer side effects. Skip Lenz felt that it had to be a night-time dose as there was evidence of a greater endorphin peak at night. It was mentioned that Prof Zagon felt that timing of dose was not important to clinical efficacy as long as the drug was only taken once daily.

A very successful first European conference concluded with the announcement that next year's conference will be held in Glasgow on 23rd and 24th April 2010. It will contain one day which will be purely medical/scientific and an open day similar in format to this conference. Next year's conference will be addressed by the author of the first paper on LDN in 1981, Prof Ian Zagon.



LDN-Better Health than past 20yrs – Sandra



I was diagnosed with Graves Disease at the end of March 2007. In May I had radioactive iodine treatment to kill my thyroid. I had just turned 35 years old and am considered morbidly obese. I weighed 218 lbs, and am 5'0" tall. Unfortunately, I was one of the few that didn't lose weight while experiencing hyperthyroidism.

Over the next 6 months, between May and November my thyroid died off quickly. On September 26, 2007, I became hypothyroid, and terribly symptomatic- I gained 20 pounds. The loss of hope, the terrible, debilitating depression, was more than I could stand.

A constant, complete exhaustion made my life a living hell. I knew at this point, that this was not how I was going to live. This is when I found a thyroid support group on yahoo, and where I learned of LDN.

Not much is known about Graves Disease, other than it is an autoimmune disease. When I first started reading about LDN, I knew without a doubt that this was the answer I was looking for. I tried to get several doctors to prescribe it to

me. None had even heard of it, or were willing to learn or listen.

After all, I was just a patient with memory issues, and terrible brain fog. How could I teach THEM anything?

So, I took it upon myself to learn.

I admit that it took me a long time for the information to be absorbed, but I knew the quality of life I had was not going to change unless I did something about it myself.

On February 18, 2008 my TSH was 3.4.... 'within range'. I could only get a TSH, since once again, doctors down here in Southern Alabama really are behind the current research, and the effects of T3 and T4 on the body. I went through 3 different doctors before I realized none of them were going to test me properly. I was told my levels were 'perfect' and maybe I needed to see a psychiatrist. I know my own body, and I was not fine, much less perfect. I was on 100mcg of Synthroid (name brand) daily.

On March 1st 2008 I began taking Low Dose Naltrexone (LDN). I purchased it from Canada, from a respected, much used

pharmacy. I get 50mg. tablets and dissolve them in 50ml. of distilled water. I started at 1.5mg per night. The first night I experienced terrible sleep disturbances. The next day, I had a racing heart and my blood pressure (BP) increased to 148/100 but I decided to just take it really easy, and ride it out.

The following day, my HR and blood pressure (BP) were once again elevated, but coming down. The sleep disturbance continued. By day 3, my HR and BP had stabilized, but sleep continued to be a problem. I decided there was no way I was going to go through this with each increase so within 2 weeks I had brought myself up to the maximum dose of 4.5 mg/night. The only time I experienced ANY sleep disturbance was those first couple of days.

It is April 2008 and it has now been 6 weeks since I started LDN. The changes in me are unbelievable!!! I feel like my old self. No, better than my old self. I have not felt this good since I was a teenager...before giving birth at 18 years old. I am certain that pregnancy was the beginning of my thyroid problems, and they just continued over the next 18 years.

We would like to thank Cris Kerr from :

Case Health - Health Success Stories
casehealth.com.au &
casehealth.com

For sharing stories with us.

Continued LDN-Better Health than past 20yrs – Sandra

Along with the Graves Disease, I had constant diarrhea. The beauty is that after several weeks on LDN, I was finally having normal bowel movements.

I now wake in the morning refreshed. My sleep has never been better. I still wake several times during the night, but the quality of sleep I am getting since starting LDN cannot compare with anything other than the sleep of a young child after being outside all day. I finally dream again, and I have not dreamt in 20 years.

Since starting LDN, I have lost 5 pounds in the last 6 weeks, with no effort. My appetite has decreased tremendously. My depression is completely gone, as is my anxiety. My energy levels have increased dramatically. I still have physical issues from being hypothyroid, eg; muscle cramps, and I still tire more easily than usual. I still do have the 'brain fog' but it has lessened dramatically.

I feel hopeful for the first time in 18 years. I no longer take any anti-anxiety medication. I had been using Cannabis to combat the anxiety symptoms and I also find I no longer want that. I am

almost 'normal' and I contribute every bit of it to LDN.

I feel better than I have in over 20 years.

To me, LDN is truly a 'miracle' drug. Please, don't let the pharmaceutical companies control the quality of life of those afflicted with autoimmune diseases. This drug needs to be mainstreamed. If someone would just step back, and consider what the world is missing by not allowing a good quality of life for us, maybe together, we could change the world. And I have already begun.

I will be getting a full-time job soon because of the positive results of LDN. This will allow my husband to finally go to college this fall, and become a high school history teacher. What better way to change the world, than to start with our youth!!

Sincerely hopeful, and it is all due to LDN.
Sandra

Prescribing Low Dose Naltrexone – A Guide

Dr Tom Gilhooly Essential Health Clinic Glasgow



In the standard doses of 25 mg to 200 mg, naltrexone is a very effective opiate blocker. Its product licence in the UK is for the management of opiate addiction but compliance is poor as the opiate blockade reduces endorphin activity which causes dysphoria, and in some cases depression.

Low doses of naltrexone were first studied in 1981 by Prof Ian Zagon in the USA, and used clinically by Dr Bernard Bihari in New York. They found that low doses caused an increase in endorphins, particularly metkephalin, which in turn modified the immune system. The immune modifying action of LDN is useful across a wide spectrum of immune related conditions and there is published evidence of its effect in Multiple Sclerosis, Crohn's disease, Fibromyalgia, Irritable Bowel Syndrome and Cancer.

The object of prescribing of LDN is to increase endorphin levels and modify the immune system without causing opiate blockade, which can occur at surprisingly low level. There is individual variation in sensitivity to this drug and the following

steps will help prescribers to find the optimal dose for each individual.

Initial dose – 1mg daily for four weeks.

Increase in increments of 1mg per month informing the patients of the symptoms of opiate blockade. If any of these are encountered then it is best to reduce the dose to the previous level until the next appointment.

Higher doses are not more effective; the usual range of LDN dose is 1mg to 5mg.

The drug appears to be safe in pregnancy and has been used for treatment of infertility.

Initial side effects can include nausea, headache and vivid dreams. These are usually transient and have settled after 2 – 4 weeks on the drug.

Timing of dose does not appear to have an impact on clinical response and can be tailored to suite individuals.

The major interactions are with opiate-based drugs, the analgesic effect of which can be blocked by LDN.

Any prescribing queries can be referred to:

contact@essentialhealthclinic.com

LDN shouldn't be taken with Steroids, Immune suppressants, opiate based pain killers or interferon drugs.

Copaxone works alright with LDN.

John Mahoney– Keep Calm & Carry On

'Keep Calm & Carry On': that's my 2009 mantra - and it works, or at least, I think it worked for me! I came across it a while ago as a free offer in a newspaper but in actual fact it dates back 70 years to the Second World War. It was devised by the Ministry of Information for possible distribution should the ultimate ever happen and we would have been invaded. Third in a series of morale boosting posters commissioned in 1939, they printed 2.5 million copies which were never used and were nearly all pulped at the end of the war.

Only a few survived and they were lost in the dust of time until the owner of the Barter (Secondhand) Book Store, located in the old railway station building at Alnwick, Northumberland, delved into an old box in the attic of the converted building. It struck an immediate chord - especially

its calm and measured message - which implied an implacable sense of stiff upper lip. Moreover designed as home front propaganda its message is equally powerful in the present day credit crunch crisis. The book store owner thought it might just appeal to a certain kind of ironic humour and decided to print a few copies on spec. Happily sales took off like a rocket and by now more than 40,000 have been sold. Stiff upper lip is big business! 'Keep Calm & Carry On' now decorates posters, bags, mugs, T-shirts, tea towels, hoodies and even duvet covers.

My copy decorates the desk in the den where I can ponder its message at various times during the day - and night. It became a sort of talisman comforter when new tenants arrived in December to occupy the flat underneath ours. An all night flat warming party on the very first night,

which didn't break up until 4 am, set the tone for what was to follow - 5 all night 12 hour parties in as many weeks! In between gala party nights, as both of them seemed to work late in a club or restaurant, it was a crash, bang wallop homecoming at 0230 every morning. High heels clip clopping on fashionable wooden floors punctuated by high pitched high spirited voices. They never seemed to master the technique of closing a door without slamming it and furniture dragging became a popular late night sport.

My wife was recovering from chemotherapy so I tottered down regularly to plead for a bit of peace and quiet. The local authority noise police were equally ineffective. We knew the loud brigade had signed a 6 month lease, so with frequent glances at 'Keep Calm & Carry On' we resigned ourselves to the long haul. Then one very fine day over the house grapevine came the glad tidings that they were moving out after only 3 months! Hallelujah! 'Keep Calm & Carry On' had done its job.

No more late night shenanigans; no need for stiff upper lips and blood pressure readings as good as they've ever been.



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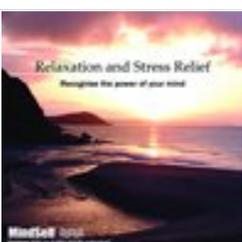
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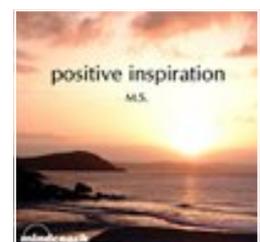
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For information how to obtain LDN in the UK or for general LDN information call:

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Calls costs 10p per minute at all times, mobile costs may vary.

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

Trustees: Linda Elsegood, Alex Parker & Neil Lucas

Medical Advisers: Dr Bob Lawrence MRCS; LRCP
Dr Tom Gilhooly MBChB; MRCP

Fund Raising Director: Steven Blaikie

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Facebook Administrator Laura Elsegood

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Graphic Designer Graham Parker

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

PayPal

To make a PayPal Donation from anywhere in the world, click the link below.....

http://www.ldnresearchtrust.org/_ldnresearch/static/donate.asp and then the PayPal Button

To Make a Donation using MyCharitypage.com

<http://www.mycharitypage.com/LDNResearchTrust>

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