

THOSE WHO SUFFER MUCH KNOW MUCH

**Health Case Studies of
Low Dose Naltrexone (LDN)
in the treatment of a range of diseases**

*In keeping with the altruism of contributors to this book
Case Health offers the book to you without charge
or expectation.*

*You can 'share-it-forward' under the same philosophy
'as-is' ... without changes or modifications*

Case Health Health Success Stories



established 2001

Brisbane, Queensland, Australia

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The 29 case studies in this book feature

Low Dose Naltrexone (LDN)

*a controversial treatment being used successfully to
treat a range of diseases linked by immune system dysfunction*

*Of those conditions that have benefited
the following are featured in this book*

Multiple Sclerosis

HIV

Hepatitis B

Primary Lateral Sclerosis

Cancer

Crohn's Disease

Supporting data for this book has been assembled from
untested patient testimony of health success.

dedicated to all

PATIENT CHAMPIONS

who through their own suffering have

grown to understand the value of

sharing their stories in detail, as case studies.

To all those

whose generous contributions

made this book possible ...

Thank you

To Linda

A very special note of appreciation goes across the waves to Linda Elsegood of LDN Research Trust in the UK. Thank you Linda, for your valued friendship and assistance with the following patient testimonies:

LDN-MS & Me – Jackie
LDN gave me Hope for the future - Annmarie
LDN has given me hope - Audrey
LDN-Crohn's and Me - Peter B

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THOSE WHO SUFFER MUCH KNOW MUCH

Cris Kerr, Administrator & Community Health Researcher,
'Case Health-Health Success Stories' website, October 2005, rev July 2007, rev July 2008

The 'Case Health – Health Success Stories' website collects and shares health success stories and case studies attributed to any successful health intervention. Though based in Brisbane, Australia, the site holds stories from all over the world and the service is provided as a community service, free of any charge.

A growing body of compelling testimony

I'm an unqualified community health researcher who first became aware of a drug that can halt or slow progression of Multiple Sclerosis (MS), and enhance prolong quality of life for sufferers, after receiving a story submission in 2003. The drug is naltrexone, and my 'Health Success Stories' database contains a growing body of compelling patient testimony that it works, and it works well - BUT, sufferers can't get it. It's not a cure, and it does not work for everyone, but it does work.

The naltrexone story is a powerful story that must be told and shared

Dr Bernard Bihari's groundbreaking work with naltrexone commenced over twenty years ago and has since resulted in a small but growing number of physicians prescribing **low doses of naltrexone (LDN)** to minimize both progression and symptoms of disease for their patients.

Bihari, who retired from private practice in March 2007, first successfully treated HIV patients, then MS and cancer patients. In the ensuing years LDN has been cited as beneficial across many other diseases such as Autism, Crohn's Disease, Hepatitis B, and a long list of others. If you're wondering how all these diseases are linked, look no further than an errant immune system.

In Scotland, Dr Pat Crowley has been prescribing LDN successfully for some time, and even traveled to New York to interview Dr Bihari for his own documentary. In the USA, Dr Jacquelyn McCandless found LDN benefits Autism and is responsible for the development of the first LDN topical formulation - a cream consisting of emu oil and naltrexone that is applied to the skin to bypass digestive issues. Dr McCandless and her husband are presently in Mali, Africa trialling LDN for HIV.

The number of doctors familiar with, and prescribing LDN is still small but growing. Other early adopter advocates are; Dr Bob Lawrence, Dr Tom Gilhooly, Dr Phil Boyle, Dr Burt Berkson, Dr Terry Grossman, Dr Joseph McWhirter, and Dr Jill Smith; who've championed patient needs and hence have contributed to positive progress for this controversial treatment option.

Due to the wonder that is the Internet, word has spread. A maiden patient conference dedicated to LDN was held in New York in 2005, and has since been followed by now annual conferences held in 2006 and 2007. This year's conference is being held at the USC Health Sciences Campus in Los Angeles, California on 11 October 2008.

Disease sufferers whose progression has been alleviated by treatment with LDN have formed groups dedicated to spreading the word. They strive to help fellow sufferers via information-sharing, emotional support, and fund-raising for clinical trials; the first of which commenced in 2007 at the University of California, San Francisco (UCSF) and was partly funded by a dedicated support group linked to SammyJo's LDNers.org.

Why are Clinical Trials important?

Clinical trials seek to answer the 'who, what, why, where, how, and when' questions that must be addressed to establish patient profile, efficacy, optimum dose and time, and of course, safety. Clinical trials establish evidence of successful, safe outcomes or unsuccessful, unsafe outcomes. Doctors therefore, quite rightly, base treatment decisions on clinical trials because this is at present the safest system to follow, and patients wouldn't want it any other way.

However, due to the absence of clinical trial data, the Low Dose Naltrexone Treatment Protocol has not achieved mainstream scientific acceptance as a treatment option for MS or any of the other diseases it has

been benefiting. Whilst a growing number of doctors are prescribing LDN 'off label', most will not prescribe a treatment unproven clinically.

Naltrexone is only officially approved as a treatment for alcohol or drug dependence at doses much higher (around 50mg), than the very low doses (up to 4.5mg) being prescribed 'off label' for the management of HIV, MS, cancer, Crohn's and other diseases. In many jurisdictions doctors can prescribe this drug 'off label', but only where there is no 'proven' treatment for a particular disease or condition. It's my understanding doctors in most jurisdictions can also prescribe a drug 'off label' as an adjunct that complements a 'proven' treatment - though this increases the risk of medication conflict for the patient.

What's wrong with our 'health system'

Clinical trials are expensive and are typically initiated and sponsored by companies that expect to patent a drug and recoup costs by commercializing the successful results. That's business and that's how it should be. If an organisation is prepared to fund the very high cost of research, development, and clinical trials they're entitled to view the cost as an investment that will turn a profit.

Naltrexone is an old drug. It's well past its patent protection period and is now a 'generic'. A clinical trial of an 'off-patent generic drug' doesn't present an attractive commercial proposition for sponsoring organisations that have traditionally initiated clinical trials - because they can't gain exclusive patent rights, and subsequent profits, from a successful outcome. To this end older drugs are often re-engineered - a molecule changed here and there - new drug, new patent, new price.

Unfortunately, health has morphed into a consumer market. That means, just like every other consumer market, the healthcare industry is 'market driven' in terms of meeting consumer 'supply and demand'. This system assumes health consumers wanting or needing a particular healthcare product that's not presently available, will create sufficient demand to drive commercial enterprises to bring a new product to market that fulfils their unmet need, or in other words, supplies their demand.

Subsequently, the primary driving force for Health Research, Development, and Clinical Trials is the potential for profit - but there's no big profit to be made from trialling a 'generic' drug such as Naltrexone, regardless of the promise it holds to alleviate suffering and deliver economic public health benefits, so nothing happens.

Where does that leave the promise of Naltrexone?

Patient testimonies crediting LDN for improved health have been growing exponentially, and a large body of stories from MS sufferers who've slowed or halted progression of their disease or had symptom improvement with LDN are building a compelling case - but these testimonies represent only one facet of evidence. At present, health success stories alone aren't sufficient evidence for most doctors to prescribe LDN.

A large body of health success stories, however; can provide sufficient evidence to advocate for governments to initiate and fund clinical trials, and; when health success stories are recorded in greater detail and numbers as case studies, they can also build into statistically significant volumes of evidence through the sheer power of numbers, achieving 'volume value' in their own right, and facilitating insights into public health priorities and improvement opportunities.

So how did we discover Naltrexone holds such promise?

In New York, USA in the 1980s, Dr Bernard Bihari was focused on improving outcomes for his patients. His research led him to Dr Ian S Zagon's promising lab research with naltrexone in mice with cancer. Bihari began trialling lower doses of naltrexone, resulting in the successful treatment of HIV, then later MS and Cancer.

In the USA, Dr David Gluck, a childhood friend of Dr Bihari and LDN advocate, manages the website lowdosenaltrexone.org and it's sub-site ldninfo.org with the help of his son, Joel. The website features the Foundation for Immunologic Research (FFIR), founded in 1989 by Bernard Bihari, MD and two colleagues in an attempt to raise trial funds for the broader range of LDN's promising applications.

In the UK, LDN Research Trust was founded in May 2004 by Linda Elsegood. Linda is an MS sufferer who's benefited from LDN, and her monthly newsletter features other LDN testimonials. The patients who've been helped by LDN are doing what they can to raise awareness and funds for clinical trials ... the hard way.

You can't help but be impressed when you see sufferers of a range of diseases raising funds and contributing to support groups, in spite of their own daily health challenges, in the interest of helping other sufferers benefit from LDN.

Please pause to fully digest what all this means:

Even though benefits were first discovered over twenty years ago, well before any drug was developed to specifically treat HIV or MS, LDN is still not readily available as a treatment option. To my knowledge, this is one of the most powerful examples of the downside of a fully commercialized health market, and why 'balance' must be restored and monitored.

Those that could be helped are not being helped

Whilst there's growing testimony LDN could be the most effective and economic treatment option in the management of MS, HIV, and other diseases (for both the patient and the health system), the absence of clinical trial data means the majority of practitioners are still not prescribing LDN.

Years have passed. Those that could have been helped have not been helped, and those who've exhausted all other treatment options will still not hear of LDN.

What's Disturbing about this Picture of Health?

When you read LDN stories on my website or others I've referenced; the first thing you'll notice is a consistent thread of optimism running through this ever-growing body of health successes:

' ... I have been on LDN for a little over 7 months now and it has given me a lot of my life back. For the first time in many years, the progression of disability has stopped. ... '

' ... I have had NO new symptoms and NO further progression since starting LDN six years ago. I still drive and do all my own shopping, cleaning, etc. I feel certain, had I not been on LDN, I would not be as active as I am, nor as mobile. I wish every MSer had the chance to try LDN to see if they are one of the ones who would benefit. ... '

The second thing you'll notice is the extraordinary difficulty MS sufferers experience when seeking to trial this treatment. MS is a debilitating condition with multiple adverse symptoms. People with MS are already suffering. You can't help becoming indignant at this injustice:

' ... I phoned the neuro ... to see if she would give me the Low Dose Naltrexone (LDN) treatment. She had never heard about it ... she was so excited about this ... she had to clear it with the legal dept ... A week later she phoned to tell me the lawyers said no! ... My health was being decided by a group of lawyers!! ... September 4, 2005: I am happy to report a small but significant improvement. Last night for the first time in years I was able to lift my left foot and take a couple of heel to toe steps... instead of dragging my foot or walking toe to heel. ... '

Patients Abandoned

Dr Bernard Bihari's patients had professional support when they first commenced LDN treatment. This meant, even though his patients had never heard of LDN, they were told what to expect, and were prepared, monitored, and supported by a professional. If an MS patient experienced an exacerbation (with accompanying apprehension) in the first three to six months of treatment, they were likely comforted by; 'this can happen, but experience has shown it does pass'.

Few doctors have knowledge of LDN, and many patients have been abandoned after their doctors learned they were taking LDN - a patient abandoned by her Oncologist, and MS patients abandoned by their Neurologists. Patients returning to their doctors after improvement have been told their initial diagnoses may have been incorrect or their MRIs may have been misinterpreted.

Even more astonishingly, patients who've experienced improvement have been advised to 'keep doing whatever it is they're doing', without any enquiry as to what that may be – not what you'd expect from an enquiring scientific mind focussed on achieving successful health outcomes for their patients.

Patients without professional support have had to back-fill the knowledge gap and support themselves. This absence of support has resulted in some patients taking LDN without any prior research, knowledge or preparation, and subsequently, with unrealistic expectations.

High expectations, little or no knowledge of what to expect, and no professional support has led to unnecessary angst and disappointment. Subsequently, some who may have benefited from LDN have not, whilst others fortunately, found patient champions within the Yahoo lowdosenaltrexone patient discussion group and were eventually guided to success.

Dr David Gluck's ldninfo.org website contains a wealth of information to aid research and preparation, yet there are still those who begin LDN in haste, who commence LDN concurrently with other medications that conflict, or who defer complementary lifestyle changes such as modifying their diet or alcohol intake, or supplementing nutritional or dietary deficiencies.

I've been observing communication exchanges within the Yahoo LDN group for years now, and it's provided many insights: Those who patiently research and prepare prior to starting LDN are those most likely to succeed. In fact, patients taking ownership of their own health future has not all been bad news: Researching LDN has often resulted in patients initiating lifestyle improvements that complement and enhance their likelihood of success – and this positive turning point to overall improved health has resulted in additional symptom improvement.

LDN is not a high impact treatment. It can take six to twelve months to benefit progressive forms of MS. Testimony of long-term outcomes varies - from halted disease progression with some reversal of symptoms, to slowed progression with minor symptom improvement such as improved bladder control.

This is where case studies reveal their value, because they provide insights into factors other than LDN that may be contributing to improved outcomes or alternatively, contributing to unsuccessful outcomes - all of which have potential to enhance the likelihood of success for others who follow.

Where's the official body that acts on behalf of patients?

Research, drug development, and clinical trials are initiated by commercial sponsors. That's okay, but there's no recognized impartial body that can officially step up to the plate to speak and act on behalf of (advocate for) all patients. I know this because I've tried, without success, to find an authority that's sanctioned to do so.

Officially recognized specialist 'societies' and 'associations' that should be acting on behalf of patients are often sponsored by organisations that are, as mentioned earlier, commercially and/or politically motivated and therefore, have little incentive to recognize, investigate, advocate, or champion the extended benefits of a generic, unprofitable drug on behalf of patients.

Doctors do record successful health outcomes in detail, but it takes time. At present, the primary motivation to devote that time is the chance of;

- a) publication in a prestigious scientific journal, or;
- b) an invitation to present at a commercially-sponsored scientific conference.

In both instances there's little incentive for doctors to devote time to recording successful outcomes from 'generic' drugs that won't enhance sales of patented, profitable drugs, or open pathways to new commercial markets within the multi-billion dollar health industry.

The present system is unjust

The present system is clearly imbalanced and unjust. It's inequitable. It doesn't place sufficient value on health success. It doesn't place sufficient value on advocating for the patient. It doesn't place sufficient value on the need for patient-driven research or clinical trials. If it did, there would be a body sanctioned to speak and act on a promising body of testimonials.

How many stories similar to the LDN story are out there? We don't know, because they haven't all been collected, stored, and shared centrally. That makes me feel uneasy and should make you feel uneasy.

Patient testimony can become evidence through 'volume value'

Recording patient testimony in a structured and meaningful way is important.

Testimonies scattered across the Internet may build awareness, but they can be easily devalued and dismissed as random patient anecdotes. They don't register on the public health radar, can't be validated or measured, are not considered evidence, and don't help build a compelling case.

A collection of health success stories presented as 'case studies' can build into a compelling body of evidence that can no longer be ignored. The collective is greater than the single, and though the LDN story is already an excellent example of the power of numbers, it is still in need of greater patient support.

It's my hope the scientific community will one day be compelled by this volume of corroborating case studies to recognize patient testimony can achieve 'volume value' in its own right.

Governments need to acknowledge the value of patient testimony

The collective LDN story is an excellent example of why 'health systems' worldwide need to balance the scales in favour of patients and give more weight and credibility to patient testimony.

It's my hope governments worldwide, presently reviewing and implementing longer-term visions for improving population health, will welcome, accommodate, and integrate patient testimony as a valued, protected, and integral part of their public health IT systems, and will create official bodies and processes chartered to act on behalf of patients and their evidence - impartially, and without prejudice or conflict of interest.

I am but an individual without sufficient resources to lobby for action on this international human rights issue, this orphan desperately in need of more champions - hence this free book in the hope of building international awareness and support.

He who suffers much will know much

Greek proverb

Supporting data for this essay is in the form of untested patient testimony of health success. I do not have the resources to validate each testimony.

This article has been previously published in earlier versions with different titles:

a) 2005 version published on News-Medical.Net, 1 December, 2005

Drug stops multiple sclerosis - but sufferers can't get it!

Cris Kerr highlights Naltrexone in her latest issue of 'Case Health - Health Success Stories'

- <http://www.news-medical.net/?id=14749>

b) 2006 version entitled 'Anecdotal evidence points to relief for MS sufferers' was published on ONLINEopinion

Australia's e-journal of social and political debate, 3rd January, 2006

- <http://www.onlineopinion.com.au/view.asp?article=3905>

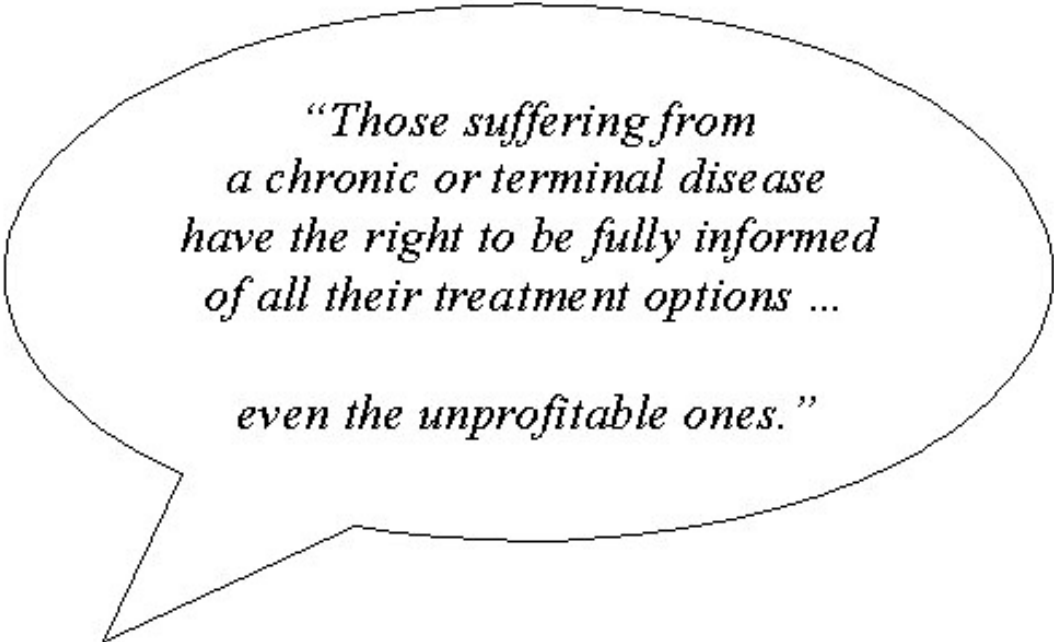
c) Drug stops multiple sclerosis - but sufferers can't get it!

was published in the Case Health LDN Booklets 2006, 2007

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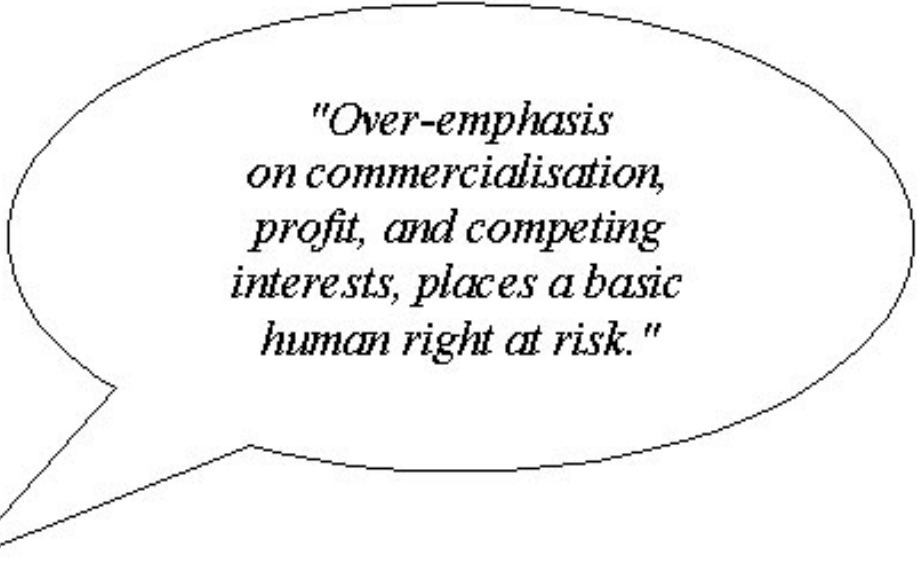
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*“Those suffering from
a chronic or terminal disease
have the right to be fully informed
of all their treatment options ...

even the unprofitable ones.”*

*Cris Kerr, ‘Case Health – Health Success Stories’
November, 2007*



*"Over-emphasis
on commercialisation,
profit, and competing
interests, places a basic
human right at risk."*

*Cris Kerr, ‘Case Health – Health Success Stories’
November, 2007*

1) My post LDN MS story – Jim

LDN since December 2003

- story submitted Dec 2005
- story updated Dec 2005
- story updated Aug 2006
- story updated July 2007
- **story updated July 2008 (4.5 yrs on LDN)**

SPECIFICS

DIAGNOSED

- Jan 2002 - Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)

- Feb 2002 to Nov 2003 - Beta-Seron

MEDICATION (post LDN)

- Dec 2003 to Jan 2004 - 3mg Low Dose Naltrexone (LDN)
- Jan 2004 to present – 4.5mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose – 3mg for 1 month, then increased to 4.5mg Low Dose Naltrexone (LDN)
- b) Time – nightly, as close to 11pm as possible.
- c) Type - Compounded capsules with pure Naltrexone powder and Avicel filler.

SUPPLEMENTS

- May 2008 – one each of the following:

Mornings, as follows:

Primal Defense (Probiotic)

Alpha - Lipoic Acid x 300mg

L-Carnitine (CarniPure) x 500mg

Super "B" Complex

Noon, as follows:

Primal Defense (Probiotic)

Alpha - Lipoic Acid x 300mg

Turmeric Extract (95% Curcumin)

Selenium x 50mcg

Resveratrol x 75mg (Japanese Knotweed)

Evenings, as follows:

Primal Defense (Probiotic)

Alpha - Lipoic Acid x 300mg

Oregano Extract x 450mg

Zinc x 50mg

Ginkgo Neuro-Mind x 50mg

Bedtime (around 11pm:

Cal-Mag (Chelated) x 250mg

Cat's Claw x 300mg

Move Free (Glucosamine 1500mg Chondroitin 1200mg Hyaluronic Acid 3.3mg)

Vitamin C x 1000mg (unless feeling 'puny' then I up it to 5000mg for a couple days)

DIET

- 2007 Joined weight watchers and lost 55 pounds - 70 lbs more to go. Attempting to quit smoking (talk about stress) haha.

- 2008 – My diet has improved since I made time to regroup and reorganize my thoughts on my eating patterns. I've adopted the advice of my Kinesiologist: I drink more water, I do the 'juicing' (which has become a favorite), I eat more green vegetables and fruit, I stay away from dairy as much as possible, and I eat very little red meat (sigh). Weight loss is still an issue but slowly improving too. All in all, I've improved my eating habits and my diet is much 'healthier' than it was previously.

EXERCISE OR INTERESTS

- 2007 - Tai-Chi & martial arts, learning to relax, as well as more walking.
- 2008 – my strength is a little better since I've started doing some more exercise. I spend less time in front of the TV, and more time up and about, looking for things to do that will occupy my time as the energy permits – and I stay away from stress if at all possible. I've 'finally' learned to calm down, and not be such an "A" type of person. For me, it was really stressful. Now, I'm 'laid back' and enjoying life more, doing some woodwork, and camping/RVing.

My Story – December 2005

My Story AFTER beginning Low Dose Naltrexone (LDN) – in December 2003: Personally, I believe it has halted the progression of my disease and it has given me back some of the abilities I thought were gone for good. No....this is NOT a solicitation, this is not some sort of scam, this is MY Story ... MINE ... you want to find out more, check out remedyfind.com, then go to ldninfo.org and you may, just may, have an inkling of why I've now got hope back in my life.

My neurologist says it's a placebo effect, and I said, okay ... you'll write the prescription for the sugar pills ... okay?? She did - then we parted company. She didn't like the fact I'm better, and I'm no longer on the poison's she wanted me to take. (My opinion of the CRABS drugs, and mine only.)

I don't stagger when I walk, don't rely on a cane for balance, don't use a wheelchair for the distances anymore. No longer do I slur my words, don't shake, spasm, tremor or any of that. The never-ending migraine ... gone. ... Now if I get a headache, it's usually due to sinuses, and a sinus tab or couple of Excedrin take care of it. Am I cured??? Not by any stretch of the imagination, and sadly, most people don't receive the almost full reversal of symptoms that I've had the joy of receiving. Most all do say they experience better bladder control.

If you've made it this far, and maybe checked out the LDN website - go back and re-read it - then read it again a couple more times before you jump up and down and think THIS IS IT!!!! Read ... 'it's intended' or I should say, 'it's believed' that it halts/stops the "PROGRESSION" of the disease.

Anything else like symptom improvement is a happy side effect and not a guarantee. Just icing on the cake ... something to be hoped for, not expected – but a bonus. Starting to sound like a 'bleep' ad for the drug ... I'll end here. May the Lord Bless you and watch over you, and remember - this is just my version of how 'I' felt, not anyone else. Some people actually feel much worse.

UPDATE: December, 2005

Been a while since I checked in with the discussion group, and today is my 2-year anniversary on LDN. Started Dec11th 2003 at 3mg, was on that for a month, then upped it to 4.5mg and have been there ever since. Like Reg, I'm another Happy Camper on LDN who has a lot to be thankful for. I still tend to 'lurk' in the shadows of the group, and will probably continue to do so, but thought I'd throw my 2 cents in for what it's worth. So, now that I'm out of my "Cave" I'll re-gale you with a short version of Thanks....

Thanks to the 'old-timers' for your encouragement a-ways back, when I was at my ropes end just looking for something that would halt/stop the onward progression of this MonSter. All I wanted, hoped for, was something, anything, that would stop me from getting any worse. Received more than I was hoping for.

As it turns out, I realised an 'almost' complete turnaround of symptoms. Not remission. I did try Dr. Bob Lawrence's 'two days off' system but couldn't walk at the end of the two days so have learned, for me, it 'appears' to work better without having scheduled breaks and missing doses. Again, thanks to all who helped me in the beginning. To try to name all of you would be next to impossible and if you remember me, then you've probably helped me at one time or another. Thank you! Cured??? Not hardly, but I will say again, my 'worst' day taking LDN is by far and away much, much better than my 'best' day on the injections.

Just my personal observation as it relates to me. I still have the ups and downs, but seem to bounce back pretty well. I have good days, and 'better' days. Any day I can get up, out of bed, make it to the 'throne'-room (blush) without falling down, having an 'accident' along the way, and make it there by myself, without a cane, or the wheelchair, is a good day. The better days are when I have the energy to last all day without falling asleep in the middle of the day, actually get projects complete around here.

Being able to (half-way) think once again, having a "Memory" once again, balance, bladder control, no more tremors/shakes, a general 'lessening' of most symptoms to the point most are easily tolerated or ignored altogether, is absolutely wonderful - more than I ever expected. It's nice to stand for more than a couple of minutes without having to sit down because the legs are starting to wobble, tingle and go numb - and if they go numb, I fall.

I have pushed myself too hard on occasion, and have paid for it, but not like in the past. No more knives in the backs of the thighs, arms, back, or elsewhere. No more electric type shock sensation, no more Intense burning over half the body – very mild now. If only ... if only I had been guided to the LDN website earlier, had

been given LDN information and the option to try LDN medication in the beginning, probably would not have (maybe?/maybe not?) ANY lingering symptoms as I have now.

I'll happily settle for what I've regained as opposed to what 'could have been' because I was lucky. I found LDN and had the courage to try LDN before I got even worse. What if I hadn't? I know many have given coffee away, but I still drink maybe 4-6 cups of coffee in the morning. Two years, no ... I repeat ... NO relapses, no flu, no colds, no pneumonia, no more migraines, no more 'Sorry honey, I've got a headache' <grin> and I really believe, NO progression. To ALL the newbies joining the group, and people I haven't had the chance to meet yet in the group ... Welcome, and hang in there. Listen to the 'old-timers' as they've been around a little while, and just want to help you if they possibly can, plus from what I've been reading, some of the newbies are pretty sharp themselves and have done some homework.

There is a wealth of information to be harvested here, and information to share that is available to all of us. Sharing is important – when you've been helped, it's your turn to help others. All we have to do is 'post' a question and someone who has information, answers ... hmmm duhh ... if I can do this, anyone can. <grin> Lot of sharp people there, and they want to help.

To anyone out there still sitting on the fence... read all you can about LDN - the pros, the cons. One thing I did that you might try ... ask if you can e-mail a couple of people off the message board (private), get their story, ask if you can call them up, or ask if they can call you. Talk to them "in person" so you get up front and personal. For me, it changed the whole way I thought about it. Figured it couldn't hurt, so why not, take a leap of faith, and maybe, just maybe, it might help. For me, it did. Hopefully for you, it will also.

Hope this makes sense to 'someone' out there, hmmm, guess I'm sicker than I thought, as it's starting to make sense to me. Haha Time to go before this becomes another book. Off to my "Cave!" Have a Great Day!

UPDATE: July, 2007 - 3 years on LDN

Just checking in to say life is pretty decent once again. :-) June 11th was 3 1/2 years on LDN. Life changed literally overnight. From the pit of despair, having to use a wheelchair, cane, or the walls to remain upright, to being able to walk again without needing any of the aforementioned as aides.

I count myself among the blessed that have received an 'almost' complete turn-around of symptoms. Three real challenges remain - extreme fatigue, weakness, and heat intolerance. I still have my 'moments' when things aren't quite right. Some of the symptoms raise their ugly heads and make a brief re-appearance to let me know they have not gone away completely...just laying in wait...no biggee...been here before and now know they are only temporary. Thing is NOT to freak out...just to RIDE it out and all quiets down again.

I find that if I stay up and moving, keeping the mind active and the hands busy, I can ward off the fatigue most of the time, and some exercise and lifting weights just to keep 'toned up' help with the strength. So far, the only thing that really combats the heat is remaining indoors under the air-conditioning unit - sigh.

It does help to wear a neckerchief with the 'crystals?' that absorb water and puff up, after it's been in the refrigerator to chill. Using a bottle 'mister' you pump up and spray, plus a small hand held portable fan. They all help 'some' but as with anything, they do have their limits. Keeping stress out of my life (much as possible) has been a big help. I remain optimistic that I 'may' improve some more...just have to keep working at the lifestyle changes.

We (wife and I) are planning on attending the next LDN conference in Nashville, TN, and hope to meet some of the people we've been in contact with via the LDN discussion group and phone calls. I don't post much anymore as there are now a lot of people to help the newbies but I still help behind the scenes. All we can do is tell our story and let those who are thinking about trying LDN get all the information they can, and make up their own minds about it.

I still try to talk to at least one person a day about LDN. Good news is; after 3 1/2 years there are now 4 doctors in town that will prescribe LDN, another two are located 10 miles south and an hour north of us. 20 people I know personally are taking it here and they've told others who are now taking LDN. This has taken on a life of it's own!!!

We are anxiously awaiting the results of the UCSF LDN clinical trials, and as soon as we hear anything I'm taking plenty of copies of the information to my doctor so he can pass it out to other doctors he knows.

UPDATE: July, 2008 – 4.5yrs on LDN

My My...time really does fly. Here it is, almost 4 1/2 years later, after starting on a 'new' (old) therapy for MS. For me, one that has worked very well and not like the 'traditional' therapies that did not work me.

Unlike the 'traditional' therapies, there are no flu-like symptoms, no nausea, no aches and pains, no cold chills, no night sweats, no headaches, no sick feeling every other day. Basically, no side effects for me, at all.

Still Hangin' in there. No progression noted. Symptom reversal still remains pretty much the same, but I still have the ups & downs but that is to be expected. I still suffer from extreme fatigue at times, weakness, and severe heat intolerance, but, I am working to improve these 'challenges' a little at a time and finding ways to overcome them to some degree. Better than before, but not great, sigh.

What I have to give thanks for are the appearance of, 'reversal' of symptoms. Strength is a little better since I've started doing some more exercise, and diet, now that I've taken the time to regroup, reorganize my thoughts on my eating patterns, is improving. Weight loss is still an issue but one that is 'my cross to bear' at this time but slowly improving too.

I take my vitamins throughout the day. Now I do the 'juicing' which has become a favorite. I eat fruits & vegetables and stay away from the dairy as much as possible. All in all, I eat much 'healthier' than previously, spend less time in front of the TV, and more time up and about, looking for things to do that will occupy my time as the energy permits – and I stay away from stress if at all possible. I've 'finally' learned to calm down, and not be such an "A" type of person. For me, it was really stressful. Now, I'm 'laid back' and enjoying life more.

General overall Health: Pretty decent. At times, or brief periods, I can "almost" forget I have MS. "Almost."

For Zil: It all goes back to what a friend said..."Never Give Up!" "Never Surrender!"

Sooo, with that in mind, I start my day.

For you, and anyone who may read this...Have a Great Day!

Jim, USA (Cap'n Caveman & Wo-man)

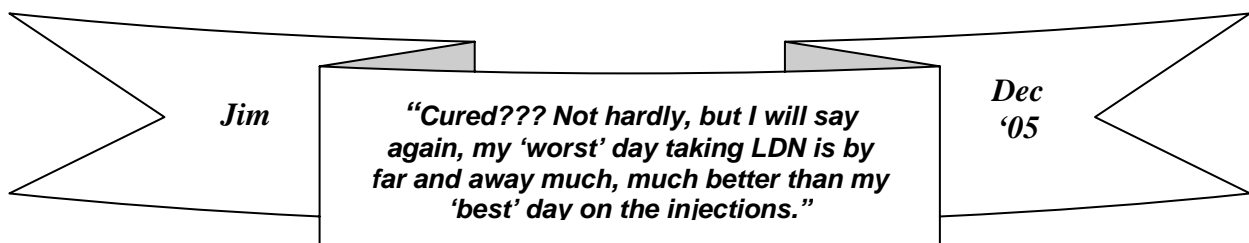
MY RECOMMENDED READING:

To any and all who don't know there are a few books you might be interested in checking out...

- 1) '20 Years And STILL Coping and Prevailing' (with MS) by Thomas Bayuk
- 2) 'The Things We Don't Talk About...OR....You Better Smile Through The Tears' (also) by Thomas Bayuk
- 3) 'Up the Creek with a Paddle' by Mary Anne Boyle Bradley

MY RECOMMENDED SITES (apart from this one):

- 1) ldninfo.org & lowdosenaltrexone.org
- 2) remedyfind.com



2) Until there's a cure there's LDN - Carol

LDN since Sept 2002

- story submitted July 2006 (almost 4 yrs on LDN)
- updated August 2007 (5 yrs on LDN)
- **updated July 2008 (almost 6 yrs on LDN)**

SPECIFICS

DIAGNOSED

- Jun 1999 – Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)

- 1999 to May 2006 - Topamax 100mg

(I started on Topamax after I had 3 seizures, 2 of which were in a Walmart Store in Florida in 2003. My Neuro felt it was due to my MS and the store lighting. I stopped taking Topamax in May 2006 because after a few years on LDN I felt so much better and hadn't had a seizure in years. I'm prepared to go back on Topamax, if necessary, but am hoping that won't be the case.)

MEDICATION (post LDN)

- Sept 2002 to present – 4.5mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose – 4.5mg Low Dose Naltrexone (LDN)
- b) Time - I take the Naltrexone between 10pm and 2am each day
- c) Type – Compounded capsules with pure Naltrexone powder and Avicel filler.

MEDICATION OTHER (post LDN)

- 10 mg of baclofen, twice a day

SUPPLEMENTS

- May 2008 - I take the following:

Vitamin D x 1 daily
Multi Vitamin x 1 daily
Fish Oil x 1 daily

DIET

– July 2007 - Always been careful - fresh vegetables, fruits, chicken, fresh fish, whole grains - rarely eat red meat, and limit my dairy, white flour, refined sugar intake - occasional sweets.

- May 2008 - I have the same eating habits as I've always had. Fresh vegetables and fruits, very little red meat, a lot of chicken and fish, whole grains, occasional sweets, but I do limit my dairy, sugar and white flour intake.

EXERCISE & INTERESTS

- LDN has helped me get more exercise. I take slow walks.

My Story – July 2006

My name is Carol. I am 49 yrs. of age, and I was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) in June of 1999. When I received the results of my final test (spinal tap) and was told of the ABC's (an acronym for the first initials of MS drugs, also known as CRABS) I had to chose from (none of which sounded good to me) I told my Neurologist from the very beginning ... "I Will find something better".

I was immediately prescribed Avonex and remained on it for 2 yrs, along with a handful of pills each day to help with fatigue, loss of sleep, and spasms. The stress alone of having to inject myself with an intramuscular shot once a week was a horror. Dealing with the side effects was just as bad. But I did have hopes the Avonex would help me.

I found myself going into extremely bad relapses (every 3-4 months), which kept me from walking for sometimes up to 6 weeks at a time. Along with each relapse came the Steroid IV treatments, followed by 13 days of weening off with Prednisone pills. This DID NOT make me happy, nor did it make me any better.

My Neurologist, finally, decided to try me on Copaxone. Injecting myself every day led to more stress and I found myself having extremely bad side effects. After two months of extreme side effects, I realized I was allergic to it and again changed my therapy.

I moved on to Beta-Seron - every other day injections - still hoping I would find some relief and start slowing the progression but around this time I started using a cane to get around and found my health and life was changing dramatically - for the worse - as time passed.

The relapses didn't stop although they weren't hitting me quite as often, but my symptoms were definitely worsening and my health deteriorating. I was "In search of" something better, something that was actually going to HELP or STOP my MS before the rest of my body was destroyed.

That's when I heard about Dr. Bihari and Low Dose Naltrexone (LDN) from a friend who also has MS.

I immediately made a call to Dr. Bihari's office and set my appointment with him for a month later. During that time I stopped all my medications, injections included, to rid my body of all other chemicals. I wanted to start the LDN with nothing else in my system so I would know EXACTLY what, if anything, it was doing for me.

I did however, let my Neurologist know what my intentions were and showed him all the printed information I had on LDN. I told him I respected his opinions but that it was MY body, and as I was the one with MS I should be able to make MY own decision on how to treat it. He was not impressed because LDN is not yet FDA approved for MS, but I stood my ground.

On September 9th, 2002 I met with Dr. Bihari in NY. I lived in Florida at the time but I would have travelled from anywhere. Dr Bihari prescribed LDN and I started my first dose of 4.5 mg Naltrexone capsules the same night.

On the second day after starting LDN I woke up without spasms. I was convinced it was too soon to be the LDN and was thinking it was "just a coincidence". By the third day I was feeling strong enough to walk along the beach - something I had NOT been able to do in the three years since my MS diagnosis, and certainly not with any of the previous drugs I'd been prescribed. I walked a good 3 blocks in the sand ... I couldn't believe it!! I was elated and by now convinced LDN was already having an effect.

Nothing happened quickly, but as time progressed I noticed small incremental improvements – gradually increasing body strength, more clarity, less spasms, less numbness and tingling, fewer headaches - and my sleep pattern was getting better.

I have been on the LDN for almost 4 yrs now, and will NEVER stop taking it.

My life has Quality again now - something I feared I'd lost forever. I won't sit here and say I don't have some down days - I still have MS after all! But, my days are mine again. They belong to me now, not the MS - and I'm feeling stronger than I have in years. I no longer use my cane unless it's for extremely long distances and this pleases me immensely.

I haven't had one relapse since starting LDN. LDN has STOPPED my MS progression - not just SLOWED it down like the other therapies I've used. I don't have to worry about side effects either – another reason I wasn't worried about trying LDN.

I'm a true believer in LDN and here's why: After starting on LDN I had an MRI (in 2003). It showed that my (4) "lesions are healing themselves". Those words came from my Neuro when he showed me the films and I couldn't see the lesions any longer. Yes, they were Prominent, and now only one small spot is visible.

I asked my Neurologist if he was still questioning the benefits of LDN after seeing the wonderful improvement: His cautious reply was ... "Don't stop doing what you're doing" ... yet he still will not write a prescription for LDN. My last words to him were, "Shame on you for not sharing this with the rest of your patients".

After moving back to NY I made an appointment with a new Neuro - and that's a whole other story!! Let's just say 'she was shocked' by my MRI results. In the past 4 years (since starting LDN) there has been no progression.

There she was - telling me my lesions HAD to be multiplying - and that IF my results showed more lesions, she wanted me to consider going back on the injections – and she added that if I didn't go back she wouldn't take me on as a patient! Needless to say I left her office with a copy of my MRI report and told her I'm doing what is BEST for MY body and I now had to decide whether or not I wanted HER as my Neuro!

I was diagnosed with Lobular Breast Cancer in February 2006. It was my first Mammogram (wrong on my part to have waited so long). It turned out to be Pre-Cancerous but I still had to have the tumor removed. In my heart I honestly believe this could have resulted in a very different outcome - a horror story. I believe taking the LDN has kept it at bay, kept it from growing. I turned down the hormone therapies (which I found out can cause Cervical or Uterine Cancer) and am sticking to my LDN.

I hope all doctors will take notice of this wonderful treatment option - that the major media will finally acknowledge LDN - that LDN clinical trials for MS and other diseases will happen and will prove LDN to be an effective and economical treatment - and that the FDA will approve it - so everyone suffering from this and other Auto Immune System Diseases will be able to benefit from it.

UPDATE: July, 2007

I'm happy to say.... LDN has NOT stopped working for me! I'm still quite content with how I've been doing since this time last year. June was my 8th anniversary of being diagnosed and this September will be 5 yrs on LDN. I truly haven't experienced too many changes, other than slowing down a bit more. (I did just turn 50!!)

My legs get a little more worn out than they did a year ago, and I've had a few minor flare-ups - but no relapses, and nothing major like before LDN. I have an appointment with a new Neuro this month. I'm sure that will be interesting! I plan on taking all my info on LDN with me, along with my MRI films for the past 8 yrs (those of which have no changes in them) and see how that goes. I love knowing that I can help others in some way when it comes to my experiences with LDN.

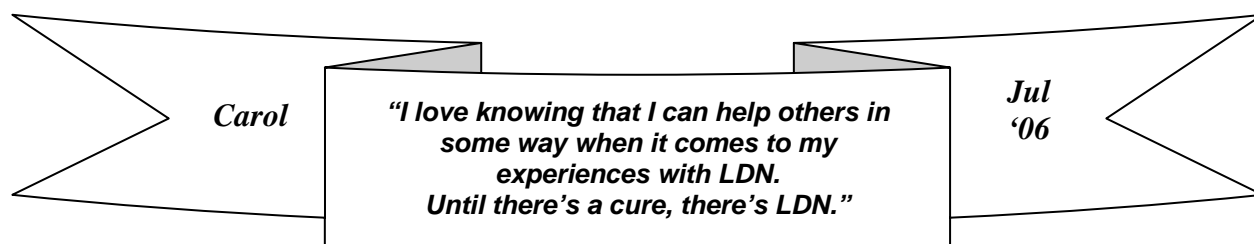
I AM a BELIEVER

UPDATE: July, 2008 – almost 6 years on LDN

I am still benefiting from LDN. I can't imagine a day without it! And, may I add, that I am extremely pleased to have been asked again to have 'My Story' added to this year's book. I can only hope that someone finds it helpful in their fight against M.S.

Remember my quote:
"Until There's A Cure...
There's LDN"

God Bless, Carol, USA



3) LDN-Out of wheelchair under a week - Scott

LDN since July 2004

- story submitted May 2005
- story updated Jan 2006
- story updated May 2006
- story updated July 2007
- **story updated July 2008 (4yrs on LDN)**

SPECIFICS**DIAGNOSED**

- Oct 2001 - Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)

- Jan 2002 to Apr 2004 - Avonex
- Apr 2004 to July 2004 - Rebif

MEDICATION (post LDN)

- Jul 2004 to Aug 2004 – 3mg Low Dose Naltrexone (LDN)
- Aug 2004 to present – 4.5mg Low Dose Naltrexone (LDN)

DOSE & TYPE

- a) Dose – 4.5mg Low Dose Naltrexone (LDN)
- b) Time - I take the Naltrexone at 11pm each day
- c) Type - My Naltrexone capsules contain pure Naltrexone powder with Avicel filler.

SUPPLEMENTS

- July 2008 – This is my complete current list:
 - B-12 sublingual Multi-Vitamin
 - Vitamin A
 - Vitamin B complex
 - Vitamin C
 - Vitamin E
 - Folic Acid
 - Ginkgo Biloba
 - Vitamin D
 - Calcium
 - Fish Oil
 - Magnesium
 - Valerian Root

DIET

- Swank diet since 1 January 2004

EXERCISE & PHYSICAL THERAPY

- 2007 - aqua therapy at the YMCA three times a week plus exercising at home three days a week
- Jun 2008 - aqua therapy, exercising at home, physical therapy instead of YMCA

My Quest for LDN - May 2005

Hi, I'm a 31-year-old male diagnosed in October 2001 with Relapsing Remitting MS. I had slurred speech that went away before the diagnosis. I felt all right in 2002 and then in mid 2003 I began to have problems.

In January of 2004 I was laid off from my job because of poor balance, bladder problems, deteriorating vision, and poor handwriting. In March of 2004 I began to use a wheelchair due to leg weakness.

I began to read everything I could on what helped others with MS. I found Remedyfind.com. I read about Low Dose Naltrexone (LDN). What was this? The more I read the more I liked the idea.

I asked my doctor about it and without batting an eyelash she said "NO! It's horrible stuff." Why was I told 'no' so quickly without a discussion? Many people were on this medication and it was working well for them. I thought I deserved more than a simple "no".

I found another doctor who would prescribe it and began LDN on 23 July 2004. Within two weeks my muscle spasms went. My bladder urgency was the same but I could deal with that, as my other symptoms were getting better. Within a few days I was out of my wheelchair (I was in it for five months) although I was using the walls to aid my walking.

Ten months later, I mow my own grass. I still have balance problems and muscle spasms but they are not as bad as they were. My "brain fog" has gone completely. The problems I have with my vision have lessened and I plan on seeing an ophthalmologist. My eyes are stopping me from driving.

I use a pedometer to track how much walking I do each day. I tend to walk about 2 to 2.5 miles a day, I also exercise 3 times a week to help keep up my strength. LDN has given me my life back.

UPDATE: January, 2006

First I'll relate a little more history to help you understand why I was happy to try LDN and why I continue to take LDN.

I am now a 32-year old male. I was diagnosed with Relapsing-Remitting MS in October of 2001.

I was on Avonex and Rebif (two of the CRAB drugs) for over two years. I quickly deteriorated, particularly toward the end of that time - winding up in a wheelchair for 5 months, and 'legally blind' for 18 months.

Three months into my wheel chair nightmare (around May 2004) I was surfing the internet (which was frustratingly difficult with my now severely deteriorated vision) and stumbled across information on a drug called Naltrexone.

It appeared other MS sufferers were having success with the drug. As my condition had deteriorated on the CRAB drugs, I was tempted to try Naltrexone but concerned it wasn't a mainstream treatment. It's wise to be cautious so I read everything I could find. It took me two months to decide and to find a doctor who would prescribe Naltrexone.

In July 2004 I stopped taking the CRABS completely and started taking low doses of Naltrexone (LDN).

In less than a week I was out of the wheelchair yet still using the walls to walk and balance myself. Being determined, I began to exercise at home. I was soon able to stand-up whilst showering.

You can imagine how elevated I felt after noticing improvement so soon after starting on LDN.

In January 2004 I had started on the Swank diet, supplemented by a strict vitamin regimen. I kept up this regimen after starting on LDN and I still use this regimen because I've noticed I just feel better all-round.

I am writing this in January 2006 after 18 months on LDN. I mow my own grass with a self-propelled mower and my vision impairment has improved enough that I have just been approved to drive during daylight hours!

I attend aqua therapy at the YMCA three times a week while exercising at home another three days during the week. I live alone and perform my own housework. I anticipate that in mid-summer I will start physical therapy.

Overall, I do very well managing the symptoms with the LDN. I can still have a bad day but my worst day now is much better than my best day pre-LDN.

During this entire time since my diagnosis, I have maintained the attitude that I would rather try and fail 1,000 times than never try at all. I am so thankful that I got off the CRABS and started LDN.

To any and all people that are still researching LDN for their condition, I urge you to go ahead and start it now while continuing your research because I've noticed the majority of individuals who post to the LDN forum (with MS or other conditions) regret not starting on LDN sooner.

UPDATE: May, 2006

I added Magnesium to my supplement regimen in April 2006. Within 5 or 6 days it made my legs feel very heavy, like walking thru knee-deep mud, and I was doing the wall walking thing again. At first I wasn't sure what had caused the change. I had been taking 800 mgs Magnesium at the time, so I tried reducing it to 400 mgs. The improvement was almost immediate and I felt a lot better. Having said that, I continue taking 400 mgs Magnesium because I think it has helped with my muscle spasms. I haven't changed anything else - LDN treatment, Swank diet, exercise, and supplements remain the same.

For the past 2.5 years (that's right I said years) I had not been able to drive. However, my eyes have improved gradually and I got the BMV's approval - so I am driving again! I am soooo happy because I'd been relying on others to drive me places. I only went to the grocery store once a month because that was the only time someone could take me – it was too far to walk safely and manage grocery bags. I used to sit alone in my house a lot.

I tell ya ... now that I have a car and drive myself places (and even though I'm restricted to daytime driving only) no one will be able to wipe this smile off my face. My eyes had improved gradually with time - until the point I suspected I'd be able to pass the test so I went to see a doctor the BMV recommended.

What do I attribute this particular improvement to? I honestly don't know. It could be due to one thing or a progressive improvement due to my complete regimen. Because I can't attribute my improvement to any one thing, I don't want to raise any false hopes.

UPDATE: July, 2007

Now a year later it is time for my 3-year update. There have not been many changes in the last year. I did, however, miss two weeks of LDN (due to 2 surgeries). Also, because of the surgeries I had to miss approximately 2 months of aqua therapy. Due to these 2 factors my health declined slightly. I now have poor balance and use a cane more than I did before.

Aside from that I don't have anything negative to say. I can say the lack of exacerbation is still a positive. I'm still driving (though not a lot and always nervously) and still living alone keeping my independence. I've tried several times to get my neurologist to write a prescription for LDN, but his only compromise was that he'd write a prescription for LDN if and only if I would take Copaxone as well. Needless to say I said 'no thanks'.

I did show him the LDN conference DVD. I also asked how he could explain me getting better on LDN. His response was; "That's just MS". I'm going to be looking for a new doctor (doctor number 5) very soon. I believe all of my improvements are directly a result of using LDN religiously. I will continue to use it until someone finds a cure for MS. As another has said; "until there is a cure there is LDN." Period.

UPDATE: July, 2008 – 4 years on LDN

No change to report. I still take LDN and it's still working for me. I still go to the YMCA for aqua therapy however, for the summer session I will not be going as I will be focusing on mowing my grass. That may not sound much, but it takes about a week to mow it (when I first bought this house 10 years ago it took an hour). I cannot do both the aqua therapy and mowing the grass. I think it will be good because I will get more exercise done.

Scott, USA

4) LDN-I have MS but walking & driving my car again - Bill

LDN since July 2005

- story submitted March 2006
- story updated - August 2006
- story updated – July 2007
- **story updated – July 2008 (3yrs on LDN)**

SPECIFICS:

DIAGNOSED

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

MEDICATION (pre LDN)

- Feb 1998 to Aug 2001 - Avonex
- Feb 1999 to Feb 2000 - Copaxone AND Avonex taken together
- Mar 2002 to June 2005 - Rebif
- Sept, 2001 to Feb 2002 – Cytosan (chemotherapy)
- Aug 2001 plasma exchange for eleven days (first infusion was in June, 1998)
- 2001 to 2005 - multiple infusions of Solumedrol IV steroids (at least four infusions a year before LDN)
- Gabapentin (Neurontin) x 3 per day 300mg
- Clonazepam (Klonopin) x 1 at bedtime 1mg
- Effexor XR x 1 twice per day 37.5mg
- Aricept x 1 a day 10mg
- Provigil x 1 a day 100mg
- Flomax x 1 a day 0.4mg
- Singulair x 1 a day 10mg
- Baclofen x 3 per day 10mg
- Potassium CL 10 MEQ CAP x 1 a day 10 MEQ CAP
- Furosemide (Lasix) x 1 a day 40mg

MEDICATION (post LDN)

- Jul 2005 to present – 3mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose – July 2005 - 1.5mg for 1 week, then 3mg thereafter. I stopped taking Rebif at the same time.
- b) Time - I take the Naltrexone between 10pm and 2am each day
- c) Type – Compounded capsules with pure naltrexone powder and Avicel filler.

MEDICATION OTHER (post LDN)

- Jul 2005 to present - 10 mg of baclofen, twice a day

SUPPLEMENTS

- Jul 2008 to present - one multiple vitamin daily

DIET

- average, no particular diet

EXERCISE & INTERESTS

- walking, lifting light weights, and abdominal exercises, landscaping, President of Local Beautification Council, Member of Local Tree Commission

My Story – March 2006

I am 56 years old. I was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) in 1998, and upgraded to Secondary Progressive (SPMS) in 2002. My chief symptoms are (were) extreme mixed sleep apnoea, chronic obstructive pulmonary disease (COPD), inability to walk, total deafness in my left ear, and inability to concentrate for any period of time.

I have been treated with Avonex, Copaxone, and Rebif of the ABCR drugs, chemotherapy (Cytosan, plasma exchange, as well as many, many sessions of IV steroids (Solumedrol).

As of June, 2005, I was on oxygen 24/7, wheelchair bound, having a flair of my MS on an average of once a

month, and doctors had told me that my breathing difficulties, caused by the MS, would ultimately result in my demise.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

UPDATE: July, 2007

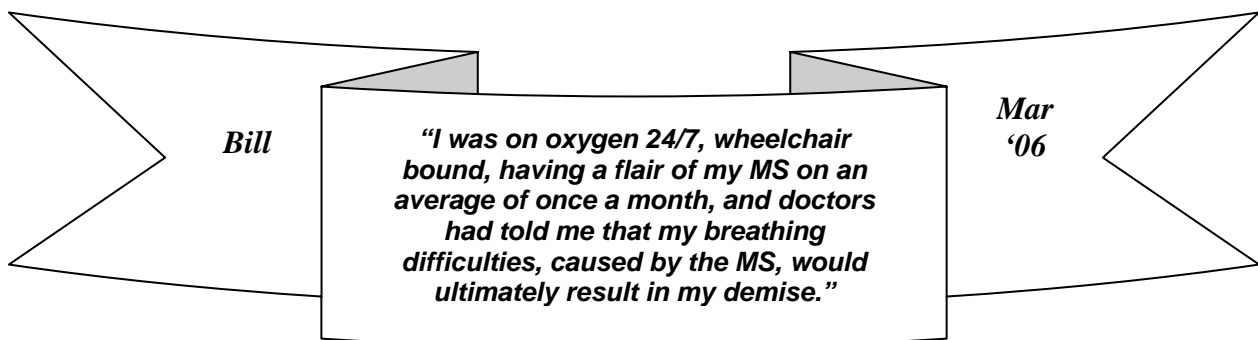
I continue to do very well on LDN. I cannot know how long my good fortunes in health will continue, so I am trying to make the most of it while I can. I am doing landscape consultation for our city, finishing a backyard landscape project of my own that I began last summer, and I'm doing some landscape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

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

UPDATE: July, 2008 – 3 years on LDN

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

Bill, USA



5) LDN-Improvement was gradual and subtle - Julia

LDN since August 2005

- story submitted November 2005
- story updated August 2007
- **story updated July 2008 (3yrs on LDN)**

SPECIFICS

DIAGNOSED

- Apr 2005 - Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)

- none

MEDICATION (post LDN)

- Aug 2005 to Jun 2006 – 3.5mg Low Dose Naltrexone (LDN)
(NB I suffered a relapse between March and June 2006. Initially, I felt the LDN wasn't as effective as it had been and changed to the liquid version. However; the relapse occurred during a particularly stressful period for me (relationship, money, moving house) so that may have been the catalyst.
- Jun 2006 to Nov 2007 – 2.5ml to 3ml (varied) Pre-prepared liquid Low Dose Naltrexone (LDN) from Glasgow
- Nov 2007 to present – 3mg Low Dose Naltrexone (LDN)

DOSE & TYPE

- a) Dose – 3mg Low Dose Naltrexone (LDN)
- b) Time - I take the Naltrexone at bedtime (not earlier than 9pm)
- c) Type – capsules compounded with avicel filler from Dicksons

SUPPLEMENTS

- 1 x multivitamin (multibionta or Pharmaton from Supermarket)

DIET

- nothing special, everything in moderation

EXERCISE

- work, everyday activities

My Story – November 2005

I used to have a great sense of humour, always had my finger in many pies and generally lived life and was rarely still for 10 minutes. Then I got multiple sclerosis. I didn't want to go out, meet people, or do anything. If problems arose, I would hide from them and rather let someone else sort it.....not like me at all. I had to have someone with me everywhere I went. I was afraid of falling, getting lost or confused and several times forgot entirely what I went out for in the beginning. It got so bad I didn't go out for nearly a year.

As my Mum has Relapsing Remitting MS, my diagnosis was expected, so I had a chance to read up on the offered disease modifying drugs (dmd's); Interferon alpha and beta, Copaxone, Avonex, and Rebif; and frankly none appealed to me because of the side effects. Whilst doing some digging, I came across something in the Lancet medical journal which says the dmd's on offer aren't working as expected, etc.

I discussed this with my neurologist when he gave me my diagnosis in April 05 and said I qualified for Interferon. Although he was surprised I knew about the article in the Lancet, he did discuss it honestly and said taking the Interferon was catch 22 as yes, they knew the dmd's on offer weren't working as was hoped in stopping relapses and further progression of MS. He admitted the success rates weren't as expected when they were first introduced as an option to treat MS.

I said there was no way I was going on Interferon and would look for something myself. I wanted to feel better, not worse. He agreed and I was given 3 months to go away and look for an alternative before going back to see him again.

My search led me to a treatment involving 'low doses of Naltrexone' (LDN). It's a tablet taken at bedtime which works with your own body's natural endorphins. As at 1 November '05, I've been taking LDN for three months.

I've never felt so well. In fact I feel like the old me! I can't begin to describe the difference after nearly 4 years of feeling unwell and a list of over 86 symptoms. Initially, the improvement was gradual and subtle - you were aware something was better but couldn't quite say what or why. Then you think back three months and remember how you were. That's when you realise how much of a difference LDN has made.

Some GP's will prescribe LDN on the NHS in the UK. As for me, my GP and Neuro said a flat 'no', so I just looked 'em in the eye and said I would buy it myself and take it anyway. My neurologist said it was my body and whilst he couldn't agree or disagree with my decision, it was my body and I had to do what I thought was best.

Thank God I ignored the drugs they were trying to get me to take, made my own decision, and went on LDN!! Once I'd made my mind up, I had the tablets within 4 days and noticed an improvement from day one. The only side effects I experienced were a slight worsening of existing symptoms i.e. more leg spasms and restless legs at night, a couple of vivid dreams and constipation for the first week.

My symptoms got worse for about 3 weeks but I was well aware that might happen - I stuck with it - then suddenly the worsening eased off and my symptoms got better. After feeling rough, achy and stiff every morning (almost like I was coming down with the flu), I noticed a change at weeks 3-4. I suddenly felt really good in the afternoon and have stayed pretty much the same since.

I saw the neurologist a month after starting LDN and he asked me if I was the same woman. He was sufficiently impressed to say he would prescribe it on the NHS in future and send my GP a letter telling him he can see its benefits, so the GP should be able to prescribe it. My friends and family have seen the difference too.

I have no horrible mood swings - I am alert, not confused - better humour - better memory - better concentration - better sleep - far less fatigue - from 5 trips to the loo down to none or one - legs are better and they don't ache or twitch so much - shakes in the morning have gone - better appetite - taste has returned. I feel better all round, ready to face the day and not hide. Yes, I still get blips when I've overdone it but I guess I hate wasting all this new found energy - so I only have myself to blame and frankly, I feel its a small price to pay for something that has given me so much back.

UPDATE: August, 2006

I've been taking LDN for one year now. My only update is that I am now on the liquid LDN from Glasgow (month 2) at 2.5ml and have no reason to up that dose, as I'm doing very well on it (I was previously on 3.5mg capsules from Martindales). I changed to liquid because Martindales was taking too long to deliver and was more expensive for the NHS. £93 per 60 tablets compared with around £45 for 3 months from Dicksons in Glasgow.

The last couple of batches of tablets didn't seem to have the same effect but the jury is out on whether it was something to do with the filler. I will probably never know for sure. I find the liquid easier and the 2.5ml suits me well. I vary between 2.5ml - 3ml. It also gets delivered to my door, so no trips back and forth to the chemists, I can just get a repeat over the phone now and have it delivered to my home.

After suffering a relapse from March to early June, I saw the neuro in June 06. The relapse was put down to overdoing things after splitting with a partner, moving house and money worries. The neuro will see me in 6 months then if all is the same (as I was back to the usual me again) I will go onto yearly appointments. I felt at times that the LDN was trying to pull my system back in line. Some days I felt okay and the next I was awful but gradually I've felt well again and had no problems since. I didn't need to take steroids.

I now have a part-time job, 16 hours per week and am managing that okay. The only downside I can see is that LDN doesn't help with persistent neuropathic pains but overall, I'm very pleased and will continue taking LDN, for the rest of my life if necessary.

If LDN's claim to fame is to stop progression and relapses, then the side benefits are indeed an extra bonus. I would urge anyone to try this drug and give their honest opinion, as honesty is what it's all about. Information on LDN spreads by word of mouth and I would recommend it to anyone.

UPDATE: July, 2007

My LDN carries on being a success. I changed GP's and am at present waiting for the paperwork to catch up from the old surgery, which has the letter from my Neuro saying he is happy for my GP to prescribe it on the NHS. As my new GP hasn't ever prescribed LDN, she feels this is necessary. Unfortunately for me, my timing was not on the ball and I found myself without LDN for 2 and a half weeks.

The brain fog, fatigue and bowel problems came back, along with a loss of appetite and general off colour feeling. I managed to get an emergency bottle from Dicksons and within 2 days of restarting it, I was back to how I was before. LDN is not a cure all. It helps me in certain areas, mainly bladder (don't have to go every 5 minutes), bowel (keeps me regular and stops diarrhoea), and brain fog (I can think clearly and complete tasks and remember things). I feel up to doing many things with the added energy I believe LDN provides - things I just wouldn't attempt otherwise, such as trips to town and walking the dog.

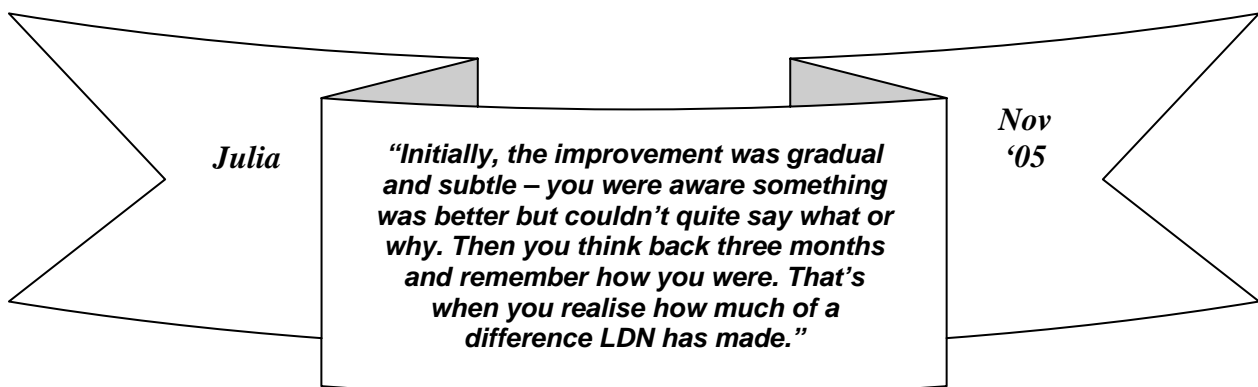
This year (2007) has been very stressful from the start. I still believe LDN plays a major part in keeping me on an even keel. The two weeks without it, certainly showed me what things would be like if I wasn't taking it. I still have "blips" but remembering what I was like without the LDN certainly makes me wonder what those "blips" would have been like if I'd never started LDN. I would say I'm very happy to be on LDN since Sept 2005 and if I had to pay for it instead of getting it on the NHS, then I would still take LDN without hesitation.

UPDATE: July, 2008 – 3 years on LDN

I moved house again in January and my partner moved in with me in May. Lots of work on the house and garden in progress and I had a car accident that wrote the car off in late May.

I've also been trying to set up a new business as a courier, so I have lots going on. Apart from periods of stiffness and fatigue, everything else is great and (fingers crossed) no relapse since 2007. I'm back on the 3mg capsules from Dicksons as it's easier to transport around and my GP is still happy to prescribe it on the NHS.

Julia, UK



6) LDN allows me to work with MS - Neil

LDN since May 2004

- story submitted October 2005
- story updated September 2006
- story updated August 2007
- **story updated July 2008 (4+yrs on LDN)**

SPECIFICS

DIAGNOSIS:

- 1989 - Multiple Sclerosis

MEDICATION (pre LDN)

- 1997 - Interferons: I was on them back in 1997 and all they did for me was to make me 10 times worse. Pre-interferons I was a 14 handicapper at golf ... post-interferons I was in a wheelchair.

MEDICATION (post LDN)

- May 2004 to present - 4.0 ml Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose – 4ml Low Dose Naltrexone (LDN) liquid preparation
- b) Time - nightly, between 10pm and 2am
- c) Type - I make up a batch of liquid LDN using 50ml sterile cool water and one 50mg naltrexone tablet. I keep it in the fridge. I shake the bottle well and use a syringe to draw up a 4ml dose once a day.

SUPPLEMENTS

- Jul 2008 - Yoghurt-based probiotic drinks to aid digestion

DIET

- average, nothing strict.
- Jul 2008 - My diet has improved. I've been buying quality meats and vegetables

EXERCISE or INTERESTS

- I was working four days on, four days off (May 1999-May 2007), the rest of the time working at home on the computer = seven days on, so no time for hobbies or interests.

MY STORY – October 2005

This is my story on low-dose naltrexone, I am not the best typist in the world, and I am using a program called Dragon NaturallySpeaking, which is a voice recognition program so I hope everything is okay and please feel free to make any changes.

I read about low-dose naltrexone on the Internet, pre-May 2004. What got my interests up was an article written by an undergraduate, called the unprofitable cure and hating drug companies and doctors, I chose to read it and pay attention to its content. That made me start to look into it with more depth, and I discovered there was no information on it in Australia which made me look even further.

It was by chance that I stumbled onto Dr George O'Neil, the local heroin doctor in Perth, and he distributes naltrexone to the addicts. I was doing a double up in a taxi, with his best friend, and things snowballed from there after I explained LDN to them.

After a meeting with George O'Neill, I decided to start taking LDN as there are no harmful side-effects, and I could see it doing nothing but good for me. After the first dosage I noticed I had greater mobility, less fatigue, better speech, and overall I felt better. The people at work, noticed the immediate change in my abilities to be able to maintain my composure and dexterity better and to do the job with more confidence.

I am classed as an emergency worker in my position, because I control the operations of the Perth tunnel, so my ability to be able to handle pressure is paramount to my ability to be able to do my job. For that reason alone it was worth the gamble to take low-dose naltrexone and see if it helped in any way, which it did.

I was told by a neurologist that I could only work 12 hours a week, which is for me a load of garbage because I need to continue to work to keep my brain active and my self-esteem. A working week for me encompasses four 12 hours shifts - two days 10 a.m. to 10 p.m., two nights 10 p.m. to 10 a.m. with no breaks - and I have

been doing this since day one, 5 1/2 years ago.

I sit at eight computers for 12 hours straight staring at \$1 million worth of monitors and watch 90,000 cars per day travel through the 1.6 km of tube. If there is a crash or a disturbance down below, it is up to me to organise what needs to be done, eg; tow trucks, police, ambulance, fire department, RAC or a simple phone call for a motorist; so as you can see low-dose naltrexone, kept me working. I have got to have my wits about me to pick up any discrepancies in the flow of traffic so my brain needs to be in gear and low-dose naltrexone does it for me.

I've been on interferons. I was on them back in 1997 and all they did for me was to make me 10 times worse. Pre-interferons I was a 14 handicapper at golf ... post-interferons I was in a wheelchair ... thus my hatred of drug companies and my distrust of the medical fraternity.

I saw a neurologist six months ago - the first one I had seen for three years. He had an open-mind to LDN and is looking forward to seeing what improvements LDN has done for me. My original neurologist was so stupid that he once said, "The only problem Neil has is showering so take him out in the back yard and spray him down with a hose.". If I could have walked over to him, I would have broken his jaw. How insensitive can one person be?

I was a very athletic person at 6 foot 2 inches and 14 stone. I've played regular sport all of my life so to get a disease like MS gutted me. Pre-MS I worked in the music industry for 10 years as a roadie. I am now a shell of the man I once was and for me that alone was very hard to stomach, but to have the so-called experts belittle me as well really got my goat up.

According to everyone I know I haven't changed a bit but according to me, I've changed a lot and that was the hardest aspect to get used to. I still haven't come to terms with it but that's probably been fortunate in a way: I didn't 'resign' myself to MS. I rose to the challenge, researched, and found out about LDN.

One of the best things about low-dose naltrexone is the price. At six dollars Australian per tablet (which lasts approximately 2 1/2 weeks) you can afford to continue medication whether it's on the pharmaceutical benefits scheme (PBS) or not. So far as I know I'm the only person here in Perth that uses this medication. If there is anyone else here in Perth using LDN I would love to know and swap notes with them.

The local MS society over here does bugger all to check these things out so I do not even worry about speaking to them about it. It appears too difficult for them to look on the Internet to check it out so I don't trust them at all. While on the price of drugs, it costs approximately \$1000 Australian per month (Oct 05) for someone to be on interferons for which they get the luxury of sticking a needle in themselves once every two days. I'm no expert, but doing the math it makes sense to me to go with the cheaper and better option!

If anybody out there has any reservations about low-dose naltrexone and its side-effects I can say there are none that I have experienced, whilst I experienced multiple side-effects whilst on crab drugs. \$12 Australian compared to \$1000 Australian per month makes sense to me. Politicians don't seem to be prioritising what's right for the patient and the economy, otherwise, the system would not be commercially driven.

As I stated at the beginning of this story I'm using a program called Dragon NaturallySpeaking version 8 and I've typed this entire letter at 160 words per minute without touching a keyboard or a mouse! This program makes using a computer very simple and I cannot recommend it highly enough. It took me five minutes of talking for the program to store my vocal patterns on its database!!!!!!

STORY UPDATE: 18 September, 2006

I now work seven days a week with four days off in-between at the tunnel. Recent changes to industrial relations laws in Australia added unnecessary stress to my workload. I'm the main breadwinner, supporting one wife and two children in private school.

My employer can now sack without having to build a case so I have had to be especially careful and protect myself as best I can. I wasn't in a union but joined recently because I thought I might need that support. My employer then sent me a warning letter without reason. So life has been pretty tough this year looking over my shoulder all the time and working seven days a week - a bad year stress-wise.

I'm still on the low-dose naltrexone and I dare say if I wasn't I would be in hospital. I don't know if it is doing anything as I seem to have plateau-ed for the last six months (no further symptom improvement) but the

amount of stress I've been under would have something to do with that. I'm trying not to dwell on what could lie ahead, but with employers these days more concerned with profit than people, it's hard not to.

STORY UPDATE: 7 August, 2007

Things have changed just a little bit. I no longer have a very stressful work situation. Compliments of Australia's new industrial relations laws, my employer sacked me with no warning for going to the toilet on Easter Sunday!

I'm still taking the low-dose naltrexone but because my life has got even more stressful I think it is plateauing a little bit.

What has changed is that they pulled an occupational health and safety issue on me for using the scooter at work, so I had to move to an automatic wheelchair. The only movement you use is your two fingers on your right hand and that has had a detrimental effect to my quality of life and health - so even though the hospital thought they were helping me out, this change has actually been detrimental.

I hate to be the bearer of bad tidings, but things aren't getting any better for me, getting the sack will probably cost me my house, any chance of a job and my family, because I don't think my wife and children will hang around.

To give you a full indication of what happened:

- (1) I was terminated because I broke a procedure! I rang my wife who was half an hour away instead of ringing my boss who was two hours away, broken procedure? Common sense I would have called it.
- (2) Sitting next to me in the meeting was the union and there was absolutely nothing they could do, so basically I have no rights whatsoever.

LDN would still allow me to work with MS, but my concern now is getting another job.

STORY UPDATE: July, 2008 – 4+ years on LDN

Things here have changed a little bit. As you know I lost my job, and as I said earlier, everything that could happen did.

My wife left me. She took the children and I saw them for the first time in six months two weeks ago.

I've been dragged through the legal system for the last six months by the wife for settlement of the property, which has been now been sold.

Stress has been incredible during this period and if it was not for low-dose naltrexone, I think I would be in hospital. So as you can see things have not been the best, I started to take the pill form of a low-dose naltrexone, but that did not seem to work as well as the liquid form so I reverted back to the liquid.

The only problem I have now is my bowels due to the fact that I got terminated for going to the toilet and psychologically, that has had a major impact on my system, but I am slowly getting over it and getting back to a regular routine. In about six weeks, the property settlement will be over and I will be able to buy a unit and modify it to suit my needs which will make life a lot easier because at the moment I am in a totally disabled, unfriendly accommodation environment where I have to shower in a 1 foot by 1 foot area and have been doing so for four months.

The disability services commission have been fantastic in getting me accommodation and care but according to the combined application process, I am not disabled enough to require carers? My body does not work at all any more and the only movable part is my right hand so you tell me!

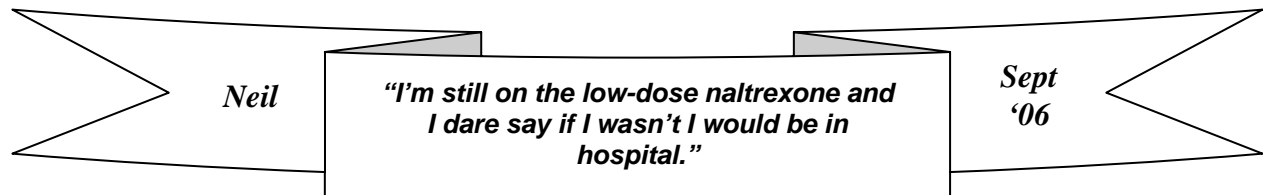
I don't like to whinge about things so I am doing what I normally do, just getting on with life.

There seem to be a few people in Western Australia using low dose naltrexone but I don't know who they are and I have made no contact with them, but the practitioner at the heroin clinic rang me and asked me where I was able to get compound pills.

Since I have moved out from the wife and kids I must say that my stress level has decreased and I am now in a more relaxed frame of mind - as the doctors, lawyers and anyone that gets in my way has found out; you

don't mess with a person that has a brain, because they will snap back and I have been enjoying it because I enjoy a good argument and challenge, and most people think that people with multiple sclerosis can't argue, but they are grossly wrong. I hope this is of some value to you and please do not hesitate to use any of this in any way you can.

Neil, Australia



7) Paul's MS & LDN story began in 2004 - Aletha

LDN since July 2005

- story submitted May 2007
- story updated August 2007
- **story updated July 2008 (3yrs on LDN)**

SPECIFICS

DIAGNOSIS

- 2004 - Multiple Sclerosis

MEDICATION (pre LDN)

- no standard MS medication

MEDICATION (post LDN)

- Jul 2005 to May 2008 - 3mg Low Dose Naltrexone (LDN)
- May 2008 to present - 4.5mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose - 4.5mg Low Dose Naltrexone (LDN)
- b) Time - Paul takes his Naltrexone between 9pm and 3am each day
- c) Type - Compounded capsules with pure Naltrexone powder and Avicel filler.

DIET

- Paul changed his diet. He lowered his fat intake (minimal red meat). No dairy. No wheat products.
- May 2008 - Paul is eliminating salt/sodium from his diet in response to recent high blood pressure.

SUPPLEMENTS

- Oct 2004 to present - as follows:

Q-10 75mg

B-12 500mg

Lecithin 1200mg

Alpha Lipoic Acid 600mg

Coral Calcium with vitamin D and Magnesium

Curcumin Complex (Swanson brand with Bioperine)

Evening Primrose Oil 1000mg

Flaxseed Oil 1000mg

Echinacea-Goldenseal

Either Fish oil, Salmon oil or Cod Liver oil

Benfotiamine-V at 150mg (a non-toxic form of Vitamin B1)

- Jan 2005 - the following was added:

DL-Phenylalanine (DLPA) - 1 x 500mg morning, 1 x 500mg afternoon (empty stomach, half hour before eating)

- Feb 2007 - the following were added or changed:

B complex

Niacin 500mg

Zinc 50mg

1 x 500mg DL-Phenylalanine (DLPA) per day, morning, half hour before eating (After a while Paul found one morning pill was sufficient.)

- May 2008 - the following was changed;

1 x 500mg DL-Phenylalanine (DLPA) - scaled back to only once a week.

ACTIVITIES OR EXERCISE

- May 2007 - regular sports.
- May 2008 - Paul surfs about 4 days a week and he plays tennis, kayaks, and works out the other days.

HOBBIES & INTERESTS

- Regular sport

OUR STORY - May 2007

When nearing the end of my husbands 48th year we had decided to purchase a rental property in a rapidly growing community in Florida. We worked for months doing research and finding a good property manager. Then there was the hard work of finding the right property and securing a loan. The most difficult part of our

venture was doing this all from California and not being able to see the home in person. Things began to fall into place in a way that seemed almost orchestrated.

We came to find out that a friend of ours was in the process of moving and had taken a job as a mortgage lender near the area that we were looking in and she was happy to scout at houses for us with the realtor. Within a few weeks she found a house that met our criteria and she had the loan papers underway. Once we felt things were going very well we booked a vacation for the family and flew to Cancun. From the resort we checked our e-mail and the house had closed escrow one morning. The next morning the internet reported that Hurricane Charlie had hit the coast of Florida.

When back home in California, my husband worried for the entire month of September while the Sunshine State was ravaged by four consecutive hurricanes. He worked at a weather center where the days were filled with the topic of the hurricanes. Then he would come home and check the internet and spend the evening watching CNN. At the end of the month our new house was fine, but my husband was not.

Paul went to his doctor complaining of neck pain and, within a few weeks of extensive testing and a series of different specialists, we were told he had what appeared to be Multiple Sclerosis. The news was completely devastating to my husband as he pictured his life in a wheelchair and being unable to surf, play basketball, and play tennis.

Paul's symptoms began appearing in rapid succession. He experienced a strong depression and lacked the feeling of well being; he found that he could not coordinate a cordless screw driver to put up our new curtains; he had bladder frequency and could not stray far from restrooms; and one day he came home in tears because he could no longer shoot and make a basket.

Paul's depression grew despite going to a psychologist, learning to meditate, going through hypnosis and trying a selection of antidepressants. Every morning I would sit with him in bed and give him a pep talk. I would point out all of the people that do just fine with MS and how it can be very slow in progressing for some people.

Although he would try everything suggested to him to get beyond the empty spiral of extreme depression he was not getting out. The worst of Paul's symptoms was extreme fatigue. Everyday for two and a half months Paul would go to work for half a day and come home after lunch break. He was too tired to stay at work and too depressed to concentrate on getting anything done while he was there. Paul began thinking of how to end it all.

After going through a series of neurologists, our family doctor got us an appointment with a young neurologist in the area. She was very kind and caring. She took the time to explain everything to us. We felt like we were finally getting somewhere. She explained the four C.R.A.B. drugs to us and told us that Paul had a little time before deciding which one would be best for him. That evening I went on a quest to find out everything I could about these four drugs. Most of the sites that I found were from the drug companies themselves and from other organizations that advocated using them. (NB The term CRAB is often used as an acronym for the four main MS drugs - Copaxone, Rebif, Avonex, and Betaseron.)

Over the next few days I spent countless hours trying to find out what people who were actually using these drugs had experienced. I finally happened upon a site called Remedyfind.com, which lists many ailments and their treatments. People themselves rate the drugs they have tried and they are able to write a paragraph about their experiences.

The news was pretty bad for all of the CRAB pharmaceuticals. They required taking shots, having a lot of nasty side effects, were very costly (\$800 to \$1400 per month) and did not appear to help very many people. When I looked at the overall rating of these drugs I was stunned to find them at the bottom of the list with a rating of 4 to 5.5 on a scale of 10.

I looked up to see what was in the number one place and it was a drug I had not heard of. It was called LDN and it was rating at 9.1. I quickly read that this drug was taken in a pill form and it had very minor side effects that typically disappear within the first month - and the drug only cost approximately \$20/month. The most amazing thing however was the stories of how people were getting their lives back. An added bonus was that a majority of people were experiencing a lack of progression. Their MRI's were coming back with no new lesions and their symptoms were disappearing. I spent the better part of an evening crying as I read through more than 60 stories from LDN users.

I printed out all of the stories so that I could give them to our new neurologist. I was sure this was a no-brainer and she would write Paul a prescription and we would be on our way. But she did not seem interested in looking them over or doing further research on this miracle medicine. I could not understand because it was FDA approved at a much higher dosage of 50mg, while you only took 3 to 4.5mg for MS. Certainly there was no danger in trying it.

While I concede that I am not a scientist, I cannot understand how this many people could be wrong. I decided we needed to take my husband's health into our own hands. The following week I made an appointment with the doctor in New York that originally thought through the idea of administering this drug in a low dosage for people with auto-immune disorders. Dr Bihari said that most neurologists are concerned about giving LDN a try because it up-regulates the patient's autoimmune systems which they are concerned might then aid the immune system in further hurting and attacking the body.

Three out of the four CRAB drugs are immune suppressants (Copaxone being the only one that does not suppress the immune system). But as it turns out once the immune system is up-regulated it actually goes into gear and remembers how to behave. The day after my husband took his first dosage he went to work and did not come home until 5pm. His feeling of well-being returned and within a week his bladder frequency was gone. Within a month Paul could use the cordless screwdriver and he was back to 2 sports a day in the next few months. After nearly two years my husband has never come home due to fatigue and his MRI's show no new progression. The only symptom that Paul has is minor numbness and tingling in his hands.

Incidentally, Paul's neuro worried him by saying that his follow-up MRI had a suspicious new area and that he should get on one of the Crab meds. She did not know Paul had started LDN a few months earlier and she did not even notice the huge differences in his symptoms. Later, Dr Bihari got a copy of the same MRI's and called Paul to congratulate him because the original lesion was no longer enhancing (the other doctor did not say a thing about that).

When Paul asked about the suspicious new area, Dr. Bihari told him to read the written report that accompanied the MRI because it said the suspicious new area was just a glitch in the slide. Paul read it, and low and behold that is exactly what it said!

What I have learned from being on the Yahoo LDN chat site ([groups.yahoo.com /group/lowdosenaltrexone](http://groups.yahoo.com/group/lowdosenaltrexone)) is that about 85% of people with various auto-immune diseases have lack of progression and/or some form of symptom relief. Not everyone reacts as quickly as my husband and not everyone has miraculous recoveries. But once in a while I hear of people that get out of wheel chairs, get their vision restored, gain their cognitive skills back or feel like they no longer have the dreaded Monster.

I believe that neurologists that truly care about the health and well-being of their MS patients should first try LDN and move onto the CRAB drugs only if LDN is not effective for them.

UPDATE: August, 2007

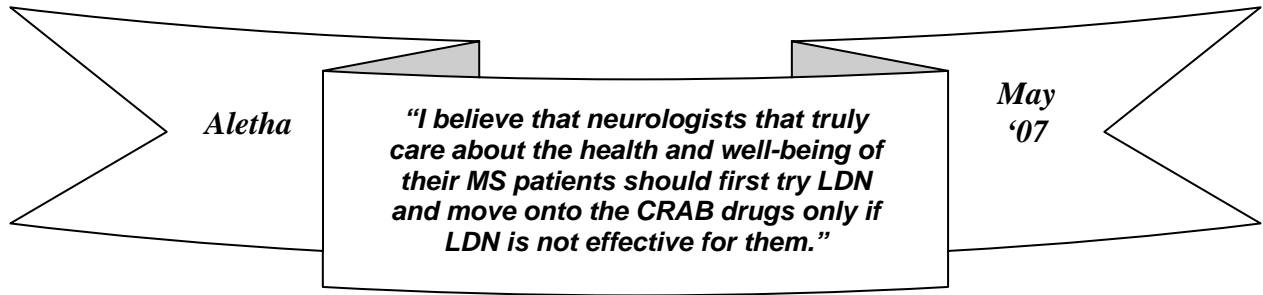
Paul continues to do exceptionally well. He has not had any re-occurrence of symptoms and he continues to do one to two sports per day. This year we plan on going on a trip to France for two weeks, a trip to Hawaii for a week and most importantly to the LDN conference in Tennessee. We know in our hearts that it would not be possible for Paul to be doing all of this if it were not for LDN. We are eternally grateful to all of the wonderful doctors, pharmacists and the most wonderful group of helpful and giving people I have ever met from the LDN Yahoo chat site. They have all made it possible for my husband to have his life back, and me to have my husband back. Bless them all.

UPDATE: July, 2008 – 3 years on LDN

Paul continues to do well with LDN. He no longer needs the DLPA every day and has scaled this back to once a week. There have been no significant changes in Paul's MS since last year. His only symptom is areas of numbness and tingling in his palms.

Paul recently found out he has high blood pressure, so Paul is working on changing his diet to eliminate salt and sodium intake.

Aletha, USA



8) LDN 4 me - Maurey

LDN since August 2007

- story submitted April 2008
- story updated July 2008 (1yr on LDN)

SPECIFICS

DIAGNOSIS

- May 2007 – Optic Neuritis
- July 2007- Multiple Sclerosis
- January 2008 - Neurologist report says "may turn out to be benign MS"

MEDICATION/TREATMENT (OTHER)

- May 2007- 5 days 250mg oral Prednisone for optic neuritis

TESTS:

- July 2007 – Neurologist ordered MRIs of brain, cervical, thoracic, and lumbar regions - pages of blood work - lumbar puncture - Visual Evoked Potential - Chest x ray - Sensory evoked potential – Neuro-ophthalmology Eye Exam – test for Lyme disease

MEDICATION (LDN)

- Aug 2007 to Sept 2007 - 3mg Low Dose Naltrexone (LDN) nightly
- Sept 2007 to present - 4.5mg Low Dose Naltrexone (LDN) nightly

LDN - DOSE & TYPE

- a) Dose – 4.5mg Low Dose Naltrexone (LDN)
- b) Time - I take my Naltrexone around 10 pm each night.
- c) Type - my 1.5mg capsules are compounded by Skip's Pharmacy with pure Naltrexone powder and avicel filler.

DIET

- Since July 2007 as follows:
No dairy, very little wheat or sugar. Little saturated fats.
Breakfast - Smoothie with banana, berries, apple, whey protein, rice milk

SUPPLEMENTS

- Since July 2007 as follows:
Fish oil capsules
Multiple vitamin
B Complex
Calcium/Magnesium/D
Vitamin E
Grapeseed Extract and Bromelain when I feel inflammatory or "MS ey"
UltraInflamx powder "Medical Food" by Metagenics in Rice Milk or Almond Milk at night with my vitamins and LDN.

ACTIVITIES & EXERCISE

- April 2008 as follows:
I raise Welsh Ponies so most of my exercise is practical; stacking hay, cleaning the paddock, and training ponies. Running is a challenge, but I work to lengthen my stride and increase the distance by running with ponies. Lots of stretching. I have an exercise ball chair at home and at work. The chairs come with stretching exercises. Yoga is new to me. I use the Rodney Ye PM yoga DVD to aid sleep and help with balance.

MY STORY – April 2008

I was diagnosed with MS in July '07. Looking back before my major episode, I had strong symptoms that I denied for 5 years or so. In July 2007 I couldn't climb steps, I dragged my legs to get around, had no central vision in one eye, cried for no reason, had slurred speech and couldn't find the words for my thoughts, and I was so dizzy I walked into walls.

I started LDN in August '07, right after receiving my diagnosis. The first month I took 3mg, and I've been taking 4.5mg ever since. The greatest improvement in my symptoms occurred in the first 30 days. Improvement is slower now, so I keep a diary and check in with myself every 3 months. I haven't been disappointed yet. Once in a while if my legs feel stiff I drop back to 3 mg for a day.

I follow most diet and supplement recommendations related to my condition. I also have high cholesterol but my new diet has reduced my bad cholesterol by 20 points and increased my good by 7 – a nice side benefit.

I have 80% of my leg function back, no more dizzy spells, and no more speech problems. I have some loss of color vision in one eye, but I can see. My MS taps me on the shoulder every now and then, but I no longer think about it 24x7. I continue to work on my balance and leg strength with various activities.

At my 6-month check up with the same neurologist, he gave me a lecture on LDN not being FDA approved and strongly recommended Rebif to slow the progression. I asked him how he could possibly recommend expensive painful injections when I'm doing so well on LDN.

My LDN was prescribed by my GP who said "Why not? It makes perfect sense, won't hurt you, and the CRAB drugs are limited in their effectiveness."

My Neuro report came in the mail. He must have done some thinking after our visit. It reads, "The patient has done quite well since I saw her in July. She has had no attacks of multiple sclerosis. She takes low dose Naltrexone. She gets that medication through her primary care provider. She is aware that there is no evidence that this is helpful in multiple sclerosis. She is not interested in going on Interferon medication at this time and I do not think that it is necessary at this point either. It may turn out that she has benign multiple sclerosis."

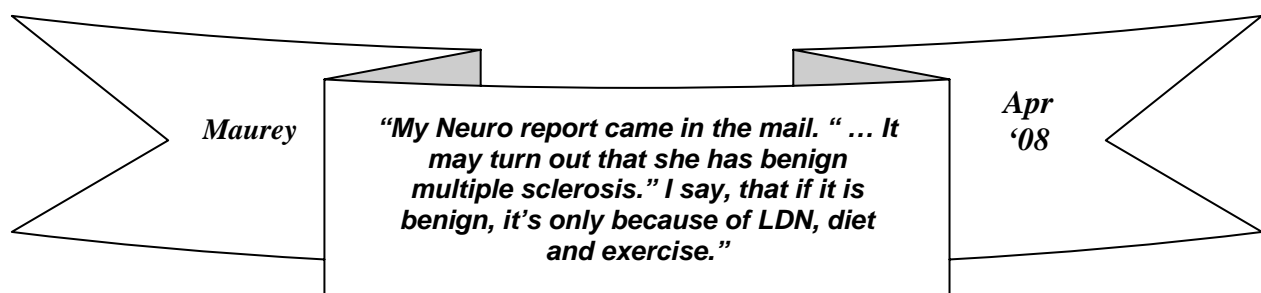
I say, that if it is benign, it's only because of LDN, diet and exercise. I do believe attitude plays a big role. I'm putting a son through college and have 5 horses that must be fed and cared for. I cannot be disabled and will find the way.

That's my story and I'm sticking to it.

UPDATE: July, 2008 – 1 Year on LDN

Certainly! I've read through the specifics section, and all remains the same. Still doing very well on LDN - no further progression or attacks, no medical information to report. Still following the same routine, LDN, supplements and exercise. No episodes, no progression, slow but steady improvement in leg strength and balance. Tolerating the heat of summer much better than last year.

Maurey, USA



9) LDN-MS & me - Jackie

LDN since April 2004

- story submitted October 2005
- story updated Jul 2008 (4yrs on LDN)

SPECIFICS

DIAGNOSED

- Apr 1980 - Relapsing Remitting Multiple Sclerosis (RRMS)
- 1995 - Primary Progressive Multiple Sclerosis (PPMS)

MEDICATION (pre LDN)

- 1993 to Aug 2004 - detrusitol LA
- 2003 (approx 9 mths) - beta interferon
- 2003 (approx 1 mth) - baclofen (horrible stuff, I'd rather deal with the spasticity)

MEDICATION (post LDN)

- Apr 2004 to May 2004 - 3mg Low Dose Naltrexone (LDN)
- May 2004 to present - 4.5 mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose - 4.5mg Low Dose Naltrexone (LDN)
- b) Time - bedtime, between 10.00pm and 11.30pm
- c) Type - 4.5 mg capsules compounded by Skips Pharmacy (not sure about the filler)

SUPPLEMENTS

- May 2008 - I take Dr Gilhooly's recommended MS supplements, plus fish oil (also from Dr Gilhooly)

DIET

- May 2008 - I eat a generally healthy diet, lots of fruit and veg, fish, not much red meat, no dairy except a very small amount of skimmed milk, limited caffeinated drinks - 1 or 2 cups of tea a day, 2 cups of coffee a week. A fair amount of wine, mainly red - no other alcoholic drinks. No fizzy drinks at all, no sugar, no cakes biscuits etc.

EXERCISE OR INTERESTS

- art and creative software

MY STORY – October 2005

When I first started taking LDN I also began a daily journal to record my symptoms and any changes I observed.

Looking back over it prior to starting this piece, I was impressed by how quickly things seemed to change for me. Taking LDN has definitely made a significant difference to my quality of life. Some of its effects have taken rather longer to become apparent than others but the two most immediate results, there before my eyes and still evident, were a significant increase in stamina and a welcome improvement in my sleep pattern.

Since the mid 1990s when my MS became progressive, this has been the first winter I have survived without deterioration in my condition.

My bladder has improved so much in the past year that I no longer take any medication for it. Spasticity has also decreased and I am a little more mobile. I have maintained a standard over a timed walk for the past seven months, having gradually improved to that level after starting LDN.

I am hopeful that my condition has stabilized. My outlook has certainly improved and I am working hard in my studio. I only regret that I did not discover LDN sooner, but am thankful to have at last found something that seems to work for me.

UPDATE: July, 2008 - 4 years on LDN

Prior to beginning this up-date I re-read my previous, 2005, piece on my experience of taking LDN (low dose naltrexone) for progressive M.S.

What struck me most strongly was the positive tone of the article and the sense that the drug had given me hope for the future despite a rather gloomy prognosis. I felt then that LDN had improved a number of my symptoms and was hopeful that that improvement would be sustained; and by and large, it has been.

I am still taking LDN - four years now and counting, during which time I would say that my M.S. has stabilised. It would be wrong to assume that the disease has not progressed at all - I have an increase in spasticity in my right hand and arm for instance; but that increase has been very gradual and is fairly slight.

The important thing is that I am still on my feet - despite a badly fractured ankle a couple of years ago, and continue to enjoy life.

I am still working as an artist. See <http://homepage.mac.com/jackie.smith/PhotoAlbum2.html> for images and information from my last exhibition and am currently teaching myself how to use Adobe Illustrator. A thankless task!

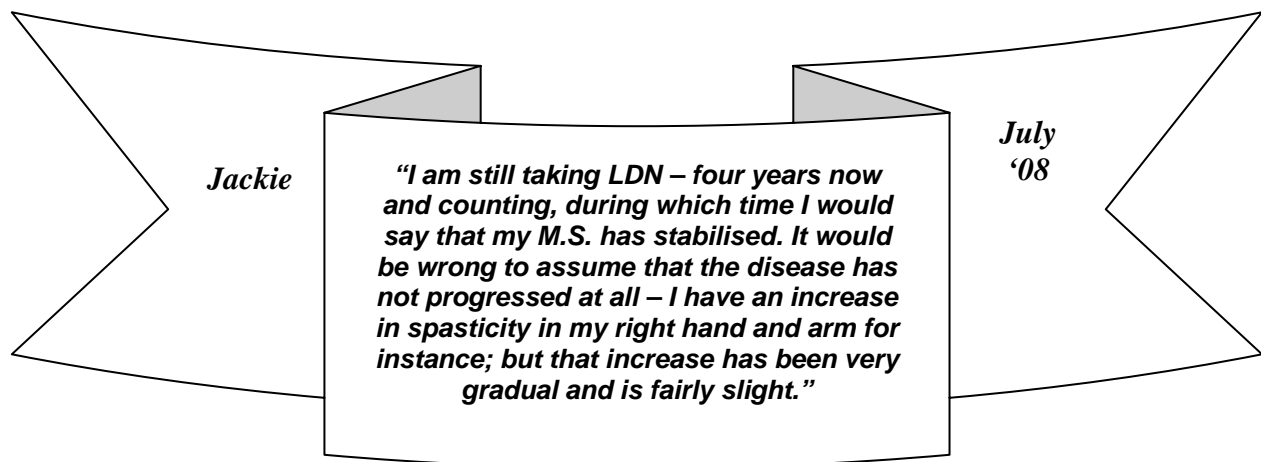
I now walk with the aid of an FES stimulator (see <http://www.salisburyfes.com>), which has helped enormously with my characteristic M.S. dropped foot. I still drive with the addition of hand controls to my car and remain optimistic for the future.

It is impossible to quantify what effect LDN has had in maintaining my condition, perhaps when trials at last take place on this therapy we might better understand its potential to assist in M.S. management. My belief is that it has been of considerable benefit and I intend to continue taking it - at least until the cure comes along!

Jackie, UK (written whilst in a cast with yet another broken leg)

Jackie is an artist who lives in Perthshire with her partner and their dog.

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health in October 2005.



10) MS & LDN since May 2002 – Joyce F

LDN since May 2002

- story submitted 19 November 2003
- story updated August 2006
- story updated August 2007
- **story updated July 2008 (6 yrs on LDN)**

SPECIFICS

DIAGNOSED

- 1984 - On reflection, first sign was Optic Neuritis
- 1989 - Multiple Sclerosis

MEDICATION (pre LDN)

- nothing to May 2002

MEDICATION (post LDN)

- May 2002 to present - Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose – 4.5mg compounded capsule
- b) Time – At bedtime, between 10 pm and 2 am
- c) Capsule Filler – fast release (not calcium carbonate that can compact)

SUPPLEMENTS

- May 2008 – the following is a complete and current list:
 - 1680mg cranberry capsule twice a day
 - Super booster softgel once a day (life extension supplement)
 - 2 digestive enzymes twice a day with meals
 - Super EPA/DHA with Sesame Lignans and Olive Fruit Extract (life extension supplement)
 - 1000 mg Vitamin C x 3 times a day
 - Mitochondrial Energy Booster capsules 4 in the morning. (This contains Alpha Lipoic Acid 300mg, Acetyl L-Carnitine 1000 mg, Benfotiamine 150mg, along with several B vitamins, D3 and chromium)
 - Gamma E Tocopherol capsule once a day
 - MSM & glucosamine once a day
 - 1000 mg Chlorella 3 times a day
 - 6 Life Extension Mix Caps twice a day
 - 500 mg DL Phenylalanine once a day
 - Fuco-Thin 3 capsules 3 times a day (Fucoxanthin)
 - Evening Primrose Oil 1300 mg once a day
 - 1 Tablespoon of apple cider vinegar with juice
 - Natural Cellular Defense (zeolite drops) to remove heavy metal
 - Green tea drops into my morning cup of tea
 - Mynax 3 tablets, 3 times a day (Calcium EAP product from Koeler, as recommended by a naturopath)
 - ½ teaspoon of freeze dried aloe vera (As recommended by a naturopath)
 - 1 teaspoon of Homozon nightly for colon health
 - oxygen drops for water
 - I no longer use the electrical impulse unit
 - Selenium 200 mcg once a day
 - Lithium aspartate 5mg once a day
 - Silica 500mg once a day
 - 1 scoop of a Boku Superfood green powder in a smoothie with 1 tablespoon of coconut oil once a day

DIET

- normal, balanced

EXERCISE

- regularly

MY STORY – as at May 2002

My story starts quite a few years ago when I had an episode of Optic Neuritis. I've had several such attacks that led to a diagnosis of MS. I could never quite understand why I was doing so well with it, for example...very few attacks and almost no permanent physical impairments... this went on for about 10 years or so.

I would have the typical bouts of numbness here and there. I started to go downhill with my balance and walking a few years ago and knew that it was time to research a medication for my MS as I always said that I would when that time came.

There are several clinically tested medications on the market these days for MS but regrettably they are all injectable and come with some potentially bad side effects. I've heard it said that they could possibly help about 30% of the people about 30% of the time. I thought...wow...I don't like those odds, so I searched further and thank God I did because I was able to find the good work of Dr. Bernard Bihari in New York City.

He has been working with LDN or Low Dose Naltrexone for many years with HIV patients on the theory that a lack of endorphins rather than an overactive immune system is the cause of all autoimmune diseases. You see, LDN, when taken once daily causes your body to create 200% to 300% more endorphins, which in turn regulates the immune system back to normal. Hence, no further progression of the MS.

I have been on it for about 18 months now. It is November of 2003 and I started with it in May of 2002. My endorphins have increased again, and I haven't looked back. So far so good.

There is a website dedicated to information about it with regards to MS and a wealth of other diseases like Lupus and Fibromyalgia, ALS and Parkinson's www.lowdosenaltrexone.org.

Virtually all autoimmune disorders should respond to this therapy. I only have experience with it and my MS. Dr. Bihari has been doing work with it and cancer for years. Treating people with MS came after he helped a friend's daughter who suffered with MS.

Naltrexone is an FDA approved drug, but one that has been in existence at a much higher dose of 50 mg for almost 19 years now (as at Nov 03). Therefore, an orphan drug? There is no money to be made by these huge pharmaceutical companies who are the ones that do clinical testing. Any doctor can prescribe it but one must have it compounded down from the original 50mg tablet to a 4.5mg dose.

Several compounders are doing just that and some of them are listed on the website. One such compounder has statistics of many MSers being helped by it and he claims that it is the one medication that he would take if he had MS. One of the things that convinced me to look into this whole thing further was the knowledge that no one is making huge amounts of money from it.

There is some work in finding a doctor to prescribe it for you and then in finding a compounder to make it up for you in a dose of 4.5mg. It must be formulated into a fast release version as well.

Good luck to all who have come here to read my story God bless Now back to my story.... you see this all makes good sense to me because I never really did start going downhill until I slacked off from my very vigorous aerobic exercise routine a few years back. You see, that is what was producing all those endorphins and I never knew of the connection till now.

Us MSers are always being told that exercise seems to help but I'm certain that most don't know the true reason behind it.

UPDATE: August, 2006

As far as an update. I'm sure that I could but there's not much to tell. People are always asking for an update but I think hmmmmmm how many ways are there to state that there are no MS issues?...lol.

I must admit that I no longer think that the LDN will halt the MS but rather it should slow it down considerably. The reason I say that is that my legs aren't as good as they were. My legs would get a little rubbery towards the end of the day. Now my legs get that way soon after waking. My balance seems to be just a tad worse as well so that spells progression to me.

Other than that, as I stated, no real MS issues and as far as I'm concerned, that's great. I lead a pretty normal life here. I have the usual MS issues about making sure that there will not be a lot of walking involved with any activities and such and an occasional day with some vertigo but other than that, nothing different than any others.

Having said that, no one would even know I have MS and indeed, my co-workers still do not know.

It is now just over 4 years on the LDN and I love not having to see any sort of doctors other than the internist that prescribes the LDN for me. I also think it's important that one uses a compounder that is well-versed on how the LDN must be compounded in order for it to work. It must contain fast-release filler because of the mechanism by which it works.

I think that the time has come for the world to be aware of this remarkable therapy. Then, Godspeed to a cure! Until that day comes, I am happy to take my little LDN capsule once a day.

UPDATE: August, 2007

There is really not a whole lot to update. The only change is that I have been tending to just keep getting a bit worse as each year goes on. Nothing major and no attacks really but I know how I was walking and how my balance was just a year or so ago and it just seems to mysteriously get worse. It's hard to explain that really.

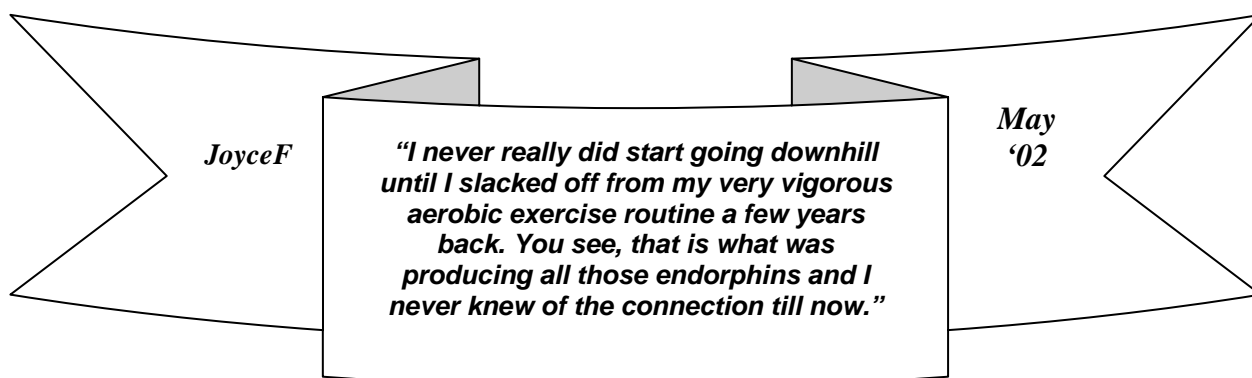
The only thing that comes to mind is that I am experimenting with a few things such as taking oxygen products like drops for the water and taking a teaspoon of Homozon nightly for colon cleansing. I take many supplements and have just gotten information about something called Mynax from a California naturopath. It is a calcium EAP product. I've been taking it for just over a week so too soon to tell whether that will help.

I've also been advised by a Canadian naturopath to take Aloe Vera internally. I've been taking a half teaspoon of a free dried aloe vera product for a few weeks now, so we'll see how that goes. One has to wonder if any of these things affect the outcome of the LDN in any way. I do know that I will continue to take the LDN because I do believe it is the best thing out there for MS and many other immune system based disorders.

UPDATE: July, 2008 – 6 years on LDN

Since I noticed some minor progression, I've been experimenting with various supplements to try to interrupt it. I'll keep you posted on the outcomes.

Joyce F, USA



11) Thanks to LDN I can enjoy life - Vickie

LDN since August 2007

- story submitted 13 January 2008
- story updated July 2008 (2yrs on LDN)

SPECIFICS

DIAGNOSIS

- April 26 2006 to Dec 2006 – Sudden onset of frightening symptoms, eg: girdling referred to as MS hug - this resulted in a frustrating series of doctor visits and tests, including MRI, and the following diagnoses – a syrinx (a cyst in the spinal cord) - neurologist, and transverse myelitis - neurosurgeon.
- Dec 2006 – Symptom progression resulted in a Lumbar Puncture, diagnosis of MS, and prescription for Rebif.

MEDICATIONS (OTHER)

- Jan 1 2007 to Jul 2007 – Rebif
- Aug 2007 to Aug 2007 - Prokarin
- Jun 2007 to Dec 2007 - 10 mg Baclofen 3 or 4 times a day
- Sept 2006 to Dec 2007 - 200 mg Lyrica 2 or 3 times a day
- Jan 2008 – reduced dosage to - 5mg Baclofen 3 or 4 times a day
- Jan 2008 – reduced dosage to -100mg Lyrica 2 or 3 times a day

MEDICATION (LDN)

- 1 Aug 2007 to June 2008 – 4.5 ml Low Doses of Naltrexone (LDN) – 3ml for one month. Soon after increasing to 4.5 ml I experienced some anger issues and increased spasticity so I dropped back down to 3 ml for another two months before again increasing to 4.5 ml and staying there. (I bought 50 mg tablets and dissolved one 50mg tablet into 50ml cooled, sterilized water to make the liquid myself. I'd shake the bottle and use a needle-less syringe to draw up the exact dose and squirt it into my mouth.
- June 2008 to present – 4.5mg compounded capsules Low Dose Naltrexone (LDN)

LDN – DOSE & TYPE

- a) Dose – 4.5 mg Low Dose Naltrexone (LDN)
- b) Time - I take my Naltrexone around 10:00pm each night
- c) Type – 4.5mg compounded capsules

DIET

Modified in response to allergy testing and guidance. No wheat, beans, dairy, eggs, cheese, walnuts, chocolate, or tuna. No nightshade vegetables. Nothing made with yeast. Limited caffeine, alcohol, sugars

SUPPLEMENTS

I also supplement with the following:
D3 - 9000 IUs daily – specially compounded
B12 injections – 3 times per week - self-administered
Enzymes - 2 capsules - three times per day
Probiotics – 2 per day - two different types taken on alternate days
Cytozyme-AD - 80 mg - twice per day
MSM – 30mcg - twice a day
Multivitamin – 1 per day
Chlorophyll tablets – 8 tablets - three times per day
Acetyl L carnitine – 1 per day
Evening primrose oil – 1 capsule - twice per day
CoQ10 - 300 mg - twice per day
B complex – 1 per day
Inf-Zyme Forte –1 per day - with a meal

ACTIVITIES & EXERCISE

My lifestyle had become increasingly limited and restricted by extreme fatigue. I'm more productive. I can go out with friends, stay up late like a grown up! I can shop. I can walk my puppies.

MY STORY – January 2008

I had a sudden onset of symptoms beginning April 26, 2006. Most notably was the girdling or MS hug. I was misdiagnosed by a GP but eventually referred to a neurologist. I had test after test, including MRIs, and was originally told I had a syrinx. This didn't feel right to me. I took my MRIs to a neurosurgeon who told me I had transverse myelitis.

My symptoms continued to progress so I had a lumbar puncture and in December 2006 I was told I had MS. In January 2007 I started on Rebif.

Over the course of the next seven months my physical condition deteriorated. I had to take naps, sometimes on the floor of my office. I didn't think I was going to be able to continue working.

I felt as though I had a large boulder on my shoulders. My lifestyle had become increasingly limited and restricted by extreme fatigue. I shuffled along slowly. I used a cane if I had to walk any distance. On the rare occasions I went to the grocery store I had to use the carts, so I had begun 'shopping' for an electric cart because I couldn't walk.

This was a very difficult time for me. I'd spent twenty years in the military and was very fit mentally and physically. During all those years I was always the person others had a hard time keeping up with when walking, but I'd reached a point where I didn't feel like doing much of anything. I'd go to work, come home, sit for a little while, then sleep.

I wasn't getting anywhere, and my first neurologist didn't listen and didn't seem to care. Once I made up my mind to discontinue the CRAB medication, I cut my ties with the intent of going it alone.

In July 2007 I stopped taking the Rebif. I just couldn't bear the thought of another shot. As each day passed I felt stronger and stronger.

Then, during my travels over the Internet I came across the low-dose naltrexone treatment (LDN). I was intrigued. I had a good doctor but he appeared to be influenced by the Rebif people – and he certainly wasn't open to alternative medicine.

I took a leap of faith on 1st August 2007 and started LDN. I'd read a lot about LDN. I was hopeful it'd halt progression of my MS and I also hoped to benefit from symptom improvement.

During the same period I also tried Prokarin for a very short time, but I found it too difficult to work with and stopped taking it.

I now go to the Veterans Administration for my MRIs and medications. I have not discussed my taking LDN with the VA. I'll raise it after I see the results of the MRI at the end of the year.

My condition has improved greatly. If nothing else LDN has increased my energy level. I think it also helps me sleep. I've been able to cut my use of Baclofen and Lyrica in half.

I had MRIs of brain, cervical and thoracic spine in December 2007. The neurologist told me that the lesion over T8 was inactive, no change when the contrast was introduced – and there were no new lesions in my brain.

I've also found an ecological internist. She's started me on high doses of D3, shots of B12 and a box full of supplements. I was tested for allergies and have been working hard on cleaning up my diet.

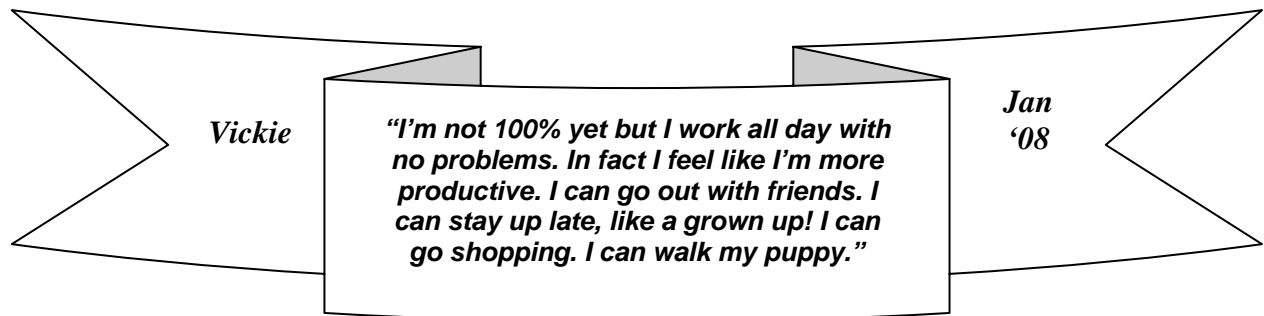
I'm not 100% yet but I work all day with no problems. In fact I feel like I'm more productive. I can go out with friends. I can stay up late, like a grown up! I can go shopping. I can walk my puppy.

Now I feel like I've got my life back I want to tell everyone who might benefit about LDN. Some people are very receptive, others not so much. But I figure if you plant the seed, when they're ready they'll remember. Low-dose Naltrexone has given me my life back so I'm sharing my story in the hope it'll inspire and benefit others.

UPDATE: July 2008

Changed from liquid LDN preparation to compounded capsules. Also switched doctors. The new doctor is an M.D. who runs a clinic offering infrared sauna, acupuncture and other services. I am starting chelation therapy in a week to reduce my heavy metals load. I'm still benefiting from LDN and will continue to take it.

Vickie, USA



12) LDN has been a miracle for me - Art

LDN since March 2005

- story submitted Dec 2007
- story updated July 2008 (3yrs on LDN)

SPECIFICS

DIAGNOSIS

- 1988 - Relapsing Remitting Multiple Sclerosis (RRMS)
- 2002 – suspected Secondary Progressive Multiple Sclerosis (SPMS)

MEDICATIONS (pre LDN)

- 1992 to Mar 2005 – Medicinal Marijuana – occasionally on weekends – helps relax stiff muscles, aid sleep
- 1994 to 1994 - IV Solumedrol, oral Prednisone
- 1997 to 2001 - Avonex
- 2001 to June 2005 - Copaxone, plus five treatments of Novantrone, plus numerous IV Solumedrol/Prednisone taper-offs

MEDICATION (post LDN)

- 1992 to present – Medicinal Marijuana – occasionally on weekends – helps relax stiff muscles, aid sleep
- Mar 2005 to present - Low Dose Naltrexone (LDN) - continued with Copaxone at the same time but only for 2-3 months.
- July 2008 - Prokarin patch for pain - 1 x 1.65mg in the morning, lasts 16 hours
- July 2008 - 4-aminopyridine (4-AP) 5mg x 8 times a day

LDN DOSE & TYPE

- a) Dose – 4.5mg Low Dose Naltrexone (LDN) - started at 3.0mg, after one month up to 4.5mg, there ever since.
- b) Time - I take my Naltrexone at 10.45pm every night
- c) Type - My naltrexone is compounded into capsules with Avicel filler.

SUPPLEMENTS

- Jul 2008 – I was taking the following:
 - Custom Pro K Therapy Multivitamin x 2 with breakfast
 - Sublingual Vitamin B-12 5000mg x 1 per day
 - Cranberry capsules 400mg x 4 per day
 - Citrucel fiber capsules 500mg x 6 per day
 - Acidophilus x 2 per day
 - Montmorency Tart Cherry Juice daily
 - Calcium/Magnesium/Copper/Zinc Capsule Combo x 6 with breakfast
 - Malic Acid 800 mgs x 4 per day
 - Cat's Claw 20mgs x 1 per day
 - Magnesium 400mg x 3 per day
 - Pomegranite (anthocyanins) Softgels 80mg x 3 per day
 - DLPA 500mg x 1 or 2 per day

DIET

- Dec 2007 - I restrict my diet: I don't eat dairy, sugar, soy, legumes, eggs, red meat, or gluten (found in wheat, barley, rye, and oats). The foods I do eat are fresh fish, organic chicken, and fresh raw organic fruits and vegetables I drink only bottled distilled water, and believe highly in the benefits of Coconut Oil (3 tablespoons a day) and Stevia (which is an excellent sugar substitute and has replaced my desire for sugar).

ACTIVITIES & EXERCISE

- Dec 2007 - light stretching and casual walking

HOBBIES & INTERESTS

- Dec 2007 - reading, music, my girlfriend

MY STORY – December 2007

I was diagnosed with MS April 1988. I was very messed up for two years after the initial attack. Couldn't see or walk straight. Was actually blind for a few weeks. Never thought I would recover and become independent again. I briefly considered suicide because I was very depressed.

I gradually pulled out of the attack with the help of IV Solumedrol and oral Prednisone, which was all the doctors had to offer back then. CRAB meds were unheard of. At first, the IV Solumedrol was like a miracle, always pulling me out of an exacerbation. I think I probably got more relief from the IV solumedrol and oral prednisone than anything else, but over time even these drugs became less and less effective.

I made a full recovery and was symptom free until around 1994. It was like I never had MS. At the time I wasn't under the care of a neurologist, which, in hindsight, was a mistake.

1996 was a very rough winter here in New York. We had a major blizzard and snowfall after snowfall. I work as a maintenance supervisor for a real estate company and part of my job is to see that the snow is removed from their properties. It was a very stressful winter for me both mentally and physically.

MS returned with a vengeance that year so I ended up seeing a Neurologist who put me on Avonex. I don't recall the Avonex doing anything very positive for me, in fact, it made me very ill. I had flu-like symptoms and became depressed, and the injections were very painful.

Even so, there was nothing else recommended so I took the Avonex for over three years until it stopped working for me. What I mean by 'stopped working' is that I was told I'd developed antibodies against interferon medications, so the Neurologist changed my prescription to Copaxone. I took that for over three years.

Did I notice any change with Copaxone? No, nothing - zero, zilch - but the injections were a pleasure compared to the Avonex. My Neurologist also prescribed five treatments of Novantrone.

I had many, many IV Solumedrol/Prednisone taper-offs in between all of this, but I'd reached the point where nothing was holding the MS off - nothing - so the Neurologist then suggested Betaseron.

I was incredulous. I asked him why he suggested Betaseron when he'd led me to believe I was immune to interferon meds. He responded; "well, we have to try something".

He also thought about putting me on Tysabri - just before it started killing people and was pulled from the market. It was then I realized he was only experimenting on me and really didn't have any definite answers.

I am 6'7" and weigh 240lbs but I broke down and cried in his office. His nurse saw me and suggested I look into LDN even though the neurologist was against it. She is my special angel. So, I researched LDN.

Shortly after, Tysabri was pulled from the market. My neurologist already knew I didn't want to use Betaseron (hard to argue with someone my size), so he agreed to give me the script for LDN.

I've been on LDN since March 2005 and I shudder to think where I'd be without it.

It was VERY scary deciding to go on LDN. I felt like I was taking a big risk - like a victim of a shipwreck dumped into the sea without a life preserver. It was either swim or sink.

Thankfully my fears didn't last long. I noticed positive improvements within days of starting LDN - better bladder control, less blurry eyesight and a bit less fatigue, those being the main ones. Like a miracle!

I know everyone doesn't experience symptom improvement, so I feel very lucky. I had improved my diet before starting LDN so maybe that made the difference for me.

I was originally diagnosed with Relapsing/Remitting type MS but my Neurologist upgraded it to the next level around 2002. I think it's called Secondary Progressive Multiple Sclerosis (SPMS).

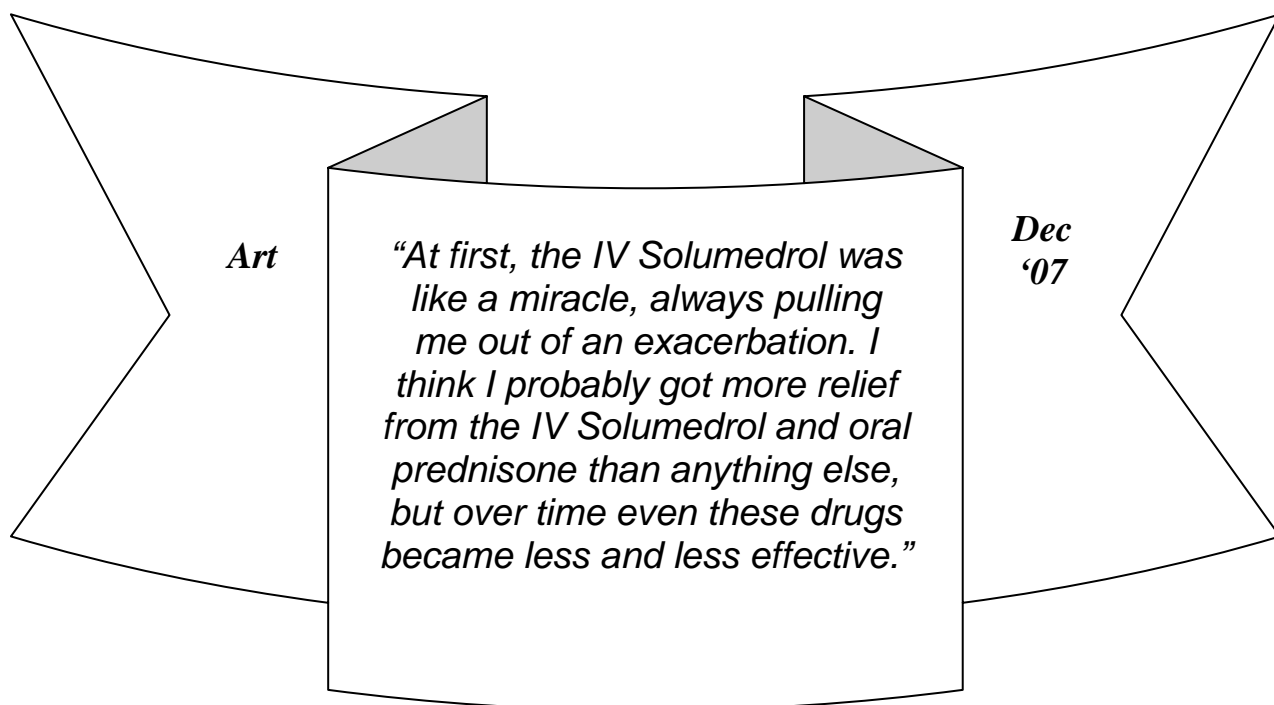
Yes, I'm a BIG advocate for LDN and wish I could sue someone's ass off for the years I used the dangerous, expensive, ineffective CRAB/Novantrone meds. They only made me worse.

LDN has been a miracle for me.

UPDATE: July 2008 – 3 years on LDN

No change in health.

Art, USA



13) LDN-My MS & TM Story - Crystal

LDN since 3rd September 2005

- story submitted July 2008 (almost 3yrs on LDN)

SPECIFICS

DIAGNOSIS

- late 1960s - Viral Meningitis
- late 1960s to late 1970s – seizures requiring hospitalisation
- 1998-1999 – pressure in my head led to doctor prescribing blood pressure medication that resulted in emergency trip to hospital
- Nov 2004 – Secondary Progressive Multiple Sclerosis (SPMS) and Transverse Myelitis (TM)
- Jun 2005 to Aug 2005 – bad case of Cellulitis at injection site, then progressive decline over next 8 mths - walker, to a wheelchair to a Hoveround power chair.

TESTS

- Nov 2004 - x-ray, MRI, lumbar puncture
- Mar 2006 – brain MRI
- Dec 2006 - MRI

SURGERY, TREATMENT

- Aug 2005 – Cellulitis - surgery to drain fluid

MEDICATIONS (pre LDN)

- late 1960s to late 1970s - Phenobarbital for seizures
- 1998-1999 - unidentified blood pressure medication taken for 2 weeks
- Nov 2004 - 3 days of IV steroids in hospital, oral steroids at home
- 2004 - Methocarbamol, Klonopin, Darvocet
- Nov 2004 to Jul 2005 - Betaseron injections

MEDICATION (post LDN)

- 3 Sept 2005 - 3mg Low Dose Naltrexone (LDN)
- Feb 2006 – 4.5mg Low Dose Naltrexone (LDN)

LDN – DOSE & TYPE

- a) Dose – 4.5mg
- b) Time - I take my Naltrexone around 9pm each night
- c) Type – my naltrexone capsules are compounded from pure naltrexone powder and Avicel filler by Skips Pharmacy.

DIET:

- average, no restrictions

SUPPLEMENTS:

- none

ACTIVITIES & EXERCISE

- Some walking and whatever I can do when I can do it

MY STORY - July 2008 – almost 3 yrs on LDN

My name is Crystal and I am a 40+ mother of 3 teenagers (a son and beautiful twin daughters). On November of 2004 I was diagnosed with Secondary Progressive Multiple Sclerosis (SPMS) and Transverse Myelitis (TM).

I'm pretty sure it started when I was very little. After I was born I was diagnosed with Viral Meningitis and I had seizures and was on Phenobarbital up till I was 12-13 years old, then I out-grew it. I had been in and out of the hospital over the years throughout my childhood because of the seizures. I remember my mom telling me she would say things to me to try to get my attention but it would take her a while. She also said that sometimes I would not remember things that she and others would tell me.

While I was growing up I had gone to see many doctors regarding different symptoms and they would always tell me something different was wrong or that nothing was wrong with me.

Around 1998-1999 I started having symptoms that I couldn't explain but all the Dr's I went to kept telling me nothing was wrong with me, it was all in my head or I was having panic/anxiety attacks. One time I was having

a lot of pressure in my head that I knew was not normal so my first husband took me to this Dr and he gave me these pills and said to take them and it would take the pressure away. So I took the pills for 2 weeks until I woke up one morning feeling really strange; like I was drifting away. I called my mother and she told me to lay on the couch and I'd be ok.

At that time I was getting no support from anyone in my family because they believed all the Dr's that said it was all in my head. Anyway I just didn't feel right and felt like I was dying so I called 911 and lucky I did or I would be dead right now. They came and my blood pressure and heart rate was so low they had to give me something in the ambulance to bring them back up and I spent 2 days in the hospital. Well I found out that the Dr gave me blood pressure medication for the pressure in my head.

One morning I managed to get out of bed and made it to the living room and collapsed because my legs were totally numb. So my husband took me up to the little hospital in town and they left me lying on a hospital bed for a few hours not doing any tests and then just sent me home. They did nothing and said nothing was wrong with me. I wasn't even able to drive, but yet there was nothing wrong with me.

Eventually, I started feeling better, driving and went back to work as a CNA in a Nursing Home for 2 years. Later I got a job at a small family-owned office supply store. Things were going really bad with my marriage and it was affecting my health so I got the courage up and told my husband I wanted a divorce and he tried to force me to stay but I said no. A week later he came home, had my mother take my kids out of the house without me knowing and kicked me out of the house with nothing. My ex dragged the divorce on for 2 years while telling my kids it was all me. Talk about stress...

After my divorce I was in 2 car accidents that were not my fault. I moved back in with my mother and stepfather for a year, then I met a guy from Florida and ended up moving down to Florida.

On March 20th, 2004, a year after moving to Florida, we got married. Eight months later I was diagnosed with SPMS and TM. At the time I had been working for a brochure company driving a van to hotels and other places putting in brochures in the racks to keep them full. I was with them for almost a year before my diagnosis. My first symptom was feeling extremely tired all the time. When I got home from work I would have to lie down and take a nap, which was unusual for me. Later I read that tiredness is one of the first signs of MS. I then started having a lot of back and neck pain and then went numb from my feet up to my chest and could barely walk. I ended up working for a week driving a van and delivering brochures in this condition.

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

The next day that doctor asked me to come in right away. The 10 minute drive to his office was the longest drive, filled with fear and anxiety, I'd ever felt. When I arrived for my results he told me he could not examine my back or carry out any procedures on my back because there was a mass in my spinal cord from the lumbar region to my shoulder blades but he could not tell me if it was a tumor or just a mass. He said he'd made an appointment for me with a Neurologist the next day. The hours before the appointment with the Neurologist were the longest that me and my family had to endure at home wondering what was in store for me and us.

The next morning at the Neurologist, I explained the symptoms I was having. He did some more tests in his office, and asked for another MRI with and without contrast (important to diagnose MS) and admitted me to the hospital to do a Lumbar Puncture. He ordered three days of Steroids through IV in the hospital and another week at home. A week later my Neurologist explained that after reviewing the symptoms I had complained about and reviewing my medical records he determined that I had Transverse Myelitis. Also, he said he knew I had Multiple Sclerosis before he got the results of the Lumbar puncture, and that he believed MS had been present at other points in my life. He just needed the Lumbar puncture results to confirm.

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

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

My Neurologist started my treatment right away, which is essential in treating MS. He prescribed Betaseron injections, a medication for MS which is supposed to help slow down the progression of MS. What the doctors don't tell you is that it's only supposed to help Relapsing Remitting MS (the 1st stage). I was on Betaseron for the first 8 months after my diagnoses, but it wasn't helping me at all and just made me feel worse.

I ended up getting a bad case of Cellulitis, a bad infection, in my right upper thigh from the injections. I was bedridden for 3 months during the summer of 2005. I ended up having to have surgery to drain all the fluid. It was the most painful thing I have ever felt in my whole life. My husband had to help me up to the bathroom because I couldn't walk by myself and I cried all the way there and all the way back because of the pain.

In the next 8 months I went from using a walker, to a wheelchair to a Hoveround power chair.

While I was bedridden with the infection I did a lot of research online and found out about another medication that some MS people were using and it was helping them a lot. I started e-mailing with them and got all the information I could. The medication is called Low Dose Naltrexone (LDN) and it is compounded into a capsule you take every night between 9pm and 3am. I went to my Neurologist and asked him about it but he had never heard of it because it had not been approved to treat MS or TM.

I had printed a bunch of information about it and gave it to him and he said he would read through it and get back to me on it. A couple of days later he called me and said it looked good and we could give it a try if I still wanted to. I said yes and he called it in. I started taking 3mg on September 3rd, 2005. My understanding was it could take up to a few months to get the full effect from LDN but I started feeling beneficial effects from it the very first night. I didn't have any side effects until around five months later when I increased the dose to 4.5mg. I had a hard time sleeping and had really vivid, weird dreams for about 2 weeks, then they went away and I've been fine since.

LDN took away my 'MS Hug', and helped me walk without a walker, wheelchair, or Hoveround power chair. It also helped with some of my back pain, muscle spasms, most of the numbness or tingling in my legs, and my swallowing problems. Another benefit was that I was no longer fatigued most of the time. LDN gave me back the ability to do a lot of things I never thought I'd be able to do again.

It's difficult for people that don't have MS or Transverse Myelitis to understand what you are going through. These are Neurological disorders, and some of the symptoms can't be seen on the surface, so those who don't understand these diseases may think there is nothing wrong with you.

After I was diagnosed with MS and TM I recalled different things that had happened to me over the years and I could link them to symptoms of these diseases. I was always misdiagnosed with something else or the doctors would tell me it was all in my head. Believe me, I wish it had all been in my head.

After I was diagnosed with SPMS and TM we went looking online to find information. We had to go through tons of different websites and I thought, 'this is crazy'. So, I decided instead of sitting there and pitying myself, and not doing anything that I would start my own website.

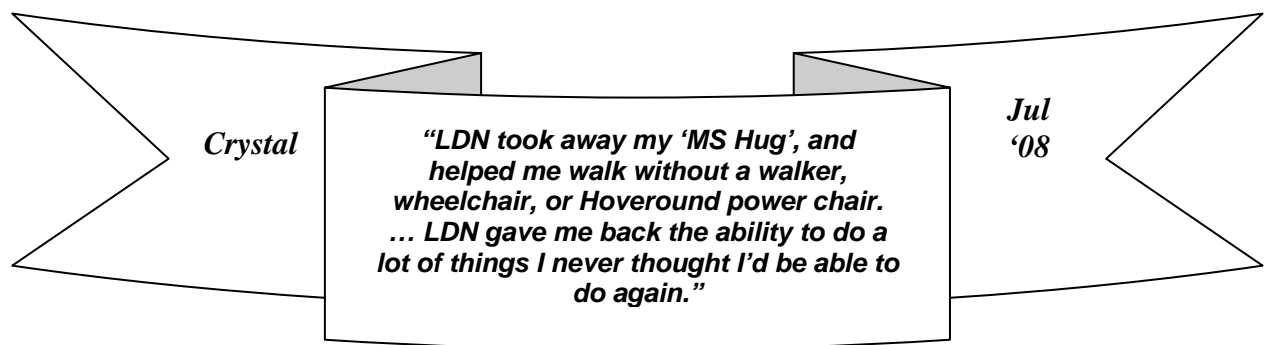
I started Crystal's MS, TM and LDN website in 2005 and on it I published a list of all the websites I found about MS and TM, plus other information that would make it easier for people learn more. I also started an LDN_Users Support Group for people that need support and information about LDN for autoimmune diseases, and I started Crystal's LDN Gift Shop. I now send out a monthly newsletter about things that have to do with MS, TM and LDN.

May there be a miracle in YOUR life today and may you have the EYES to see it.

From My Heart to Yours
Love, Hugs & Blessings,
Crystal, USA

"We either make ourselves miserable, or we make ourselves strong. The amount of work is the same."

1. Crystal's MS, TM and LDN website: freewebs.com/crystalangel6267/index.htm
2. LDN_Users Support Group: health.groups.yahoo.com/group/LDN_Users
3. Crystal's LDN Gift Shop: cafepress.com/crystalldngifts



14) LDN-I have PPMS but doing well - Emily

Low Dose Naltrexone (LDN) since April, 2006

- story submitted February 2008
- story updated July 2008 (2+ years on LDN)

SPECIFICS

DIAGNOSIS

- Aug 1991 - Diagnosed with Multiple Sclerosis
- 2004 - Stage 4 Breast Cancer
- May 2005 – Diagnosed with Primary Progressive Multiple Sclerosis (PPMS)

MEDICATION/TREATMENT (pre LDN)

- 1961 to 1990 - 1 x .50mg Synthroid daily
- 1990 to 2008 – 1 x 1.25mg Synthroid daily
- Feb 2008 to present - 1 x .75mg Synthroid daily
- 2000 to 2003 - Baclofen 10mg - 3 times daily
- 2003 to 2005 - Baclofen 20mg - 3 times daily
- 2005 to present - Baclofen 10mg - 3 times daily
- 2004 - Mastectomy, chemotherapy, radiation therapy
- 2004 to present - Amantadine 100mg – 2 times daily
- 2004 to Feb 2008 - Lexapro – once daily in the evening (after improving on LDN I stopped taking Lexapro)
- 2004 to present - Arimidex - 1mg - once daily (for estrogen positive cancer)

MEDICATION (post LDN)

- 2004 to present - Amantadine 100mg – 2 times daily
- 2004 to present - Arimidex - 1mg - once daily (for estrogen positive cancer)
- 2005 to present - Baclofen 10mg - 3 times daily
- Feb 2008 to present - 1 x .75mg Synthroid daily
- Apr 2006 to Jan 2008 – 3.0mg Low Dose Naltrexone (LDN) nightly
- Jan, 2008 to present - 4.0mg Low Dose Naltrexone nightly

LDN DOSE & TYPE

- a) Dose - 4.0 mg
- b) Time - I take my Naltrexone around 9:00pm each night. I get up at 5:00am every morning so I go to bed early.
- c) Type - my 4.0mg capsules are compounded by Skips Pharmacy with pure Naltrexone powder and avicel filler.

DIET & SUPPLEMENTS

- as at July 2008
- Multivitamin – 3 times daily
- Calcium 1000mg + Vitamin D – 3 times daily
- Magnesium 500mg - once daily

ACTIVITIES & EXERCISE

- I walk for at least 45 minutes each day

MY STORY – February 2008

I was first diagnosed with Multiple Sclerosis in August 1991.

In 2004 I was diagnosed with Stage 4 Breast Cancer that had metastasised to the lymph nodes. My treatment consisted of a mastectomy, chemotherapy and radiation therapy.

Then in May 2005, after almost 14 years of slow MS progression, my diagnosis was changed to Primary Progressive Multiple Sclerosis (PPMS).

I had to use a cane to walk and was so exhausted I could only shop for around 30 to 45 minutes at a time. This meant I only shop for a few things at a time. Walking was terribly painful due to osteoarthritis and osteopenia, the first stage of osteoporosis. I could not stand up long enough to cook supper or even to clean my house in an afternoon. Life for me was slowly closing in and I felt as if I could not put my family through this pain.

In 2006 I heard about Low Dose Naltrexone (LDN) as a treatment for my MS. I joined the Yahoo LDN chat group to learn more, and in April 2006 I began taking 3mg every night. I can tell you my physician is thrilled with the results.

I started taking 3.0mg Naltrexone but in January 2008 I increased my dosage to 4.0mg. I cannot tell you how wonderful it has been to know I'm responding to this drug, especially as I'm well over 50 years old.

After commencing LDN my MS symptoms did not increase. If anything, some of them decreased. It was not an overnight miracle either. As the months, at least 4 or 5, went by I really did not notice any marked decrease in my symptoms - but my family did.

I began to stand for longer periods. I was not using the cane nearly as much. I planted flowers and worked at weeding the garden. My husband brought it to my attention that my housecleaning seemed to be improving. (I hate housework so I schedule it on Saturdays and if I can't do it on Saturday it just does not get done.)

My shopping trips went from minutes to hours. I'd began to shop for longer periods, without carts, at the department store and I'd begun doing more of the types of activities I used to do without thinking before I had MS, but was constantly challenged by after I developed MS.

The improvement was so very gradual I reached a point where I forgot about my MS limitations and pushed myself a bit more into doing things. As I exercised more I got stronger. This could be the key to those folks who may expect LDN to right the symptoms. I pushed because I wanted my abilities back. I would walk farther and not let feeling sorry for myself get the better of me, and LDN (gradually) allowed me to do that.

There have been other benefits as well. Up until recently I was taking 1.25mg thyroid medication (Synthroid), but within 3 months of commencing LDN my doctor noticed my levels were too high. I began reducing the dose and as at February 2008, I am now down to .75mg Synthroid daily.

I also gave all the LDN information to my Oncologist who is one of the top men in his field and he too is interested in the effects of LDN.

So far I am cancer free and my MS is at bay. LDN is not a cure. I still have my good days and my bad days but I do feel that my bad days are less since I have been on LDN. I am ambulatory and I no longer need my cane.

Here's a hint for those of you thinking of going to your family doctor: Take all of the information from the LDN website which describes LDN, and ask him/her to read it. The rule of thumb is - 'he who speaks first loses' - so if he reads it in front of you don't say anything until he's finished. If he states he will read it later then tell him you will set up an appointment to go over the information with him. (They get too busy and it ends up in the round file.)

When I took the LDN information to my family doctor he was intrigued, then after a long silence he said, "Let's do this" – and he is amazed at the results. I wish everyone could have the kind of doctors I do. My family doctor is fresh out of Medical school and is willing to listen to patients.

My Oncologist is tops in the field and even he is looking more closely at LDN. Same scenario, I gave him the literature and asked him to review it. He is a very busy man but on my next appointment 4 months later he was so amazed with how I was doing he said he was going to go back and revisit the information for some of his other patients.

I'm still taking 10mg Baclofen three times a day to relax my muscles. I continue to take Arimidex (for estrogen positive cancer), and I take Amantadine to counter extreme drowsiness. Also, my oncologist has me on a cancer regime of eating more fruits and vegetables (minimum 5-6 servings a day).

Thanks to the LDN website and Yahoo group I'm on a lower Synthroid dosage and I have lost almost 40lbs since improving my diet. My symptoms haven't increased - some have decreased, and I hope yours will too.

UPDATE July 2008 – 2+ years on LDN

I still take LDN and am still benefiting in the same way from LDN. No changes to report.

Emily in Iowa, USA

15) LDN giving me my best friend back - Nancy

LDN since September 2006

- story submitted January 2007
- story updated July 2008 (almost 2yrs on LDN)

SPECIFICS

DIAGNOSIS

- 1994 – diagnosed with Chronic Progressive Multiple Sclerosis (CPMS)
- 1996 to 2005 – As a result of chronic progression Mark was in a wheelchair, had either constant diarrhoea or constipation, had constant bladder pressure (never felt empty), had frequent urinary tract infections (UTIs), had consistent brain fog and confusion and speech difficulties. Mark's progression had led to no feeling or reflexes in his legs, no movement of his legs, no feeling in his arms, and subsequently, no capacity to feel pain. He had phlegm on his lungs, loss of both short and long-term memory, physical exhaustion and constant sleep, he had no bladder control, a cataract in one eye, and an inability to speak at all. He became diabetic, had more frequent and more severe seizures, and even had episodes where his speech was backwards.

MEDICATION, TREATMENT (pre LDN)

- 1994 to 2005 - Betaseron, Avonex and Copaxone
- 2002 to 2005 - Mark was hospitalised, on average, 2 to 3 times a year.
- May 2005 - Mark had a seizure (which just like every other time) put him into the hospital, ventilated and using a feeding tube. That admission was the start of the end according to doctors.
- 2006 – Another hospital admission, ventilator, feeding tube, another poor prognosis - we were told again he's not gonna get better only worse, asked about his 'Do Not Resuscitate' (DNR) instructions.

MEDICATION (post LDN)

- Sept 2006 to June 2008 - 3mg compounded Low Dose Naltrexone (LDN)
- 2002 to May 2007 - digoxin, amiodarone 200mg x 2 day (for heart) - ceased, no longer needed
- June 2008 to present - 4ml liquid mixture Low Dose Naltrexone (LDN)
- June 2008 to present - Keppra for seizures, Metoclopram for stomach, Pancrease for digestion, occasional Advair, occasional heartburn pill
- June 2008 to present - Benadryl (if he's been restless or needs to rest), not every day, usually 1, but on a bad day he may get 3 over a 24 hr period.

LDN - DOSE & TYPE

- a) Dose - 4ml Low Dose Naltrexone daily
- b) Time – between 11pm and 2am, but usually around 2am each night
- c) Type – We're dissolving 4 x 3mg LDN capsules in cooled, sterilized water, shaking and measuring that into 3 equal parts to make his daily dose of 4ml.

SUPPLEMENTS

- 2007 to July 2008 – Mark was taking the following:
 - Vitamin D3
 - Magnesium 250mg
 - Super B-complex
 - B-1 (Thiamine)
 - Flax seed 1000mg
 - Fish oil 1000 mg
 - Vitamin E 1200iu
 - MSM 500mg
 - Garlic 1000mg
 - Lecithin 1000mg
 - Potassium 100mg
 - Glucosamine 500mg
 - Co-Q 10 200mg
 - Fresh blueberries
 - Calcium 500mg
 - Vitamin C 500mg
 - Cranberry Concentrate Juice 1oz daily
 - Pomegranate concentrate Juice 1 oz daily
- We'll be reviewing these after some tests are done by a new doctor.

DIET

- 2006 – overweight – around 228lbs
- 2008 – normal weight was 135lbs, he was 5' 5" (before he shrank) - weight is down to around 118 lbs now

EXERCISE & INTERESTS:

- 2008 – planning physical therapy and speech therapy

MY STORY – January 2007

Okay. Here goes. Now I'm not good at typing so please excuse me if I make any mistakes, okay?

My brother's name is Mark. He's 55. He was diagnosed with multiple sclerosis (MS) about 12 years ago (in 1994). Soon after diagnosis his health declined quickly.

He was in a wheelchair by the end of year 2 (1996). He had all the same problems, and then some – similar to most who suffer with chronic progressive MS. He went thru all the typical symptoms like spasms, leaded feet, dropping things, slurred speech, imbalance, loose bowels without any notice, falling down, eye twitching, sensitivity to light, depth misconception (like he would go to put a glass on a table and it would end up on floor).

The four years 2002-2006 were the hardest for him. He tried Betaseron, Avonex and Copaxone. None seemed to help and only hurt his condition. He was hospitalised, on average, 2 to 3 times a year. In May 2005 he had a seizure which (just like every other time) put him into the hospital. But that hospital admission was the start of the end - according to doctors.

They kept telling me there was no hope. They told me he was getting worse – that is body was failing – and that I had to face it that MS is a debilitating, progressive, and yes, fatal, illness. They said he would not die from MS but from the cumulative damage MS had caused his body.

Well, our family wasn't prepared to sit by and accept a death sentence for Mark. We fought the doctors and were determined not to put him in a nursing facility where he would wither away and die.

2005 was a big, worrying, draining year for our family. Long story short – he was in and out of hospital all year and needed the aid of a respirator to breath during two very harrowing periods. In January 2006 he was in and out of hospital again and additional complications ended up keeping him there until April 2006.

On one occasion the hospital had released him but he had to go back into hospital 2 weeks later due to an infection. The next time the hospital wanted to release him I made sure he did not leave until all signs of infection were gone.

In 2006 Mark was on the ventilator for a second time, and using a feeding tube for a second time, then sent home with a poor prognosis. We were told again, "He's not gonna get better, only worse. It's just a matter of time". We fought hard to get him the care he's had because doctors saw no reason to put him through anything else. We were asked many times about his 'Do Not Resuscitate' (DNR) instructions. My response has always been, "You do whatever you need to do to help him. I'll worry about his quality of life." If we're being frank here, Mark was sent home to die a long time ago.

On April 8th 2006 when he was finally able to come home, he had a feeding tube and didn't talk much. He was having trouble with muscles that help project the voice.

The family searched for some way to help him. We found out about LDN and early in Sept 2006 we put him on 3 mg LDN, along with a vitamin regime we'd developed.

Sometimes improvement can be very slow and gradual, but when you're so far down the track, little things become big things.

He had no feeling in his legs. He now has feeling in his legs. He could not move his legs. He can now move his legs. He had no feeling or reflexes in his arms. His arms now hurt and ache (good and bad huh?)

He was overweight but he's lost weight. He was on heart medication – now he's off it. His lungs had phlegm but they're now clear. He had brain fog and confusion but now his concentration and thinking have both improved, and his memory has also improved a little.

He was constantly exhausted and slept most of the day and night but he stays awake for longer periods now. He had a bedsore that should have caused a major problem but it healed very well.

Now this is a big one for me, because before LDN his bladder leaked all day and night - but now his muscles are working better his bladder is working better. He has a catheter but his bag is not constantly filling. It will often contain the same amount of waste as it did say 5 hours before.

He has a cataract in one eye which looks like its clearing up - if that's possible. He even has less depth of wrinkles then he did a couple of yrs ago. His wrinkle folds have filled out a bit so he looks healthier and younger. He says (as best as he can) that he feels great inside.

All of these improvements have been happening since he left hospital and since we started him on LDN and have been caring for him. This man, my brother, has not been able to even move his big toe for 6 yrs or more. MOST IMPORTANTLY – he now has some movement of legs and even extremities - his toes.

He had no feeling at all when he came home - not even pain. Now he's very sensitive to touch. I can run my fingers along his leg and he jerks. I can touch his feet and he gets very annoyed because it tickles.

One more thing before I go. Mark's seizures never stopped on their own. They would always last for hours necessitating hospitalisation. After his last 2 seizures he was sent back home from the emergency room without being admitted because he now has seizures that are not as severe. He can answer questions while having a seizure where before he could not - nor could he understand what you were saying.

Before, his seizures affected him more mentally – like no-one was home. Now they don't. It's like the seizures are only superficial and not coming from the brain. Does that make any sense to anyone? All I know is between his alternative therapy of vitamins and the LDN I am getting my best friend back!!!!

UPDATE: July 2008 – almost 2 years on LDN

Between September 2006 and a kitchen fire in May 2007, Mark was on LDN uninterrupted and had not one problem, not one Emergency Room visit.

Mark was doing well before the kitchen fire, but because his room is close to the kitchen he took in a lot of smoke. He seemed okay after we put him up in a motel for 11 days while a cleaning crew did their work, except for a fall while Mark was in the motel. His hoier didn't fit under bed and it fell. There were two of us but we couldn't stop the fall. He broke his nose and got a forehead cut above his left eye that needed stitches, as well as 2 black eyes. He looked like hell but within a week - no black eyes and no real visual signs of the fall, just a scar above his eye that was barely noticeable - now that's healing power!!!!

After he got home he got sick – had a seizure, developed pneumonia, and then a urinary tract infection (UTI). He was hospitalised again and he went from the emergency room (ER) to the ICU due to the pneumonia. He was told he had it for at least 10 days, so that was a shock.

The next day he was out of the ICU and ready to go home!!!! I can't recall days but I remember he went in, I think late night on a Wednesday, was admitted and sent upstairs about 2am. By midday when I saw him, I was told how serious he was. I made him give me a strong cough, suctioned him, and retrieved a lot of mucus. He's always congested due to being bedridden.

Being in an ICU, I felt comfortable going home for the night. The next day he was out of the ICU and doctors said he was ready to be released the following morning!!! I'm pretty sure what his cough brought up was the pneumonia. Either the doctors misdiagnosed him or the cough he was able to bring up cleared his lungs well enough to send him home on antibiotics.

In June 2007 we had to take care of a Methicillin Resistant Staph (MRSA) infection he'd picked up during his hospital stay. Then on thanksgiving night he had another seizure and another trip to the ER. This was also a short stay of about 8 hours. Through all this Mark was feeling fine - no discomfort, no pain, and when I searched his eyes I could see he was gonna be fine.

The year ended reasonably well, considering everything he'd been through. For several months there were no real problems, then everything started again – fever, seizure, UTI, pneumonia, bacterial pneumonia, signs of liver damage, blocked bowel ducts, kidney stones, gallstones, you name it then dang doctors threw it at me.

Unfortunately, every time Mark went into hospital he'd be off the LDN and we'd have to start it again when he returned home.

In March and April 2008 he had 3 hospital stays, but he now seems to be improving. I think the fact that we had so many setbacks these past 12 months is cause we had him off his program of LDN and vitamins. We put him back on LDN and vitamins, then another trip to the ER resulted in only a few hours stay. I often wonder if he would've responded faster or better to hospital treatment if he'd continued on LDN during his hospital stays.

After they did kidney drainage and laser treatment (lithotripsy) for an hour to bust up the stone, his bowel unblocked itself, and other stones were not stones after all because the liver tested fine and so did the gallbladder!!!!

He had a staghorn stone so big it almost completely blocked and filled up his kidney!! They said it would have been growing for about 5 yrs to get that big, then added the same ole things, he's getting worse and we have to accept that.

After all this they sent him home early, a few days too soon, and because of that the next week he was back in due to bacterial pneumonia, but that stay was only 4 days, not 2 weeks like before - but he did need oxygen to return home with.

Now, after 6 weeks back home on LDN we are seeing good things again.

I figured out his seizures were the result of panic attacks. He panics if he gets too congested, or has a swallowing problem, and the brain takes over and a seizure follows.

A couple of weeks ago I fell asleep for 4 hours, then awoke to him having a seizure. I forced suction on him, got him to cough, and gave him 2 Advan – and followed that with watchful waiting. He relaxed, and the seizure stopped!!!! This was the first seizure ever when I did not have to call 911.

We're in the process of finding him a new alternative doctor. We're going to get his saliva, stool and urine completely analysed. He's still on 3 mg LDN but we're going to increase the dose to 4mg this week. We're going to do that by taking 4 x 3mg capsules (12mg) and dissolving them into cooled, sterilized water, then we'll divide that into 3 equal doses of 4ml each.

So far he's off almost all drugs. He's on Keppra for seizures, Metoclopram for stomach, Pancrease for digestion, an occasional heartburn pill if he gets acid reflux (though he says he does not get it). Everything else he takes is alternative or over counter!!!

For a while back in 2005 he was even diabetic (when he was eating a little by mouth such as certain meds and food, he was testing as diabetic). He's not diabetic at all now and I don't even check his sugar. His seizures were getting more frequent and more severe (now we can control them and they are not as often or severe). He even had episodes where his speech was backwards - that's right his words made no sense until we realized he was talking backwards (he hasn't done that in 2 yrs).

So, let's see what LDN has done for us. His ability to heal is a great example: His skin, bedsores, and collapsed blood veins heal faster. Though he's had several cases of pneumonia, his capacity to overcome it has improved. He now feels pain, which also means he can now feel it when we touch him. He can concentrate and hold his thoughts and his comprehension. He understands everything we say.

We aren't aware of any new lesions. His swallowing has improved. He sleeps more peacefully. He's told us his dreams are more vivid. He can remember dreaming, but he isn't able to describe dreams to me because he doesn't have the strength to speak.

His eyes have also improved. A cataract has dramatically improved with only a slight film left over his pupil that most wouldn't notice (you have to look hard to see it). He's had major weight loss and this has improved his breathing, blood pressure and heart issues.

When he's awake he's more alert and demanding – always a good sign, LOL!

His skin is beautiful and looks very healthy, though sometimes a little dry. He has healthy strong, fungus-free nails (unlike me), and he has some arm and leg movement. His cough strength has also improved. For example, he was coughing yesterday and by the time I got to him he'd already managed to cough up and spit out phlegm that was so thick it was gummy. I was so proud of him. Don't get me wrong Mark always has

mucus. It's just that now he can help extract it by coughing. I still suction him daily as needed, and it is needed.

I have even had one doctor, a Neuro, say that the MRIs he's seen don't show any reason why Mark can't walk, so he does not believe Mark's inability to walk is from MS. Like me, he believes one day we could get him walking again.

Our next goal is to get him on 4mg LDN, then get tests run on stool, saliva and urine, do a body cleanse, remove other infected mercury filled teeth, get him some physical therapy to build his strength so he can use his arms more, speech therapy to help him talk, and I pray all of this will one day help him to eat unaided. Then we'll work on his walking. For now he still has no muscle tone, and his arms and legs are weak from muscle atrophy.

I don't really understand exactly what LDN does, so I try and notice everything and hope it's from the LDN. One thing I really like is that he's able to relax his shoulders and actually lay back with no discomfort. He is also able to lay on either side comfortably for several hours: These are two things that only a few short years ago were impossible without breathing distress and discomfort and pain.

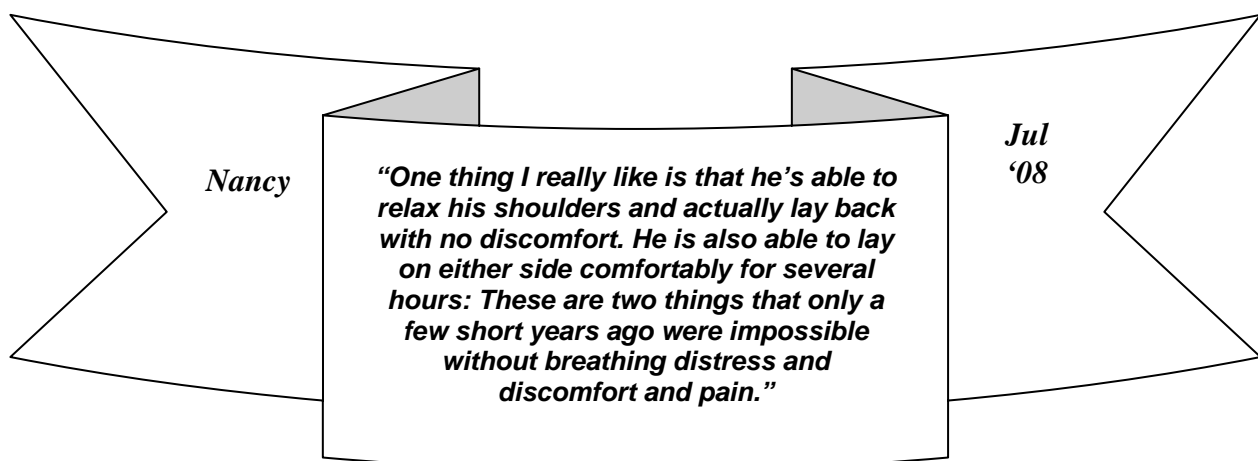
Oh yes, and one more thing. When he's shaved and we're out and about, I'm always mistaken for his MOTHER. He really does look younger. My old computer had pictures so you could see the change. I'm still trying to get it back from the repairman so I can retrieve those pictures.

We're still working on his bowel constipation, but his bladder is working perfectly. That's about it for now.

I believe a person has to have a strong will and desire to get better or nothing will help, and I know Mark has that desire.

Nancy, sister and carer of beloved brother, Mark.

Nancy, USA



16) LDN - Linda Elsegood's MS Story

LDN since December 2003

- story submitted March 2006
- **story updated July 2008 (4.5yrs on LDN)**

SPECIFICS

DIAGNOSED

- partially deaf at birth
- 1963 to 1977 - repeated tonsillitis
- 1969 - Epstein-Barr virus
- 1973 – regular urinary tract infections
- 1973 – First developed gastroesophageal reflux (GERD)
- 1988 – diagnosed with cervical cancer - I do feel confident the LDN will help me with this.
- 1988 – early MS symptoms? Strange leg weakness that only lasted a matter of weeks and disappeared, a trapped nerve in my neck that sent electric shocks down my arms to my finger tips (L'Hermittes).
- Dec 1999 to April 2000 – Extreme fatigue, tooth abscess (antibiotics), tooth removed. Pins, needles, numbness diagnosed as slipped disc (had acupuncture). Also had flu and gastroenteritis.
- April 2000 - MS symptoms first emerge - tongue numbness, pins & needles left side of face, soon followed by extreme fatigue, frequent urination, numbness spread down left side, and bed most of the day sleeping
- Nov 2000 – Optic Neuritis
- Oct 2000 – Relapsing Remitting Multiple Sclerosis (RRMS)
- Oct 2003 – Secondary Progressive (SPMS)
- Feb 2004 - Relapsing Remitting Multiple Sclerosis (RRMS) – 'in remission'

SURGERY

- 1964 – operation to restore hearing, adenoids removed at the same time
- 1974 – Dilatation & Curettage (D&C)
- 1977 – tonsils removed
- 1988 - Initial Loop Diathermy excision to remove cancerous cells, then 4 more exploratory ops on lumps, the last being Oct 2000 when I had fibroids removed, followed by D&C and check on other abnormalities.

TESTS (pre LDN)

- 1998 – endoscopy (camera) of urinary tract
- Aug 2000 - MRI scan, lumbar puncture and twenty-eight blood tests.
- Feb 2003 – Expanded Disability Status Scale (EDSS) Score 2.5
- Oct 2003 – Expanded Disability Status Scale (EDSS) Score 6
- Mar 2003 to Dec 2003 - Liver Function - initially over acceptable level but climbed higher with each subsequent test

MEDICATION (pre LDN)

- 1963 to 1977 – repeated doses of antibiotics for tonsillitis
- 1967 to 1976 – steroids and hormone pills to manage menstrual problems
- 1976 to 1978– contraceptive pill
- Aug 2000 - 3-day course of IV steroids
- Oct 2000 - 3-day course of IV steroids
- May 2002 - 3-day course of IV steroids
- Mar 2003 to Nov 2003 – Rebif (interferon)
- 2000 to Nov 2003 - Provigil

TESTS (post LDN)

- Dec 2003 - Liver Function returned to 'normal'
- Feb 2004 - Expanded Disability Status Scale (EDSS) Score 0
- Mar 2005 to Jun 2008 – Every year since starting LDN - Expanded Disability Status Scale (EDSS) Score 0

MEDICATION (post LDN)

- 2000 to present – Omeprazole for reflux (also known as Omeprazone)
- Mar 2000 to Mar 2007 – Atorvastatin (for cholesterol)
- Mar 2007 to present – Simvastatin (this reduced my cholesterol to just under 5)
- 3 Dec 2003 to 3 Jan 2004 – 3mg Low Dose Naltrexone (LDN) capsule, calcium carbonate filler
- 3 Jan 2004 to Jul 2005 – 4.5ml Liquid LDN from Dicksons
- Jul 2005 – present – 4.5mg capsule, avicel filler

LDN DOSE & TYPE

- a) Dose – 4.5mg Low Dose Naltrexone (LDN)
- b) Time – I take my Naltrexone at 10pm each night
- c) Type - (eg 4.5ml liquid, or 4.5mg compounded capsules with pure Naltrexone powder and Avicel filler.)

SUPPLEMENTS

- July 2008
4 MorEPA Omega 3 capsules
Dr Tom Gilhooly's Baseline AM & PM daily
I do suffer from reflux and take ? daily for this.

DIET

- Nov 2003 to June 2004 - wheat, gluten, dairy, red meat, citrus fruit, caffeine free diet.
- Jun 2004 to present - I'm now trying to eat a healthy low fat diet, with fresh foods and little processed foods. I don't follow any particular diet.

EXERCISE OR INTERESTS

- LDN Research Trust

MY STORY – 4.5 years on LDN

1999 started off being a good year....

My husband Marcus had been made redundant after 18 years working for Anglia TV but was managing well in the freelance "sound" world.

My elder daughter Sara was happy living away from home.

My younger Laura was 14, and had asked to go to boarding school to take her GCSEs to cut down on travelling, she wanted to spend the extra time studying.

As for me, I had the job I wanted working for the Virgin One Account (banking). The family were happy and well and life was good.

Until ... I came home from work the Monday before Christmas, my friend was already there cutting Marcus's hair and she was telling me to get my coat off and my hair washed as she was almost ready to cut mine.

Then something happened that had never happened before, my father called me, he doesn't hear well and hates talking on the phone. He said "Your Mum's had a heart attack and they are now taking her to hospital."

That statement was to change all our lives forever!

I'm an only child so had no siblings to share this difficult time with. I arrived at the hospital about 8.30 pm, mum was in ICU. I was too scared and frightened to sleep for two nights, I thought if I slept mum would slip away. I was very tired, stressed and worried, I also had the added worry of my father who is wheelchair-bound. Little did I know what the trauma would do to me.

Mum survived, even though a third of her heart died and they both had to come live with me for a while. Mum's heart attack was due to hereditary high cholesterol; this was when I found out my cholesterol level was 9.7, which resulted in me having to take pills daily.

I carried on working, feeling so very tired; the 60-90 minute drive to work every day was killing me. On my days off I was cleaning, doing food shopping, and other housework. My life was work, cooking, cleaning and spending as much time as I could in bed.

Between Christmas 1999 and Easter 2000, I had a tooth abscess that resulted in having the tooth removed, a slipped disc, flu and gastroenteritis. I had never felt so ill in all my life; I felt I couldn't cope anymore. I said to Marcus I wanted to go away on holiday and come back a new woman. He said he was unable to take any time off, so Laura and I went to Portugal for a week.

The day before we left I took Laura shopping for shorts and T Shirts. I had an odd feeling on the left hand side of my tongue, it felt like I had eaten food that was too hot and had burnt my tongue. I spent some time trying to remember what I had eaten that might have caused this, but gave up and carried on.

Portugal was very wet, cold and windy. We had the choice of sitting in the apartment or making the most of being there-going out and getting wet. I thought it very strange that the cold and the wind were making the left side of my face numb with pins and needles.

When we got home, I returned to work and made an appointment to see my doctor. After a week away I was feeling even worse than when I left. I was giving work 100% but was collapsing in bed as soon as I got home, and I stayed there until I had to have a shower and go back to work.

My GP thought I should see a Neurologist as he was unsure what was wrong with me. I also had to rethink working, as I simply couldn't manage the hours. It was agreed that I could work part-time and have 3 days off a week. I managed to do this for a few weeks until I developed double vision, at which point I had to listen to my body, stop work and rest.

All I wanted to do was sleep; I thought it was best to let my body heal; not knowing that short-term would turn out to be about a year.

I now had the problem of not working, hence not getting paid. We had Laura's school fees to pay on one salary. Marcus worked out we could afford for me to have 2 months off work. It was fortunate that at the time we didn't know I was never to return.

I was sleeping more and more, going to the toilet more often. The numbness was spreading from my face and down my left side. The hearing went in my left ear, muscles were twitching, and my thighs were burning as if sun burnt. Balance was a thing of the past, fainting and vertigo was becoming the norm. Trying to get to sleep at night my legs would thrash about and when I tried to get out of bed they felt as if they were made of rubber, I would bob up and down and more often than not I would fall over. I became a master of falling asleep either while talking myself or while other people were talking to me.

Marcus at this point of our married life hadn't learnt to cook, clean or use the washing machine, and the iron was a mystery to him. He had a crash-course and had to learn quickly. Life wasn't easy for him either, when he works he's away and he couldn't afford to stay at home looking after me.

Each day something else in my body didn't work properly, I was having really bad problems with "exploding" bowels. I was unable to put a cup to my lips, I was walking holding on to furniture but was unable to go through my front door without help, let alone shower.

My parents would come over on Saturdays to visit me, mum would sit on the bed and talk to me and I would alternate between sleeping and awake. Sometimes she would try and help me get up and sit in the lounge but it took so much out of me that she would have to help me back into bed. I was sleeping 20 hours out of 24, but it was a blessing as I felt nothing while asleep. I wasn't living I was surviving.

At this point it was killing me to see the sorrow in people's eyes when they looked at me. I knew they all wanted to help me and felt inadequate, as did my doctor.

The pains I was experiencing in my head slowly got worse and unbearable. There was a trade off, I could either suffer the pain or take strong painkillers and feel very nauseous.

I finally saw a Neurologist who thought I had either, had a mild stroke, a tropical disease, brain tumour or MS. I didn't like any of these choices to be honest but had to wait for the results of a lumbar puncture, MRI, evoked-potential tests and 28 blood tests.

While I waited for the results I was given a 3 days course of IV steroids. Six weeks later my condition deteriorated to the extent the Neurologist was concerned that I would lose my sight and hearing completely and recommended another 3-day course of IV steroids, even though the first course did nothing. I then developed optic neuritis. It was after this Relapsing and Remitting MS was diagnosed.

Marcus was away working, Laura was at school, my next-door neighbour was keeping an eye on me and the doctor came out to see me. He let himself in, brought me some more painkillers and fetched me a glass of water. I asked him when he thought I would start to feel better, and he replied; "If you were going to, you would have by now" and then he left. I felt so ill, I couldn't do anything let alone achieve anything and I was in a lot of pain. I couldn't bear what all this was doing to my family, and our friends had stopped visiting.

I looked at the painkillers and thought if I were to end it all, it would be a shock to everyone, but I felt they would understand and eventually life would carry on for them. I then had to think it through, things like, who would be the person to find me? It would have been Laura, how could I do this to a 15 year old. The answer

was simple. I couldn't do it. It was then that I decided I would show my doctor he was wrong and that I would beat this MS if it killed me!!!

The biggest problem I had was cognitive problems, suddenly I couldn't retrieve my vocabulary or if I did it was very slow and often I said totally the wrong thing and thought I had said it correctly. I feared I was losing my mind. I spoke slowly and it was often rubbish!

I was having a relapse every 6 months, and it was taking about 4 months to start to recover from a relapse only to have another start. I went for an assessment at the interferon clinic and started on Rebif. This was something I didn't want to do but my family thought it was the only thing available to help me. My liver-function tests hit the roof on Rebif, but even so, my Neurologist wanted me to stay on it. He said it would settle down, but it never did.

It was during this period Sara brought home Darren, her future husband. We didn't know they were coming and I managed to drag myself out of bed but couldn't manage to get dressed. He must have wondered what kind of family she came from.

I was spending a lot of time at the hospital seeing a variety of consultants, for my bowels, stomach, and bladder. I had cervical cancer when I was 32, around the time of the first MS symptoms, had a series of follow-up operations and was told I needed another but they couldn't operate again until I had been free of steroids for 6 months. This was extra stress I didn't need. I then became type 2 diabetic, diet controlled.

I went for a medical assessment with my company doctor, who after examining me announced that I was "unemployable for the foreseeable future". For a workaholic it was devastating news, the thought of going back to work one day had been keeping me going.

Sara and Darren planned to get married September 2003, I managed to get showered and dressed and then needed to go back to bed and sleep. I told Marcus I couldn't go to the wedding but for him my staying at home was not an option. We went and I only managed due to the fact I used my electric scooter. As soon as the speeches were over we left, which was upsetting for all involved.

Though my last relapse was back in May 2002, my MS had been progressing to the extent the strength in my left leg went, and it was at that point I was told by my Neurologist that I was Secondary Progressive and there was nothing more that could be done for me. So, no plan B: We would see about that.

When I needed the toilet I would struggle to get to the PC and I would then sit for a short time, squinting with one eye and try to find out what other people were taking for MS. I eventually, after a few weeks, found LDN and people already taking it with great results.

I printed everything and took it to my new doctor, the original one had retired. I now have a great young lady that could have been a school friend of Sara's! I asked her to read the documents and tell me what she thought and could she prescribe it. I went back two weeks later and she said the partners in the practice wouldn't allow her to prescribe LDN for me, but she said if I got it privately she would be more than happy to monitor me so that is what we did.

I contacted Dr Bob Lawrence who suggested that I change my diet, take supplements and start LDN. I started LDN 3rd December 2003. After just three weeks things were improving and I started to feel like the old me again. This continued for about two years and then I stabilised.

Before starting Rebif in March 2003 I had a 2.5 score on the EDSS scale. Three months after starting LDN in December 2003 it went to 0, where it still is today.

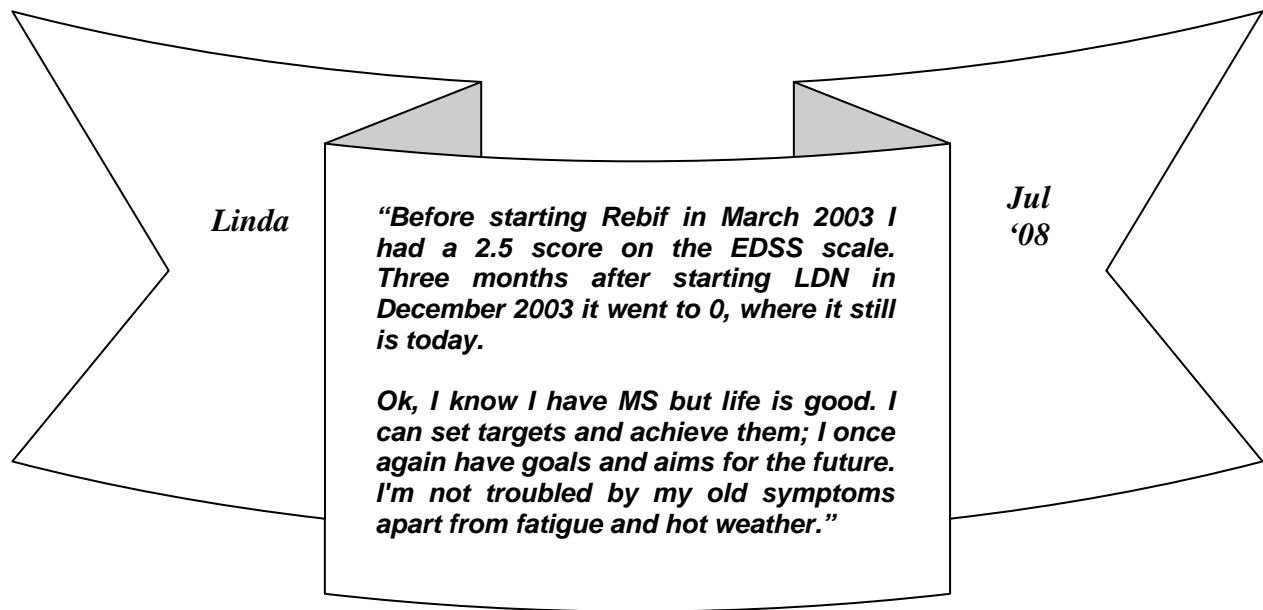
Ok, I know I have MS but life is good. I can set targets and achieve them; I once again have goals and aims for the future. I'm not troubled by my old symptoms apart from fatigue and hot weather.

After my success with LDN I wanted everyone to know about it. I formed the LDN Research Trust in May 2004 and I spent all my time trying to help other people who are in the same place I used to be in, whilst trying to raise funds for LDN clinical trials.

My biggest blessing is having my grandson Leo; I can be the grandmother to him that my mum was to my girls, something that wouldn't have been possible before LDN.

Life isn't the same as 1999 for any of us, things have changed but then nothing stays the same in life for anyone. I now am not afraid of what the future holds....

Linda Elsegood, LDN Research Trust, UK
ldnresearchtrust.org



The LDN Research Trust in the UK

6th August 2008

The LDN Research trust is very proud that over the last 4 years we've helped people learn of, and access LDN - not just in the UK, but around the world. We now have a database of 3,409 people, and the number grows daily – even from outside the internet. We've been able to help every person who wanted to try LDN, regardless of where they live.

When we started the Trust, Dr Bob Lawrence was the main prescriber and medical advisor to the Trust. We contacted over 400 private GPs, sending them the facts on LDN and asked them if they would do their own research and if they were happy with their finding, if they would become an LDN prescriber. It was at this stage we found Dr Tom Gilhooly who agreed to become our second medical adviser. 17 private GPs have joined us in prescribing.

Initially it was mainly people with MS contacting us, these days it is still mostly MS followed by Crohn's, MS/CFS, Cancer, HIV and many of the other conditions suggested by Dr Bernard Bihari, whom we all owe so much.

When people contact us, we send out an ***LDN Fact Sheet** and ask them to take it to their own GP, who may or may not prescribe LDN on the NHS (if they are in the UK).

We are delighted that over time more people are getting LDN on the NHS and we know of 11 Neurologists who are willing to write to their patients GPs saying they can prescribe LDN with their consent. This is a major breakthrough. Many GPs are prescribing LDN as they can see it isn't going to be harmful even if they are unsure it will help. We are always actively looking for private GPs to join us.

Our first LDN Survey had 600 participants, the results can be found on the LDN Research Trust website.

Our second, new and improved survey is now ready: We'd like people to take part every 6 months so we can track progress. You have to register with the LDN Research Trust to participate. As with Case Health, all data is held securely and never passed on to a 3rd party without your consent - for any reason whatsoever. Link <http://www.ldnresearchtrust.org/survey.asp>

The Trust has so far raised £19,000 toward funding needed for clinical trials of LDN. We were only able to do this with the help of our members, who've raised funds and made personal donations. We'd like to say a big 'thank you' to them for all their support. No one involved with the Trust ever gets paid. We are still awaiting the outcome of the CSO's grant application for the trial of 'LDN on Bladder Dysfunction in MS' by Dr Tom Gilhooly, the principle investigator, along with Consultant Neurologist Dr Jonathan O'Riordan. The trial will hopefully start in the Spring 2009.

For our newsletter we're always looking for personal experience with LDN for any condition. If you'd like to share your story with us, we'd love to hear from you. Please email contact@ldnresearchtrust.org.

These are the countries of our members:

Argentina, Australia, Austria Belgium, Brazil, Bulgaria, Canada, Chile, Czech Republic, Egypt, Finland, France, Germany, Greece, Hawaii, Holland, Hungary, India, Ireland, Isle of Islay, Isle of Man, Isle of Wight, Italy, Jersey, Luxembourg, New Zealand, Norway, Orkney, Pakistan, Poland, Portugal, Romania, Russia, Serbia, Singapore, Slovenia, South Africa, Spain, Sweden, Thailand, Turkey, USA and the West Indies.

The **LDN Research Trust, LDN Fact Sheet has been reproduced, with permission, in this book.*

17) My MS with LDN journey - Gigi

LDN since October 2005

- story submitted July 2008 (over 2.5yrs on LDN)

SPECIFICS

DIAGNOSIS

- 1959 - Right hip slipped capital femoral epiphysis
- 1960 - Left hip slipped capital femoral epiphysis
- 1982 - allergies - mold, and seasonal allergies
- 1987 - arthritis
- 1988 - asthma
- 1994 - narcolepsy sleep disorder
- 1995 - high blood pressure
- 1997 - chronic obstructive pulmonary disease (COPD)
- 2000 - degenerative disc and joint disease
- Jun 2005 - Multiple Sclerosis (MS)
- Sep 2006 - Colitis
- 2006 - CT scan - lung nodule detected
- 2006 - Hiatal hernia
- 2007 - PET scan - lung nodule, minimum activity
- Nov 2007 - pulmonary embolism
- Jan 2008 - PET scan - lung nodule now lobular and retracting a portion of my lung, but minimum activity, so 'wait and see'
- Jul 2008 - PET scan determined nodule was active. The thoracic surgeon believes there is a 90% chance it is a cancerous tumor not a granuloma.

TESTS

- Oct 2004 - MRI of brain - multiple brain lesions possible for MS
 - 2005 - Functional tests (coordination, balance, reflex, strength, sensation and balance. Evoked potential testing (BAEP, VEP and SEP)
 - 2006 - CT scan - lung nodule detected
 - 2007 - PET scan - lung nodule minimum activity
 - 2007 - MRI and CT scan follow ups of back and legs, surgery recommended for total left replacement
 - Jan 2008 - PET scan - lung nodule now lobular and retracting a portion of my lung, but minimum activity, so 'wait and see'
 - 21 Jul 2008 - PET scan determined nodule was active. The thoracic surgeon believes there is a 90% chance it is a cancerous tumor not a granuloma.
- (NB I've had numerous tests for diagnosis or rule-out throughout the years in addition to the above, including x-rays, multiple MRI's, full body CT scans, PET scans, arteriogram, GI function tests, breathing and stress tests, CEA blood test to reveal tumor markers, colonoscopy, plus others I'm sure but unable to recall.)

SURGERY/HOSPITALIZATION

- 1954 - Tonsil and adenoidectomy
- 1959 and 1960 - Spica casts for each occurrence of slipped capital femoral epiphysis
- 1969 - Surgical removal of benign cyst, (L) breast
- 1982 - Dilatation & Curettage (D&C) following miscarriage
- 1994 - laparoscopic cholecystectomy and biopsy of cyst (R) breast - benign
- Nov 2006 - Arthroscopic surgery (L) knee
- May 2007 - total replacement of left hip
- Nov 2007 - pulmonary embolism

MEDICATIONS/TREATMENTS (pre LDN)

- 1995 to Oct 2005 - Provigil x 400mg every morning - trialed 'Modafinil', which later came to be called Provigil after the FDA approved it (effectively treating Narcolepsy, but also helped with pain management) 1995 to 2008 - Given numerous Blood Pressure medications, including monopril, which resulted in anaphylactic reaction and angio-edema.
- early 2008 - atacand 32mg every morning

MEDICATION (post LDN)

- Oct 2005 to 2007 - 3ml Low Doses of Revia tablets to make liquid Naltrexone (LDN) in distilled H2O
- 2007 to 2007 - 3mg compounded LDN capsules (after receiving prescription for LDN)
- 2007 to present - 4.5mg compounded LDN capsules (increased from 3mg to 4.5mg during 2007)
- 1995 to present - Provigil x 400mg every morning
- 2008 to present - Lasix x 20mg every morning
- 2008 to present - Spiriva inhaler every morning for asthma
- 2008 to present - aspirin for pain as needed
- early 2008 to present - Atacand x 32mg (blood pressure med) every morning

LDN - DOSE & TYPE

- a) Dose - 4.5mg compounded LDN capsules (increased later in 2007)
- b) Time - I take my Naltrexone at bedtime (between 9pm and 2am each night)

c) Type - Initially I dissolved one 50mg Revia tablet in 50ml distilled water (H2O) to make liquid LDN. I would keep it in the fridge, shake well, then use a needle-less syringe to draw up the 3ml dose. In 2007 I switched to naltrexone capsules compounded using pure naltrexone with avicel filler from Skips Pharmacy.

DIET

- Fewer sweets, more fish, salad, and fresh fruits. Seeking most effective diet to combat cancer in conjunction with LDN treatment.

SUPPLEMENTS

I also supplement with the following:

- B complex x 1 every morning
- potassium gluconate 595mg x 1 every morning
- folic acid 400mcg x 1 every morning
- vitamin D 400IU x 1 every morning
- Omega-3 x 1 every morning
- Calcium, Magnesium, and Zinc x twice per day
- Vit C crystals - several times per day

ACTIVITIES & EXERCISE

- Swimming has been very helpful for painless exercise. Exercises by physical therapist following hip replacement were very helpful. Have been able to better tolerate routine housework, cooking, etc. and able to resume some additional activities, i.e.; some gardening and water sports.

HOBBIES & INTERESTS

- Writing short stories and poetry suffered during my brain fog but am again able to put thoughts into words. Mask making as well as other craft making has been restored with improved coordination and concentration. Cooking is once again a joy instead of a risk since I am now spasm free and no longer fear dropping things.

MY STORY - July 2008

Without a doubt LDN has given me a new chance at life! Having had slipped capital femoral epiphysis as a young child as predicted developed arthritis. Fortunately, and I am so thankful, I was treated by an 'old-fashioned' doctor who opted to Spica cast rather than the traditional cutting and pinning method. I had many years of relatively normal ambulating ability with the exception of an odd gait when tired.

Every mobility-related symptom after that was attributed to arthritis, and later degenerative disc and joint disease therefore ignoring the possibility of any other problems. In 1995 I trialed and began taking Provigil for narcolepsy which had a side effect that helped with pain management and enabled me to continue working until 2001 when falling became a safety issue and pain meds just made me sleepy. For the sake of my patients I quit working until I could 'get better'. But I continued to get worse and my doctors referred to many of my symptoms as 'an enigma' and simply treated for pain, depression, and symptoms obvious to them. By October of 2004 my GP sent me for a brain MRI after having reported waking up blind which resolved within 10 to 30 minutes on three occasions. The report stated, multiple brain lesions possible for MS. I began researching my symptoms and found they were linked to MS.

By the time I was diagnosed in June of 2005 I had lost my voice for nearly three months, had terrible brain fog, frequent falls, dropped things often, had slurred speech, b & b problems, awoke several times through the night with pain and spasms and bladder issues, choked on food and drink, could not stand to cook or wash dishes for more than 15 minutes from pain and MS hug discomfort, suffered extreme fatigue, frequent pneumonia, relied on a cane to walk, and was in constant pain.

I was a mess but refused the lumbar puncture (LP) my neuro had suggested 'to determine the level of CRAB meds' I should start on. I had no intention of using standard MS drugs.

I discovered LDN via some wonderful people on the internet who referred me to the LDN sites. I knew all these people couldn't be wrong so it was certainly worth a try. My neuro refused to prescribe LDN, so I began my LDN journey the last week of October 2005 with naltrexone tablets and mixed my own liquid. Later another neuro I was seeing said it was 'apparently helping' me, and she wrote a prescription which was sent for compounding.

Two years, eight and a half months later the only MS symptoms which remain mostly when I get tired, are some brain fog, a little pain, and some 'hug' when I've been too busy. All other symptoms are gone and no new lesions, no pneumonia, only one cold which lasted just three days. Although I have other unrelated health issues I believe LDN has already worked on some of them - fewer allergies, COPD has improved - and LDN may with continued use resolve others.

Unfortunately many of the blood pressure (BP) meds I take warn side effects may produce 'dry cough' as well as a host of other side effects. The doctor has tried numerous BP meds, which end up not working well for me. When I was hospitalized in November 2007 with the pulmonary embolism the 'hospital-ist' changed my BP med (atacand) to metoprolol, plus a heart med and warfarin to keep my blood thin.

Not only did the new BP med fail to do the job right, but I felt awful and developed bruises all over from too much warfarin, and my hair began falling out like rain...yikes! The warfarin level was adjusted and by March I quit taking all of it. The hair loss has slowed down but unfortunately not stopped, horrors!

Early this spring I went to my PC who did blood work and tried two more BP meds with more adverse effects. So, I asked to be put back on the Atacand which, while it does not keep my BP as low as they'd like (hence the diuretic), it seems to have the least adverse obvious effects. My blood work came back OK with the exception of some elevated cholesterol levels, which I'm trying to modify with diet, and kidney function is fine. The LDN has stopped my five trips per night to the loo, but I still have plenty of output.

I believe in LDN that strongly and will continue to advocate for its use and trials for all autoimmune disorders. I can see no argument against, only accolades for a medication with temporary little or no side effects which regulates our immune system into working as intended. It must be made readily available for all who seek a preferable alternative to the harsh medications that end up creating more health problems.

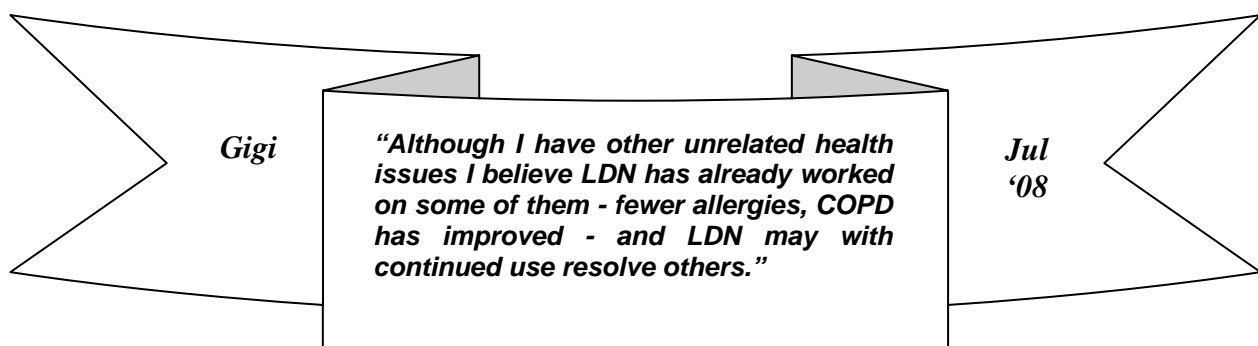
Yes LDN has given me my life back, I am grateful and feel truly blessed with better health and a fantastic group of supportive people. The main problem I'm focused on now is some recent, unexpected news that my lung nodule has not disappeared as I'd hoped but in fact become lobular and is retracting a portion of my lung, and even my second opinion pulmonary specialist recommends surgery ASAP after further tests next week. Not sure what to do since I don't feel good about more surgery.

I know there are complimentary LDN/cancer diets but they seem to be somewhat cost prohibitive from what I've read. I checked out the Budwig diet, which includes fish oil, quark, nuts and fresh berries and juice among other things, all of which can certainly add up when on a fixed income. Unfortunately when one is on SS Disability, has State supplemented insurance and is not an illegal alien, one is at the mercy of whatever treatment is offered locally. It's too bad really since I was about to interview for a part-time caregiver job, which would have supplemented my urgently needed income.

Sugar is hard to give up especially in my tea or coffee but I'll work on it as it is a small price to pay if it works. Will also increase vitamin C crystals, I'm sure Linus Pauling was right about the effectiveness of vitamin C.

I've been scheduled for a breathing test, new PET scan, and consultation with a new thoracic surgeon on Monday, July 21st and I'll be asking him about RFA, (radio frequency ablation), and VATS (visually assisted thoracic surgery), but I'd really rather not have any surgery at all since I will never give up on LDN's role in this.

Gigi, USA



18) LDN gave me Hope for the future - Annmarie

LDN since October 2007

- story submitted July 2008 (7 months on LDN)

SPECIFICS

DIAGNOSIS

- 1972 – Multiple Sclerosis (MS) benign
- 1983 - IBS & Diverticular Disease diagnosed
- 1993 - Whiplash - head-on car crash (totally fault of other driver)
- 1993-1996 - Stressful period. Fell and cut back of head. Stitches.

The following symptoms increased during this period:

Progressively losing strength below waist; Difficulty getting up from stooping or kneeling; Extreme fatigue - regularly having to go back to bed and rest; Broken sleep; Poor memory; Eye problems; Left side - pins & needles and pain; Permanently cold; Very cold extremities - hands and especially feet - real pain if knocked or anything dropped on them, however small!

- 1996 - Neurological scar tissue - MRI scan confirmed but was unable to confirm whether it was old or new scar tissue (same as 1972 or recent) as there was no earlier scan to compare it to.

- 1997 - Concussion and Whiplash due to freak car accident - my car hit oil on the road –
- 1998 – Flu - stressful period - 2 weeks in bed after bad attack of flu
- 2003-2005 - Stressful period
- Nov 2005 - Major MS exacerbation and relapse

TESTS

- 1972 – Lumbar Puncture resulting in diagnosis of Multiple Sclerosis (MS) benign
- 1996 - MRI scan – neurological scar tissue

MEDICATIONS (pre LDN)

- 1972 - A course of cortisone injections after diagnosis - type and number unknown

SURGERY

- 1981 - Appendix removed
- Sept 2007 – shoulder surgery

MEDICATIONS (post LDN)

- Oct 2007 to Nov 2007 - 3mg Low Dose Naltrexone (LDN) for 1 month
- Nov 2007 to Jan 2008 - 3.7mg LDN for 2 months
- Jan 2008 to present - 4.5mg LDN

LDN - DOSE & TYPE

- a) Dose – 4.5 mg Low Dose Naltrexone (LDN)
- b) Time – I take my Naltrexone at bedtime, usually between 10pm and 1am each night
- c) Type – My naltrexone capsules are compounded using pure Naltrexone with avicel filler.

DIET

- I've always tried to eat well - vegetables, fruits, fish and white meat, whilst minimizing animal fats and sugars, but, I am no saint ... and when I was younger I had an extremely sweet tooth!! I suppose I've been reasonably well-behaved over the last ten years!!

SUPPLEMENTS

- Oct 2007 to present - Advised by Dr Bob Lawrence, I have gradually introduced the following vitamins and minerals. Some days I don't take them all, others I don't take any - my delicate tum is the deciding factor. This is my daily goal:

Fish Oil x 6,000mg
Zinc Gluconate x 100mg (with a monthly zinc taste test)
Calcium Ascorbate x 1000mg (straight vitamin C upsets my tum)
Vitamin B complex
Vitamin D x 1000iu
Vitamin E x 400iu
Beta Carotene x 15mg
Selenium x 200mcg
M.S.M. x 1000mg
Copper x 2mg (to complement zinc gluconate)
Malic Acid (neuralgia) x 1500mg
Calcium Magnesium x 1200mg/600mg
Psyllium Husks (tum!) x 1400 mg
GABA x up to 1 teaspoon

THERAPIES

Numerous complementary therapies - homoeopathy, reflexology, magnet therapy, allergy testing, naturopathy, McTimoney Chiropractic, mineral/vitamin supplements, crystal healing, dowsing the house, shiatsu healing, cranial sacral therapy, hands on healing, replacing mercury fillings, physio.

ACTIVITIES & EXERCISE

Since taking LDN, and meeting my present physiotherapist, I have had marked improvement in balance, standing and walking.

- Sept 2007 - Physio, originally for shoulder, subsequently for lower back and legs to help with my walking
- Apr 2008 - Walking new puppy, Syd - with increased confidence, now able to take him for walks by myself.
- Jun 2008 - T'ai Chi - to improve posture, strength etc. Closely monitored by my teacher.

HOBBIES & INTERESTS

My passion is playing the piano. Over the last 4 years, I have felt too unwell to do much. Since the end of last year, I have had the energy to practise and the end result has given me and my family a great deal of pleasure. I would also like to resume playing the saxophone in the future. I've always loved cooking although it became a bit of a chore before starting LDN because by the end of my time in the kitchen, I would be doubled over - unable to hold my body upright! Happily, this happens very rarely now. I would also like to go back to Salsa Dancing when I'm a bit more sure-footed. Can't see any reason why not!

MY STORY – July 2008

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

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

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

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

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

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

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

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

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

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

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

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

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

My local doctor won't prescribe LDN, but she's watching me very closely. As I continue to improve, I can't see how she can hold out indefinitely. I also take the vitamins, minerals and other supplements Dr Bob suggests. I found a brilliant physio (originally for my shoulder) who is now helping me to re-pattern my brain to walk better and I've recently joined a T'ai Chi class. I eat healthily - but misbehave quite often.

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

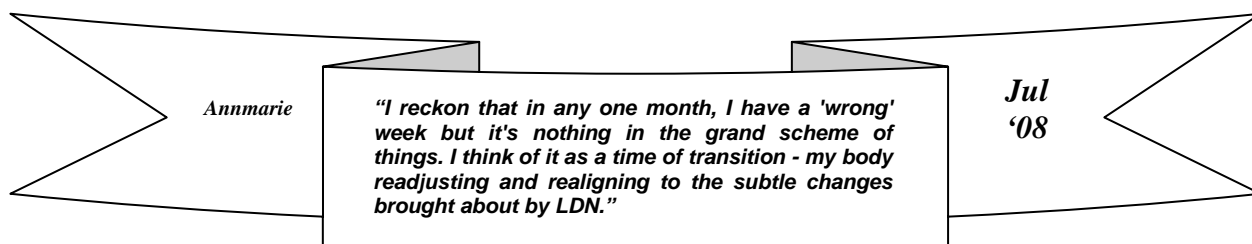
I have to sing praise to both Dr Bob and Joyce, his right-hand woman!! I've emailed them most days and always had a same-day response - it's easier than ringing and getting the engaged tone. Dr Bob and Joyce are there to help and advise whenever, whatever - even when it's not connected to LDN!!! It really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

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

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

LDN has changed my life - it's stopped me from being frightened and has given me hope for the future - and I know it will continue to. I intend to run again and I haven't done that for 15 years!!! Everyone with an auto-immune disease should know about LDN!! Not every day is good!!! I reckon that in any one month, I have a 'wrong' week but it's nothing in the grand scheme of things. I think of it as a time of transition - my body readjusting and realigning to the subtle changes brought about by LDN.

Annmarie, UK



Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health in July 2008.

19) LDN has given me hope - Audrey

LDN since March 2007

- story submitted July 2008 (16mths on LDN)

SPECIFICS

DIAGNOSED

- 1981 – diplopia, earliest symptoms of MS
- 1989 - suspected MS
- 1997 - diagnosed with MS

TESTS (pre LDN)

- 1989 - lumbar puncture and MRI - suspected MS
- 1997 - MRI (when compared to earlier MRI) - resulted in diagnosis of MS

SURGERY

- none

MEDICATION (pre LDN)

- 1981 to Jun 2007 – no medications

MEDICATION (post LDN)

- Jun 2007 to Aug 2007 – 3mg Low Dose Naltrexone (LDN)
- Aug 2007 to present - 4.5mg Low Dose Naltrexone (LDN)

TESTS (post LDN)

- none

LDN DOSE & TYPE

- a) Dose - 4.5mg Low Dose Naltrexone (LDN)
- b) Time - I take my naltrexone at bedtime, usually 11.30pm each night
- c) Type - Compounded capsules with pure Naltrexone powder from Dicksons, Glasgow.

SUPPLEMENTS

- 1989 to Jul 2008 - I tried the following supplements and some helped ...

Flaxseeds

Vitamin C

potassium and magnesium

flaxseed oil

multi vitamin

- July 2008 - I now take only the following supplements ...

Baseline AM PM

MOREPA

DIET

- 1989 to Jun 2007 - I would say I was at my most healthy when I was following a simple, gentle diet of short grain rice, fruit and vegetables, nuts and seeds with lots of juicing. I avoided all salt, never ate processed foods and drank reverse osmosis water. I used to do a lot of yoga and worked out in the gym.
- from Jun 2007 to present - I don't do any of the above now.

EXERCISE OR INTERESTS

- Energy, balance, and all symptoms have improved sufficiently to enable me to again fully participate in just about everything life has to offer.

MY STORY – July 2008

There's not much to my story really. I am in my late thirties now, but I've had MS since I was young (when I had diplopia for a few weeks). I also had burning sensations in my legs. In my early 20s I had a lumbar puncture and MRI. As it was during the late 1980s, the doctors thought it better not to tell me, even though they wrote in my medical notes that they 'suspected' MS.

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

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

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

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

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

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

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

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

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

This is one of my diary notes: 'I have been taking LDN for a month and already I have virtually no symptoms including previous bladder retention. My energy is amazing. I am sleeping the whole night through. Yesterday I got up in the morning, walked the dog, and went for a 1km swim. I went for a strenuous bike ride, walked the dog, made lunch, tidied the house, walked the dog again, went shopping, picked up my husband from the station, walked the dog yet again, and still had enough energy to make something to eat. I find if I plan, I can still spend the day somewhere like St Albans or Windsor and still find energy to drive home, walk the dog and socialize. The most noticeable difference is the reduction in numbness, pins and needles, bladder retention, sleeping the night through, energy levels and probably more. All in the first month.'

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

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

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

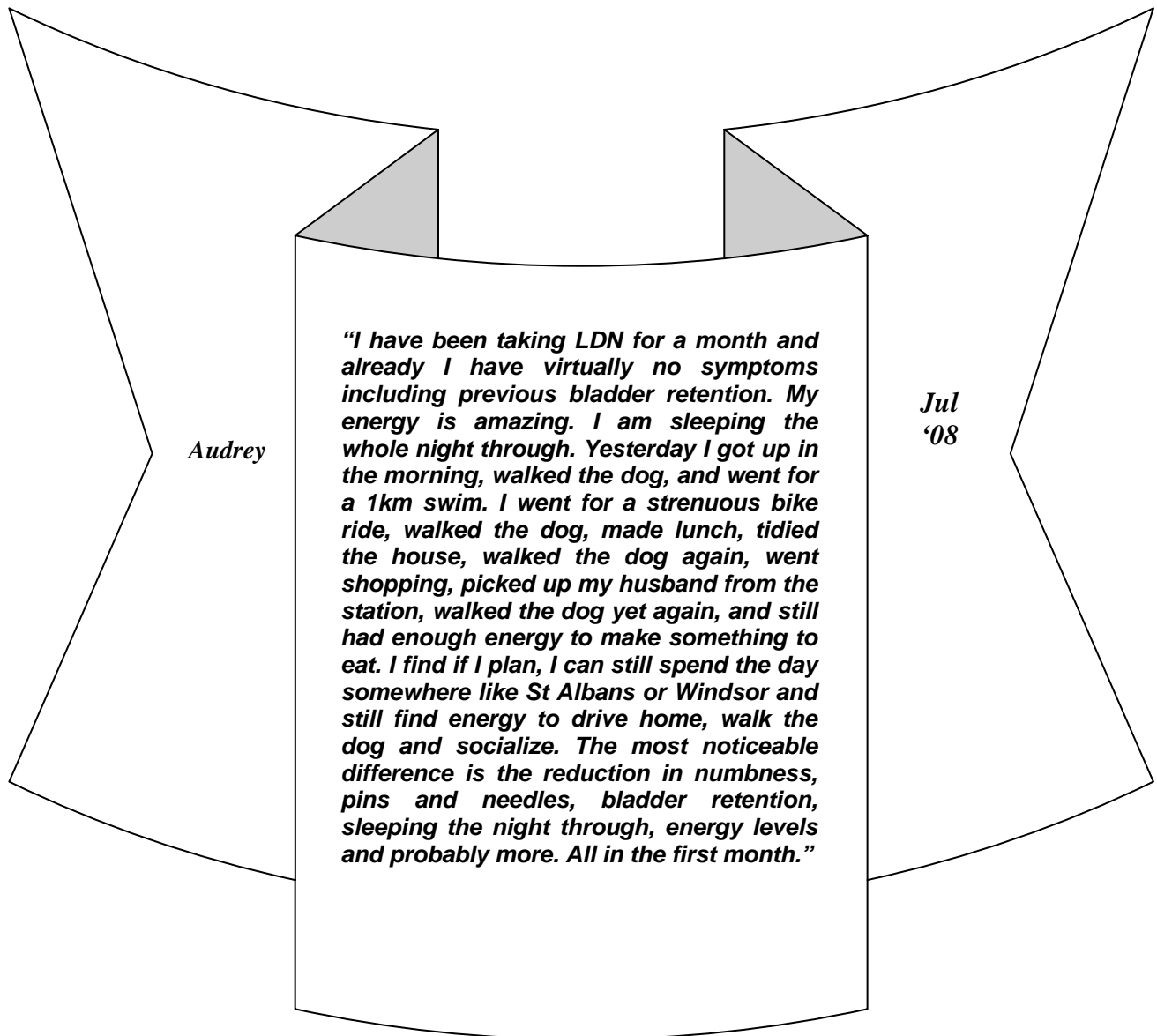
I've now been on LDN since March 2007, 16 months. Despite a short exacerbation, which wasn't as severe as previous relapses, I'm still active and full of life.

I have a border collie who is extremely active and keeps me busy.

More than anything LDN has given me hope.

Audrey, UK

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health in July 2008.



20) Mary Finds Proof of Santa for Noel - Mary

SPECIFICS:

LDN since September 2002

- story submitted August 2005
- story updated July 2008 (almost 6yrs on LDN)

DIAGNOSED

- Oct 1998 – Primary Progressive Multiple Sclerosis (PPMS)

MEDICATION (pre LDN)

- 1999 - 2002 - Avonex

MEDICATION (post LDN)

- Sept 2002 to present – 4.5mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose – 4.5mg LDN
- b) Time – Noel takes his LDN between 9pm and 11pm each night
- c) Type - Compounded capsules with pure Naltrexone powder and lactose filler

MEDICATION OTHER (post LDN)

- Feb 2007 - cholesterol, liver enzymes tested – normal range

TESTS

- cholesterol, liver enzymes

SUPPLEMENTS

- Cranberry
- Calcium

DIET

- low meat, lots of fruit and veg, chicken and fish, preservative free-ish type diet ... that includes the odd beer or glass of wine or Margarita. That's the best we can realistically do.

EXERCISE & INTERESTS

- Riding a three wheeler with the kids

MY STORY – August 2005

I was the final speaker at the New York LDN Conference (ldninfo.org) and this was my talk ... more or less ... I improvised a bit ...

I am delighted to be here today and would like to thank Dr Gluck and his son Joel for organizing this event. I hope that this will be the first of many LDN conferences worldwide.

It is wonderful to be able to match our faces to our screen names, and I am thrilled to be joined by my husband Noel, because I can now prove to him that I don't really have imaginary friends ... you guys are real.

So what do I know about LDN? I certainly don't know as much as all of the doctors present here. I don't know the exact medical mechanics by any means, but I know enough to know that Dr Bihari has discovered something wonderful that has the potential to improve millions of lives. That is why I wrote a book about it. I want Dr Bihari to receive a Nobel Prize ... I am not kidding ... I really do.

To be honest, I needed to write the book ... for me more than anyone ... because it is difficult to rest easy when you know there is something so simple that people with disturbed immune systems need ... but don't know about, because the system works against getting a cheap drug into a clinical trial and medically recognized.

It is just so wrong ... it should be considered criminal ... but that is the system we have been trying to seduce for the last few years.

However ... I have absolutely no doubt that a trial will happen because the people involved in that pursuit are relentless and dedicated ... even obsessed, and for good reason ... because LDN has changed lives. I will share how it has changed my life.

Picture this ... A young mom living in NJ, she is Irish, lets make her a size 6 for a pleasant visual, she has three kids aged 3, 2 and 1 and a dashing husband who loves her very much and she him. Dashing husband has primary progressive MS (PPMS) and as the term implies he is progressing rapidly. The handsome couple are Noel and Mary.

Noels Neurologist attends all of the MS conferences and assures us that he knows everything there is to know about MS and suggests taking Noel off the Avonex and onto Copaxone.

But ... Mary befriends complete strangers on the internet who convince her that a doctor by the name of Dr Bihari in NYC can stop her husbands PPMS from progressing.

IMAGINE!! I don't know about you guys but I completely relate to people who want to beat me up when I first tell them about LDN ... I mean we are all too old to believe in Santa Claus. But ... I was desperate ... my back was against the wall so I phoned Dr Bihari and he spoke to me for about 45 minutes and assured me that LDN would stabilize my husband.

Mary tells Noel. Dashing husband naturally deems she is demented and insists she accept his rapid decline gracefully and make the most of everyday. Mary tells him all about her virtual friends in cyberspace and the success they have had with LDN.

The duo approach the Neurologist who, after recommending intensive therapy for dismal damsel, writes a script for Noel for LDN convinced that it would not work.

He wrote the script on the basis that it would do him no harm and is therefore in line with the first guiding principle of medicine ... first do no harm.

What a wonderful concept ... that should be our starting point ladies and gentlemen ... when you look at everything else we have ... I ask you, does it even come close ????

Noel started LDN and his condition stabilized as Dr Bihari predicted. Much time has passed - three years in September - and he remains stable despite massive stress at times ... Noel has not experienced any brand new symptom since September 2002, when he started taking LDN.

To be honest, part of me is still in shock at how well LDN is working for Noel. Noel uses a wheelchair when we are out and about so people may think that he is not a great poster child for LDN ... but in my mind Noel is the perfect poster child because the onslaught stopped in the nick of time whereby he can still live a full, functional, independent and very happy married life.

As a result of that knowledge (that nobody can dispute) ... I couldn't just forget about it. I told everyone I knew about it.

I kicked off the LDN campaign in Ireland. I tried posting on MS Ireland but was constantly blocked ... and that annoyed me ... I still cannot post there actually ... but way back then I emailed each member of MS Ireland individually as their email was listed ... and I phoned each MS branch personally.

A friend of mine, Robert Joyce in Galway, the west of Ireland, then tried LDN. It arrested both his MS and sarcoidosis. He had the ultimate life changing experience and I so wish he was here today because he tells the most compelling story in such a laid back manner that he puts every Irish story teller to shame ...

Robert's Neurologist is now scripting his LDN in Ireland and the western health board ... i.e. ... the Government ... pays for it ... and a local pharmacist in Galway, Brendan Quinn distributes it.

You see ... of course the Irish and European governments have interest ... they are the ones forking out for the expensive approved meds ... the health care in Ireland and England is different to here in the USA ... There the Government pays for it. ... You would think they would jump at the chance to investigate LDN ... but I have learned and written that it is not that straight forward.

However, the LDN snowball did get bigger, Ireland joined forces with England, Scotland and Wales. Dr Bihari went on Irish radio and really got the momentum going on the other side of the Atlantic. I presented the Irish government with a trial proposal on behalf of Dr Bihari and they still have it.

Meanwhile I have contacted many celebrities and other governments and tried to entice them to investigate but to no avail. So what did I do? I wrote a book about it because I needed to write it down ... because it is a story that has to get out there and let's face it ... it was great therapy. How could anyone keep a story like that to themselves ... It is just too, too big.

I believe that my book ... Up the Creek with a Paddle ... subtitle Beat MS and Many Autoimmune Disorders will help take the LDN movement forward, and I predict that it is the first book of many on the topic. I know that. It is funny how things happen in life.

The book is actually a collection of emails to my kids kindergarten teacher. I met a lady named Rosemary Konde in September 2003 and I instantly loved conversing with her. She is about 55 and a lot of fun.

But, I accidentally included her in an email to a group of LDN contacts a couple of years ago and because of that email she told me that her 26 year old daughter at the time had an autoimmune illness, Samters, and she was hopeful that LDN could help her.

Her daughter met Dr Bihari and started LDN and thank God, it does seem to be helping her. How crazy is that?? If you believe in coincidence it was a classic.

I am glad that our connection grew because it turned out that the only way I could get my story onto paper was by telling Rosemary the whole thing from the very beginning ... from the first day I met Noel ... in a series of emails.

When I was done getting the story off my chest ... (the teachers in Bergen county are very patient - it took about 6 weeks) ... I compiled the emails into a manuscript and the first publishing house that received it, loved it and just ran with it.

That is why I dedicated the book to Rosemary and that is why when people read it, they tell me that it is as if I am just sitting there telling them a story ... because that is what I did.

It is the best story ever ... you see Santa Claus himself even comes second.

The book is an easy read and I am shameless in plugging it ... I just want the world to hear it ... the whole story ... I hide nothing ... and I want Pierce Brosnan to play Noel in the movie by the way.

I bought 50 books and intend to send one to a list of key targets in the hope that one of them will shine the spotlight on it. I have not given up on Oprah by any means.

This is the bottom line ... My husband has not experienced any brand new symptom despite having PPMS because he started taking LDN in September 2002. There is nothing better ... there is nothing better than the release from the onslaught of a progressive degenerative illness. .

I feel for everyone in our boat pre LDN ... I do .. I cant help it ... and I want them to change their future like we did .. and believe me, I have thought about the 'what if Noel found LDN earlier' ... let's not go there.

We need a large scale clinical trial of MS and LDN to blow the socks off the status quo ... such a trial would shed much light on the mechanics of the immune system and hopefully redirect research to help the children of today, like my own ... who are at risk of developing a disturbed immune system illness tomorrow.

The neurologist has assured me I have nothing to worry about ... but I am worried.

Beyond all else ... my children are my incentive... so if I do have the gift of the gab then it is my privilege to use it to get the LDN word out to all those who need it.

To conclude I will end with a relevant quote:

*'Many persons have a wrong idea of what constitutes true happiness,
It is not attained through self-gratification but through fidelity to a worthy purpose.'*

UPDATE July 2008

I am delighted to report that Noel has not experienced any new MS symptoms since he started LDN in September 2002, almost six years ago. He is in fact, healthier than most people I know. His cholesterol, liver enzymes and all of his blood tests are perfect. His doctor even told him that apart from the fact he has MS, he is in perfect shape.

I have no doubt that stress contributes to MS exacerbations because I have seen the correlation too many times, and it is fair to say that during the years post LDN, life has thrown us our fair share of stress. As a result of such hits, the pre-existing symptoms in Noel's legs are a little worse.

For example, he now needs two canes to get around. He has also lost some muscle tone because he uses his legs less and walks in such a way that the muscles he needs have weakened from lack of use. *All of this is in keeping with the initial promise made to us by Dr. Bihari. He said that we will never experience a day post LDN, worse than our worst day pre LDN.* Pre LDN, our worst days involved Noel's MS spreading up his body. His hands were starting to show symptoms, as were other areas of his body.

To be quite honest, I now feel like we are living with an injury of old, as opposed to a progressive degenerative disease. Today, Noel's MS remains confined to his legs and bladder - and some days both are better than others. Exercise and physical therapy definitely help, as does a healthy diet. I am only talking about a common-sense healthy diet; low in meat, high in fresh fish, fruit and vegetables. We have definitely noticed that if Noel eats well and exercises, he walks better, but that is hardly rocket science or remotely ground-breaking.

Noel is still the primary breadwinner of our family. He is still totally independent in every way and he is still able to live a fully functional married life. We found LDN in the nick of time and continue to encourage everybody with an autoimmune disease to try it. Noel is now as much of an advocate as I am!

My book '*Up the Creek*' has helped many people make that difficult decision to go against their Neurologist in his suit, and listen to strangers on the Internet who know better because they have lived the same nightmare and want more than anything for needless nightmares to be erased ... because they can be. I am very proud of the impact '*Up the Creek*' has had on people. It is a personal story that was absolutely worth sharing.

My uncle with Parkinsons Disease (PD) also started 4.5mg LDN in September 2002. Without question, his PD has progressed. He has experienced many brand new symptoms, but we are still hoping that LDN is slowing the progression. It is certainly not doing him any harm so he will continue to take it. I spoke with Dr. Bihari about this and he told me that his other PD patients also progressed and concluded that LDN does not work for PD because although the etiology of PD remains unknown, it seems it is not autoimmune. If I had PD, I would still take LDN. I take LDN myself and continue to take it in the hope that I will stay healthy.

My mother with breast cancer died on August 6th 2007. She also started 4.5mg LDN in September 2002. She started LDN after a mastectomy and months of the standard recommended chemotherapy and radiation. Despite LDN, her cancer spread to her bones and then to her brain. Last summer, I went back to Ireland to care for her during her final months. I scoured the Internet to try to find something that would save her. I mean, against all odds we beat PPMS ... surely there is something out there universally beating cancer. And I believe I found the answer, too late for Mom but in the nick of time for others.

I am about to publish the whole story. It's called '*Going Nowhere? Mom's final lesson: How to beat cancer.*' We tried everything on the Internet and I learned first hand why many theories out there are controversial, but I also learned that there is one theory that is not on the internet yet because once again it is based on an already approved generic drug that nobody will profit from.

The doctor who came up with this cancer theory reminds me a lot of Dr. Bihari. His name was Dr Jurkovic from Slovakia, and here is the kicker ... to make his theory even better he was exhausting methods of boosting the immune system. Nothing boosts the immune system like LDN. LDN was the missing piece to his puzzle. By combining the Bihari and Jurkovic theories and protocols, I'm certain we've struck gold. Time will tell for sure.

My mother's story details her final year, her faith and all the graces she was granted in her final months through the power of prayer. She died exactly right. No medicine, not even LDN, will keep anybody alive

forever, so when my time comes to pass, I am grateful that my mother taught me how to die right. There is no finer lesson in life.

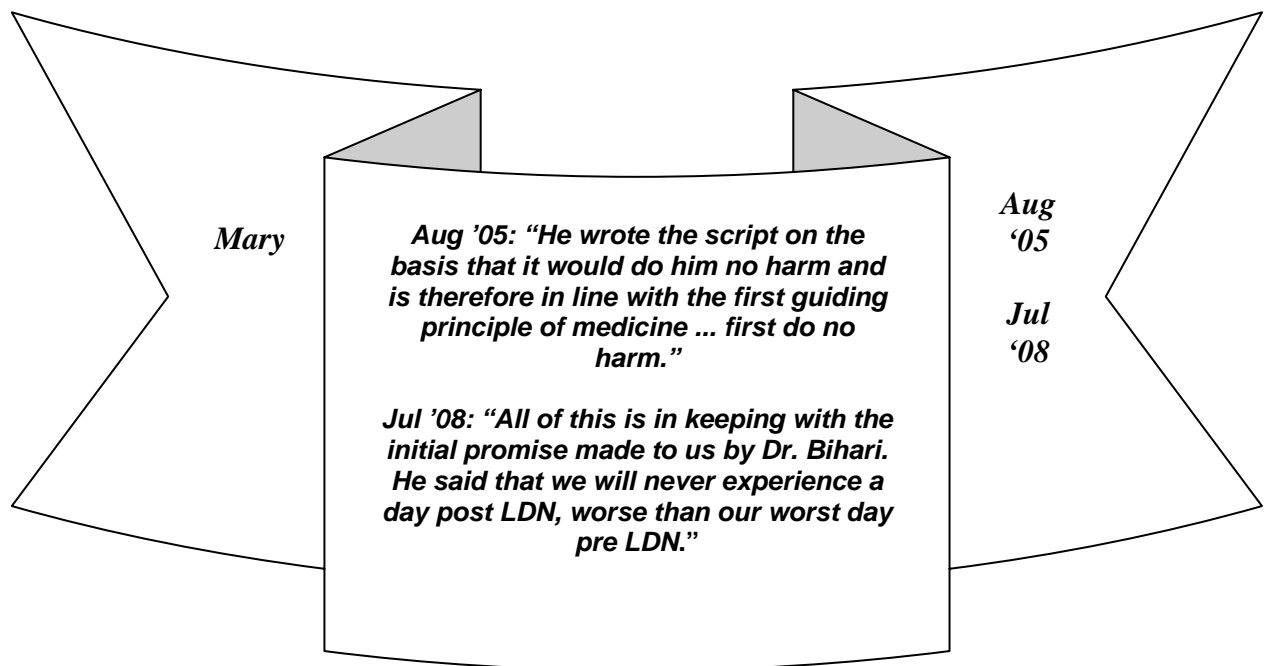
Mary, USA

Mary Bradley's Books - <http://www.marybradleybooks.com>

'Mary Boyle Bradley Speaks 2007'

Mary Boyle Bradley, Author, 'Up the Creek with a Paddle'

<http://www.youtube.com/watch?v=WCTwLbRX2Ys>



21) HIV viral load down, T-cells up - Matt

LDN since December 2004

- story submitted December 2005
- story updated Mar 2006
- story updated Jun 2006
- story updated Oct 2006
- story updated May 2007
- **story updated July 2008 (3.5yrs on LDN)**

SPECIFICS

DIAGNOSIS

- Aug 2002 - HIV positive. My infection was diagnosed early during the seroconversion period (the antibody development period which occurs in the first 1 to 6 months of infection).

MEDICATION (pre LDN)

- Sept 2002 to Sept 2003 – 5 HAART medications twice daily for one year

MEDICATION (post LDN)

- Dec 2004 to present - 4.5mg Low Dose Naltrexone (LDN)

TESTS (post LDN)

- 2004 – viral load above 5000
- Feb 2005 - T-cells increased by 50%, Viral Load went down to below 5000
- 6 Dec 2005 - CD4 500, Viral load 2079
- 8 Mar 2006 - CD4 444, Viral Load 4260
- 14 Jun 2006 - CD4 434, Viral Load 5810
- 27 Sep 2006 - CD4 640, Viral Load 9520
- 3 Jan 2007 - CD4 576, Viral Load 18200
- 11 Apr 2007 - CD4 544, Viral Load 35400*
- 11 Jul 2007 - CD4 414, Viral Load test result delayed
- 10 Oct 2007 - CD4 544, Viral Load 9210
- 4 Nov 2007 - CD4 544, Viral Load 35400
- 9 Jan 2008 - CD4 544, Viral Load 13600
- 4 Apr 2008 - CD4 740, Viral Load 6880
- 23 Jul 2008 CD4 551, Viral Load test result pending

*Note: On the April 2007 appointment, I had a bad cold, which could be why the viral load was higher. (The doctor explained that the fluctuations are normal. As you can see, the CD4 count is holding steady in the 550 range. In late 2005, the numbers were just about the same. The doctor did not have the numbers prior to June 2006, as I was on a study back then.)

LDN DOSE & TYPE

- a) Dose – 4.5mg LDN
- b) Time – 10pm nightly (always between 9pm and 11pm)
- c) Type – Compounded capsules with pure Naltrexone powder and lactose filler.

SUPPLEMENTS

- late 2006 to late 2007 Olive Leaf Extract
- 30 Mar 2007 to late 2007 - 200 micrograms of selenium each day
- late 2007 to present as follows:
Vitamin C 500 mg x once daily
Zinc 200 mg x once daily
Multivitamin x once daily

DIET

- average, meat, vegetables, fruit

ACTIVITIES & EXERCISE

- I exercise regularly - at least 4 times a week.

HOBBIES & INTERESTS

- none at present

MY STORY - December 2005

I was diagnosed HIV positive in August 2002.

My infection was diagnosed early during the seroconversion period (the antibody development period which occurs in the first 1 to 6 months of infection).

Due to early detection I was enrolled in a clinical trial at the University of Colorado, Denver, USA in September 2002. The basis of the study was to treat the HIV with a cocktail of 5 medicines for one year to see if the treatment could boost the body's capacity to control the virus by itself. I was on 5 HAART (highly active anti-retroviral therapy) medications taken every 12 hours (twice daily). I went through the year on the HAART.

It was a tough year because the medications made me feel consistently unwell.

I went off this treatment regime in September 2003. My body was able to control the virus for about a year, but then the viral load started to climb so I went in search of information.

In December 2004, I learned about a treatment involving low doses of Naltrexone (LDN) for autoimmune diseases. I learned about LDN on the lowdosenaltrexone.org website.

I made an appt. with my general practitioner doctor and asked him if he would prescribe the LDN, and he did. I began taking 4.5mg capsules at bedtime, which is generally between 9:00 and 10:00 pm each night.

Within 2 months of starting on LDN, my viral load went down to below 5000, and my T-cells increased by 50%.

I have been taking the LDN for one year now. My last doctor appointment related to the Denver study was on December 6th 2005. I was informed by the HAART study doctor that I was the only participant in the study NATIONWIDE to do so well and I did not have to go back on HAART.

The only thing I did that was different to others in the study was start taking LDN twelve months before the doctor's appointment so I am justified in believing it is the LDN that made the difference.

If you look at it ... my numbers (viral load) were going back up before I started LDN. After starting LDN they went down. The doctor in Denver was sceptical of the LDN but now hesitantly admits that it may have something to do with the fact that I'm doing as well as I am.

The downside of taking HAART medications was they made me feel awful. I have not experienced any side effects since starting LDN and I feel GREAT.

Since starting on LDN twelve months ago I have not taken any other medications or nutritional supplements and I have not made changes to my diet or exercise regime - which I'd say is fairly average.

When I got into work today I had an email from Denver:

Results: CD4 (T-cells) = 500, and my Viral load = 2079 (results from tests on Dec. 6th).

My doctor's goal is to keep my viral load below 5000, and t-cells above 400.

I've been on LDN exactly one year now. I have not taken any other HIV meds now for 2 years, 3 1/2 months. I'm very happy with the results.

My infectious disease doctor in Denver is somewhat dumbfounded. I keep telling him it's the LDN. At least he doesn't say it's a hoax anymore. Thank goodness my general practitioner is open-minded and will prescribe it for me.

Happy Holidays!

UPDATE March 2006

As you'd recall my doctor's goals are to keep my Viral Load below 5000, and my T-cells above 400.

Following my doctor appointment on 8 March 2006, I'm pleased to report my test results were as follows:

Results: CD4 (T-cells) = 444, Viral Load = 4260.

All is going well, and I feel great.

I firmly believe that the LDN has kept me from having to go back on HAART for so long. The study I was on in Denver (ACTG 371) is over. My appointment on March 8th was on my own ticket.

I decided to keep the study doctor in Denver as my infectious disease doctor. As a research doctor they're on the "cutting edge" so to speak and I'm going to keep going to Denver for my peace-of-mind. The doctor again told me on March 8th (as they did in December '05) that I was the only patient on that particular HAART study (ACTG 371) in Denver that did not have to go on a second round of HAART during the study. (This was based on the researcher's communications with and knowledge of other clinical trial centers.)

During my appointment I told the doctor again about taking LDN. There was no response - positive or negative – only a request for the website address followed by a promise to look it up.

Regardless, I'm going to keep taking the LDN. The Denver research doctor told me I'd need to go back on the HAART drugs if my CD4 count dropped below 350. I'm hopeful that will be a very long time from now.

I wish I could attend the LDN conference early in April 2006. Hopefully, I'll be able to attend another year. I enjoyed listening to the audio feeds from last year's conference.

UPDATE June 2006

Cris, I wanted to update you of my most recent check-up at Univ. of Colorado - Denver. My appointment was on June 14, 2006:

Results: CD4 count = 434, Viral Load = 5810.

My doctor seemed to feel that these were really good results since they hardly changed from 3 months ago.

September 2006 will be 3 years off HAART. My doctor stated she would not put me back on HAART unless my CD4s fell to 350 or less.

UPDATE 17 October 2006

Here is an update from my Sept. 27th, 2006 appointment in Denver:

Results: CD4 count = 640 (up from 434 in June!!), Viral Load = 9,520.

My new goal is to keep the CD4's above 350. If I go below 350, then I go back on HAART. I'm hopeful that this won't happen. My next appt. is in January 2007.

UPDATE February 2007

Here is an update from my January 3, 2007 appointment in Denver:

Results: CD4 count = 576, Viral Load = 18,200.

UPDATE May 2007

I still take LDN every night, and I've been taking olive leaf extract since late in 2006 because I read positive information regarding olive leaf as an antioxidant to help suppress HIV infection. It's a potent anti-oxidant so I take it at a different time to everything else, just in case it could interfere.

I started taking 200 micrograms of selenium each day on March 30, 2007 after reading some interesting research on selenium and HIV. It even says on the bottle that it may be helpful for cancer.

My last appointment was in Denver, Colorado on April 11, 2007 and here are the results:

Results: My CD4 count was still good - CD4 = 544. My V-Load was 35,400.

My viral load was not good news, but since I had a slight cold, the doctor thinks that may have elevated it.

UPDATE August 2007

Results from appointment on July 11th, 2007 were as follows:

Results: CD4 = 414. The Viral Load test results were delayed.

UPDATE November 2007

Results from appointment on October 10th, 2007 were as follows:

Results: CD4 = 544, Viral Load = 9210

UPDATE December 2007

Results from appointment on November 4th, 2007 were as follows:

Results: CD4 = 544, Viral Load = 35400

UPDATE January 2008

I stopped taking Olive Leaf Extract and Selenium late last year, and started taking a multi-vitamin, Vitamin C, and Zinc daily.

Just got the test results from January 9th, 2008 appointment as follows:

Results: CD4 = 544, Viral Load = 13600.

That means things are stable and no need to go on HAART drugs at this time. BTW.... As of this month, I've been on LDN for 3 years.

UPDATE June 2008

I am still on LDN. I have excellent news to report ... I had my last appt in Denver on April 4th, 2008:

Results: CD4 = 740, Viral Load = 6880.

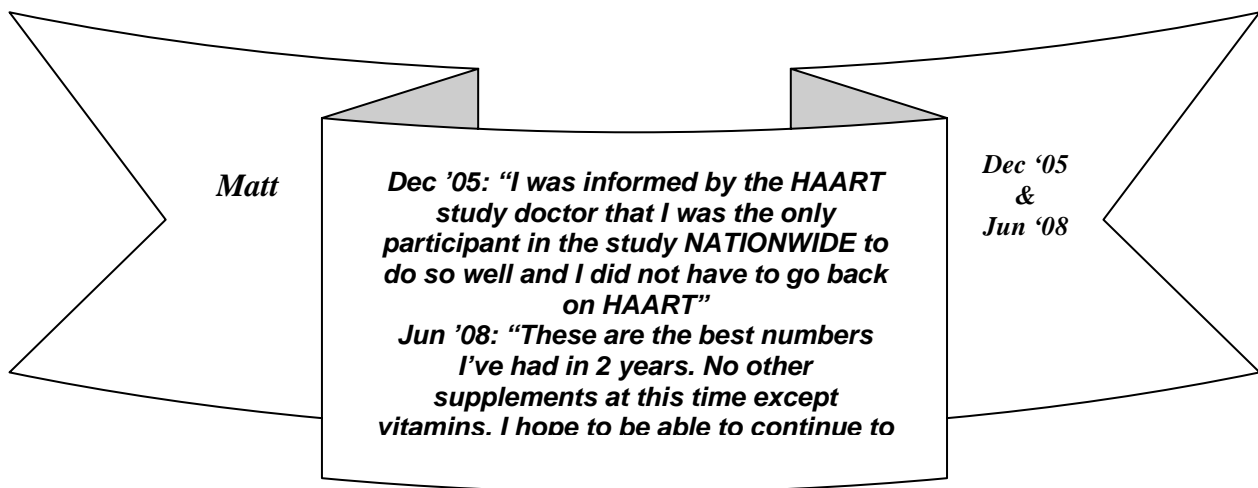
These are the best numbers I've had in 2 years. No other supplements at this time except for multi-vitamin, Vitamin C, and Zinc. I hope to be able to continue to report good news.

UPDATE July 2008 – 3.5 years on LDN

Results from appointment on July 23rd, 2008 were as follows:

Results: CD4 = 551, Viral Load result is pending.

Matt, USA



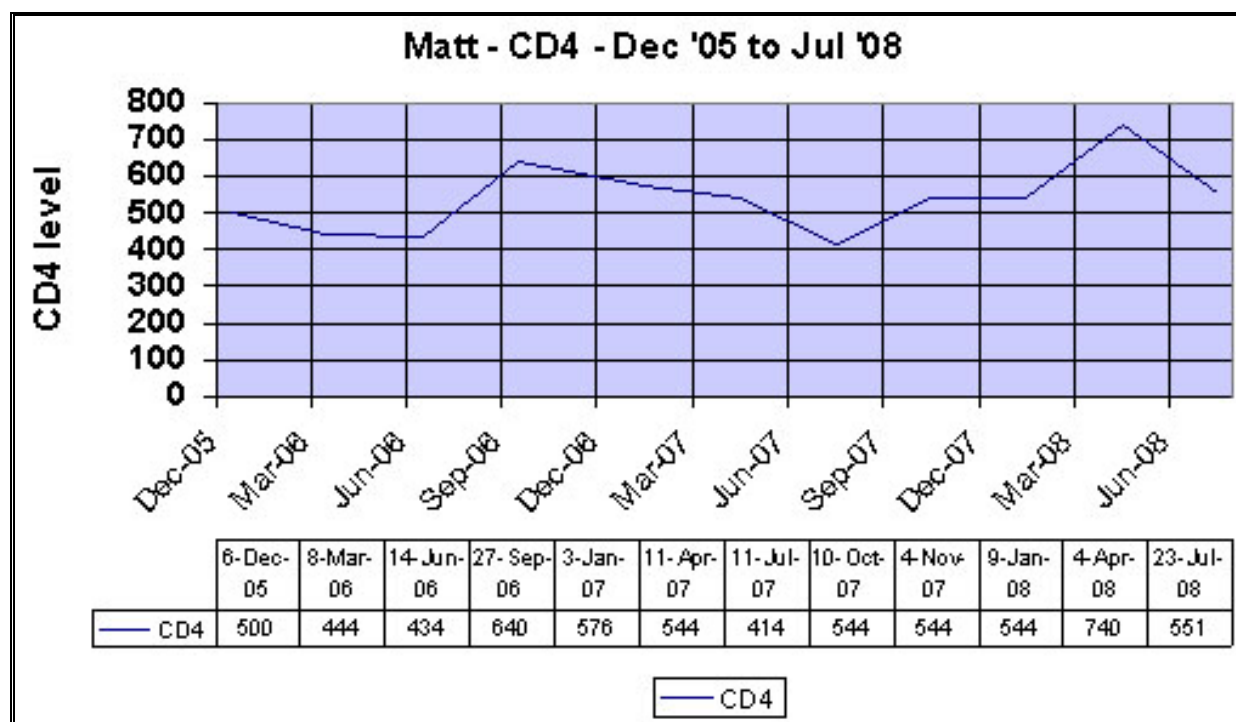
Jaquelyn McCandless

Jaquelyn McCandless, MD, Certified by the American Board of Psychiatry & Neurology, Autism Specialist and Physician Trainer, Author, 'Children with Starving Brains, a Medical Treatment Guide for Autism Spectrum Disorder' and 'Flesh & Spirit, the Mystery of Intimate Relationship' both by Bramble Books.

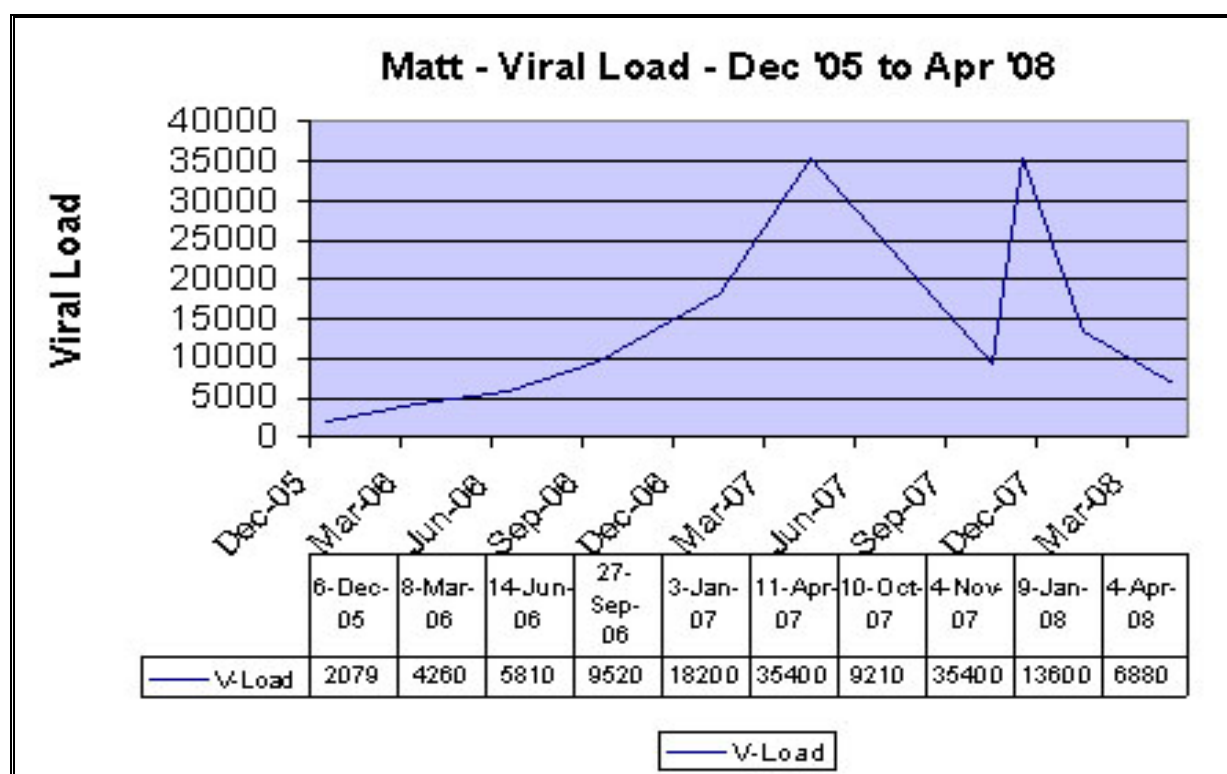
16 May 2007

' ... The safety as well as potential efficacy of LDN in preventing AIDS was discovered by Bernard Bihari, M.D., a Harvard-trained New York physician, in 1985. Since that time Dr. Bihari has treated more than 350 patients, 94% of whom have remained HIV positive without progression into AIDS for up to 18 or more years so far. Many of these individuals received only LDN and some used LDN as an auxiliary to the evolving HAART medications. Of special note, LDN used alone or in conjunction with HAART drugs has been reported by Dr. Bihari to prevent the devastating side effect of the HAART drugs for causing lipodystrophy/lipoatrophy. However, to this date no carefully designed controlled study has been done to prove the efficacy of LDN in HIV positive individuals as a preventative to developing AIDS. ... '

As at July 2008, Drs Jaquelyn McCandless and Jack Zimmerman (Ojai Foundation Africa Project) are in Mali, Africa conducting a clinical trial into the effectiveness of LDN for HIV and AIDS, in conjunction with investigators at the University Hospital in Bamako.



HIV viral load down, T-cells up - Matt



22) HIV-blood & liver enzymes now normal - Noreen

LDN since January 2006

- story submitted 26 October 2007
- story updated July 2008 (almost 2.5yrs on LDN)

SPECIFICS

HEALTH TIMELINE

- mid 70s – I believe I had undiagnosed FM (Fibromyalgia)
- 1975 – Hepatitis (type unknown)
- Dec 1979 - Cancer - abnormal pap smear. Underwent retroperitoneal surgery to biopsy six each lymph nodes. Subsequently had 22 external radiation treatments followed by 2 each radium implants. Cystitis developed due to radiation treatments. Cancer went into remission and has stayed in remission.
- Apr 2002 – left ear buzzing – impaired hearing for one month – prescribed Cipro – immediate allergic reaction – full body rash – ceased Cipro began Keflex for 2 weeks.
- Jul 2002 - initial diarrhea problems. Nurse practitioner attributes this to former radiation treatments. No special tests were run. Treated for herniated disc and pinched nerve in the pain clinic. Underwent one nerve block.
- Dec 2002 - complained to primary care physician of short-term memory loss but no tests were ordered.
- Mar 2003 - developed welts from mosquito bites, heightened emotional state, anxiety, thinning hair - prescribed Prozac and Lorazepam.
- Jul 2003 - short-term memory loss was becoming worse. I also developed GERD (heartburn/reflux) so I was taken off Fosamax, which was attributed to the cause. I had chronic fatigue and started experiencing night sweats.
- Sept/Oct 2003 - nausea, vomiting and diarrhea, which led to accidents. Lack of coordination/concentration, weight-loss, anemia - prescribed iron supplements. Had recurrent cold sores plus treated for vertigo and dizziness with Meclazine.
- Nov 2003 - diagnosed with Epstein Barr Virus, low platelets and other blood abnormalities, advised to see an oncologist as soon as possible.
- Nov 2003 – Due to delay in getting an appt to see the VA Oncologist at the Veterans Administration Hospital (VA), I saw a private Oncologist who recommended a bone biopsy but it was too expensive.
- Nov 2003 - rushed to emergency room because I couldn't breathe – breathing was noisy and laboured. Given oxygen, had blood tests, and CAT Scan. Diagnosed with extreme bilateral auxiliary lymphadenopathy.
- Nov 2003 – late November I finally saw the VA Oncologist - I underwent 2 each bone biopsies, which showed severe immune depression. Oncologist also ordered MRI for failing memory and sent me home.
- Dec 2003 – My primary care VA doctor began to take my health more seriously and ordered HIV tests on 3 Dec - two arterial blood gas tests, complete blood count tests and EKG were performed - Tachycardia, high cholesterol, abnormal blood labs. Promethazine prescribed for nausea.
- Dec 2003 – test results received 18 Dec were positive for HIV - CD4's at 78, Viral Load over 100K - referred to Infectious Disease Specialist. By now, I had Thrush in my mouth and was placed on Nystatin.
- Dec 2003/January 2004 - Saw alternative doctor - was treated with chelation therapy (Intravenous minerals and hydrogen peroxide) as well as supplements - treatment relieved fatigue somewhat. Experienced heavy labored breathing.
- Jan 2004 – Eight weeks to the day after last doctor visit, saw VA infectious disease specialist on Jan 28 - co-incidentally happened to have MRI same day. Doctors went upstairs and found that I had Progressive Multifocal Leukoencephalopathy (PML) or possible HIV Encephalitis. Spinal tap performed this day.
- Jan 2004 – Based on diagnosis of HIV Encephalitis, Infectious Disease Doctor prescribed 3 antiretrovirals and Dapsone. I was given a flu and a pneumonia shot and had an immediate reaction to this and developed cellulitis - so I was placed on a second antibiotic, Keflex. This happened again in Sept 2004 with the same shots. This time the cellulitis lasted for almost a year. Numerous reactions to various drugs was now commonplace.
- Jan 2004 – VA Pharmacist reviewed medications and recommended cessation of Promethazine, suspected of causing my unsteady gait and stumbling - symptom disappeared soon after cessation.
- Feb 2004 - MRI showed two subcentimeter hypodensities within the liver, common bile duct dilated and fatty replaced liver.
- Sept 2007 - Fibromyalgia
- Oct 2007 – Removal of dental fillings and chelation therapy.

MEDICATION (pre LDN)

- Dec 2003 to Jan 2006 as follows:

Antiretroviral medications, (Efavirenz {non-nucleoside reverse transcriptase inhibitor - NNRTI}, Lamivudine, Tenofovir Disoproxil Fumarate). I later had three more sets of antiretroviral medications, plus Cipro, Dapsone, Keflex, Prozac, Acetaminophen, Loratadine, Omeprazol, Valacyclovir Hydrochloride, Rabeprazole, Metoclopramide, Salsalate, Meclizine, Lorazepam, Oxybutynin Chloride, Tolterodine Tartrate, Nystatin, Hydrocodone 5, Promethazine, Tylenol, Voltaren, Protonix, Nexium, Alendronate, Ranitidine, Tramadol, Flunisolide (corticosteroid), Raloxifene and Chlorpheniramine Maleate.

SUPPLEMENTS (pre LDN)

- Dec 2003 to Jan 2006 as follows:

After being diagnosed HIV+, numerous patient-researched patient-prescribed supplements were taken including; colloidal silver, aloe vera, cat's claw, cayenne, elderberry, lemon balm, milk thistle, neem extract, Pau D'Arco extract, turmeric, olive leaf, shark cartilage, antler velvet, omega 3-6-9, IP6 and Inositol, coconut oil, cod liver oil, acidophilus,

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rPriflavone, transfactor, DHEA, lecithin, grape seed extract, pycnogenol, alpha lipoic acid, ellagic acid, chlorella, lycopene, beta-glucans, coenzyme Q10, bee products, thymus supplements, colloidal minerals, B complex vitamins, calcium, magnesium, Vitamin C, Vitamin E, zinc, selenium, amino acids, digestive enzymes, Essiac, oil of oregano, N-Acetyl Cysteine (Nac), enzyme Superoxide Dismutase (SOD), Dimethylglycine amino acid (DMG), noni juice, Immune-Assist 247, Agaricus Blazei mushroom (AbM) Extract, Revivo herbal tea, and Greens First (phytochemicals/antioxidant).

MEDICATION (post LDN)

- Jan 2006 to present 4.5mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE

- a) Dose – 4.5mg compounded capsules (commenced and stayed on 4.5mg)
- b) Time - At bedtime (usually between 10 pm and 2 am)
- c) Capsule Filler - avicel (non-time-release formula from Skip's Pharmacy)

DIET

- low fat, low sugar, no junk food

SUPPLEMENTS (post LDN)

- Oct 2007 – I was taking the following:

multiple vitamin

liquid minerals

omega 3

anti-oxidants

Vitamin D

selenium plus 10 brazil nuts (equiv 1000 units selenium)

3000mg Vit C

400 iu Vit E.

- May 2008 – I added the following:

Liquid Life

EXERCISE

– walking

MY STORY – October 2007

In 1975, I had hepatitis (type unknown, but I suspect Hep B) due to working in the dental field at a time when protective measures were not in place. I was in hospital under observation for a week and convalesced for another 3 weeks. I was diagnosed with cancer and had cancer treatment in December of 1979. Cystitis developed due to the radiation treatments.

Around April 2002, my left ear was buzzing and I could not hear much in that ear for one month. I was placed on the antibiotic Cipro and had an immediate reaction to it. It looked like I had the measles from head to toe, so this was changed to Keflex for two weeks.

In July 2002 I was diagnosed with a herniated disc and pinched nerves. This story relates to a period of deteriorating health, which went downhill fast, beginning in March 2003.

2003 started off as an unusually warm spring. I was enjoying life and by the end of March, I had a beautiful tan from working outdoors in my garden.

Around this time, I noticed unusually large welts, the size of a silver dollar from mosquito bites. I also began to notice that my hair was thinning for no apparent reason and I began to have short emotional outbursts. I had sought help earlier for this, so my dosage of Prozac was increased and I was also prescribed anti-anxiety medication.

By mid-summer (around July of 2003), I was experiencing worse, short-term memory loss. My long-term memory was fine. I could remember something from twenty years ago but couldn't remember something from 2 weeks ago. I'd make a mental list of groceries I needed but when it was time to go to the store, I couldn't remember anything on the list. At that time, I did not know that I had HIV Encephalitis, which would have explained my short-term memory loss.

My increasingly unreliable memory gave me rare insight and appreciation for what Alzheimer's sufferers must experience. I also started to experience (GERD). I experienced all of the above symptoms every day, as well as chronic fatigue - which I didn't think too much of at the time because I couldn't remember a time when I wasn't extremely fatigued.

By September 2003 however, things took a turn for the worse. I started to have nausea, vomiting, diarrhea and accidents in the house and in public. I lost ten pounds and I spent most of the day on the couch. I didn't have any energy nor did I feel like doing much. My health continued to deteriorate. I was worn out and wanted desperately to improve my health so I saw over ten doctors and every one of those ten doctors sent me for further blood tests. I was diagnosed with anemia and was given iron pills but I continued to go downhill.

In November 2003 my current doctor ran more tests for antibodies to Hep C, diagnosed Epstein Barr Virus, and prescribed Promethazine for my nausea, but nothing improved my health and my blood work was still really abnormal. I was told to see an oncologist as soon as possible.

Later that month the VA oncologist gave me a bone biopsy test. For those who are not familiar with this painful procedure, I'll explain: The patient is placed on one's back and is given an anaesthetic at the biopsy site. Next, a very long tool is literally screwed through the skin into actual bone.

The biopsy specimen was inadequate so the oncologist asked if I wanted to come back for another test. I said no way, to go ahead and get it over with. So he proceeded to take another sample in a different location. Being a cancer survivor, I've had many tests, procedures, surgery and radiation treatments but this particular procedure was the worst that I've ever experienced. The biopsy showed severe immune depression. Finally, the doctor gave me an HIV Antibody Test, which came back positive on 18 Dec 2003.

At this point in time, I was relieved because I just wanted to know what was wrong with me and why I was dying.

To add insult to injury, the oncologist who diagnosed my HIV sent me home with only a referral to the Infectious Disease Specialist. I wasn't given any information or told of any treatment options and I couldn't get in to see the referred specialist for 2 months. I'd just been diagnosed HIV positive and actually had full-blown AIDS. For two months I had no doctor, no treatment options, and no support from mainstream medicine. I'd developed a new symptom – unsteady gait – and I was alone and felt abandoned by the system.

However, having beaten one incurable disease, I was determined to beat another so I searched deep down for some inner strength and resolved to do something positive and constructive. I made inquiries at my local health store. The owner recommended that I see an alternative doctor and I did. The alternative doctor gave me some supplements and treated me with 8 consecutive intravenous chelation treatments (minerals and hydrogen peroxide). These treatments helped my quality of life tremendously. On therapy day, I could actually get off the couch and move around a bit.

By the time I reached the infectious disease specialist in January 2004, I was half-dead with CD4's at 78 and viral load greater than 100,000. The doctors were considering PML or HIV Encephalitis. (PML can be fatal within a short period of time as one gets better or dies.) The radiologist at VA Hospital stated that it favored this, however HIV encephalitis could show similar results. They really didn't know what I had but that I had abnormal grey matter in my brain. Doctors determined I had Progressive Multifocal Leukoencephalopathy (PML). A spinal tap was performed the same day.

I was immediately placed on antiretroviral medications and Dapsone. I was given flu and pneumonia vaccinations and had immediate adverse reactions. I developed cellulitis and was placed on a second antibiotic, Keflex for 2 weeks.

Around this time the pharmacist from the infectious disease visit reviewed my meds and unbeknown to me, the drug promethazine (prescribed Dec 2003 for nausea) had been causing my unsteady gait and stumbling. I stopped this medication and the problem resolved. (The V.A. is a training facility and I had the head doctor, a resident and a pharmacist as my infectious disease team.)

Frustratingly, the medications caused many of the symptoms I'd had in the first place such as, anemia, abnormal blood work and diarrhea. Because these medicines are linked to heart, liver, kidney failure, neuropathy and disfigurement, I was very concerned.

During all of this, I continued to research, read and learn. I wanted to understand what was happening to me and I wanted to learn as much as I could about my treatment options.

In early 2005, I stumbled upon information about an obscure treatment called Low Dose Naltrexone (LDN). There's so much information about treatment options on the Internet - so this too sounded too good to be true. I always believed in natural treatment methods and had an open mind to new treatment methods, so I

researched more and read as much as I could find before taking my info with me to discuss with my infectious disease doctors.

My two infectious disease doctors and my local pharmacist were not familiar with this drug. I usually bombarded them with information about supplements and treatment methods from the Internet. However, they were not familiar with this drug and weren't interested at all. So I pressed on.

Around a year later and after having forgotten about LDN, I saw an environmental physician and in the course of the medical history, he stated that he thought I should go on LDN. Wow, was I surprised and happy!

He prescribed LDN at the end of January 2006 and I immediately ordered it from Skip's Pharmacy. After reading about LDN on the lowdosenaltrexone.org website and learning about the great successes with this drug, on 1 Mar 2006 I stepped out in faith and stopped all other medicines and was only taking the LDN, much to the dismay of my doctors and my husband.

After much reading and soul-searching, I decided that this was my life and I had to do what I felt was the right thing to do, no matter who supported me or not. I did so well on the LDN that my husband has since changed his mind and my infectious disease doctors still follow me in amazement.

Finally, in September 2007, I was diagnosed with fibromyalgia, although I feel I'd had it since the 1970's.

It is now October 2007 and I have been on LDN for a total of 21 months. My blood and liver enzymes have been tested every 3 months since being diagnosed with AIDS. Approximately 6 months after being on LDN, my blood-work and liver enzymes reverted to normal and have been so ever since. I am no longer anemic - something too that never occurred while on the antiretroviral medications. I still have heavy metals, mercury and lead in my body so my dental fillings are being replaced and chelation therapy is underway and being supervised by my environmental physician.

Although my viral load is greater than 100,000 and CD4s stay in the mid eighties, I haven't had one opportunistic infection (OI) or even a cold while on LDN. OI is what kills AIDS patients due to the weakened immune system. The LDN is definitely helping to keep the OIs at bay and maintaining my health along with good health habits. My quality of life is so much better now. I was couch-bound, sick and dying and now I can reach for the stars!

When I reflect on my sickest days, two occasions stand out: On one particular day I knew I couldn't get any sicker and I was certain I was going to die yet, I wasn't scared and it was the most peaceful day of my life. The other occasion was on a trip to the lab at the VA. I was extremely weak, exhausted mentally and physically. There was always a line outside the blood drawing room yet few seats, so I slumped on the floor and waited my turn.

After all I'd been through, I no longer feared death and saw it merely as a natural, peaceful progression. The best way to describe it as I did in my book, is it was like the Sago coal miners who left notes when they knew they were going to die: When they realized death was imminent there was no fear, only acceptance and peace.

So much, I have placed behind me, all of the sicknesses, terrible health and lack of proper medical care. After researching my records, I also learned that I had been anemic for three consecutive years and I was not told about this. I think my health deteriorated because things that were obvious were not looked into or treated. I now only think of the future and how lucky I am to be alive!

The VA doctors know that I'm doing great and I believe they're really curious about how I'm doing this. I tell them it's the LDN, you see; my blood reports and liver enzymes are now normal and I'm no longer anemic, something that never occurred while on their toxic medications.

And here's something else that's interesting: ... In 2002 I was negative for hepatitis (test done by primary care physician at the VA). Then I was told in Dec 2003 that I had antibodies to Hep C, then later didn't have it, and finally my primary care doctor said I did. I was retested in 2005 and again told I had antibodies to Hep C. In October 2007 I was tested for antibodies to Hep B and Hep C (non VA facility) and guess what, it did not show antibodies to either. I've lost all faith in these medical tests.

For me, LDN has been a miracle drug and I know that it is also working for others and saving so many lives! My sincere thanks go to Dr. Zagon and Dr. Bihari and of course to all those who continue to spread the word because they've brought this miracle drug to us.

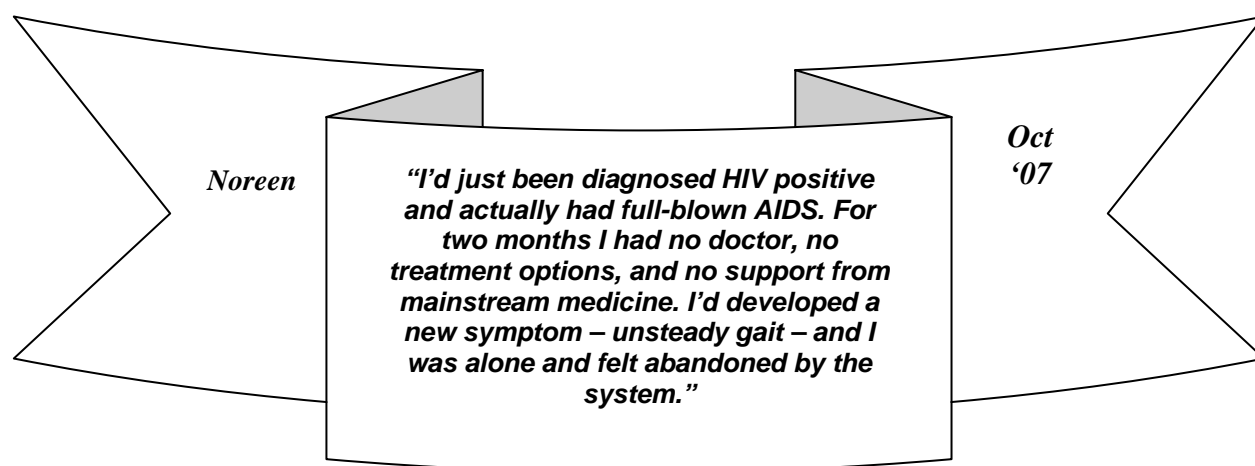
UPDATE: July, 2008 - almost 2.5yrs on LDN

LDN is truly a miracle drug, which has been my lifesaver. Because of LDN, I do not have to take the antiretroviral medications that have so many nasty, side effects. LDN's time has come and now it is getting the proper recognition that it deserves. One who say that it cannot be done should not stand in the way of one who is doing it!

Noreen, USA

'Noreen Martin Speaks'

Noreen Martin, Author, *Surviving Aids & Cancer*
[http://www.youtube.com/watch?v= Nh-t3LA6e4](http://www.youtube.com/watch?v=Nh-t3LA6e4)



23) LDN benefiting daughter's HepB - Joyce C

Low Dose Naltrexone (LDN) since July 2007

- story submitted February 2008

- story updated July 2008 (1yr on LDN)

SPECIFICS

DIAGNOSIS

- 2001 - Hepatitis B (My daughter was adopted from China. It is presumed her mother had Hepatitis B and passed it to my daughter during birth.)
- 2001 - Food Allergies, Eczema - Severe
- 2005 - Food Allergies, Eczema - Mild (Food allergies and eczema improved considerably after starting Antioxidants, Liquid Vitamins/Minerals, Probiotics, and Herbal treatments.)
- 2007 - Food Allergies, Eczema, Hepatitis - continue to improve
- Jul 2008 - Eczema - totally healed
- Jul 2008 - Food Allergies - able to eat almost all food that she was previously allergic too
- Jul 2008 - Hepatitis B - Sero-converted the 'e' Antigen (HBeAG) and gained the 'e' Antibody (HBeAB).

MEDICATION/TREATMENT (OTHER)

- Aug 2006 to present - rotations of Milk Thistle, and traditional Chinese Medicines (Schizandra, Licorice Root, Cordyceps, or Astragalus)

MEDICATION (LDN)

- Jul 2007 - Nov 2007 - 1mg Low Dose Naltrexone (LDN) nightly, at bedtime
- Nov 2007 to Jul 16 2008 - 1.5mg Low Dose Naltrexone (LDN) nightly, at bedtime
- Jul 17, 2008 to present - 3.0 mg Low Dose Naltrexone (LDN) nightly, at bedtime

LDN - DOSE & TYPE

- a) Dose - 3.0 mg as at 17 Jul 2008
- b) Time - I give my daughter her LDN at bedtime each night, around 9 pm.
(LDN should be taken right before going to sleep to enhance its effectiveness.)
- c) Type - Capsules are compounded with pure Naltrexone powder and Avicel filler (compounded by Skip's Pharmacy, Boca Raton, Florida, USA).

SUPPLEMENTS

- Jul 2005 to April 2006 - supplements as follows:
Hemp or Fish Oil (Essential Fatty acids (EFAs) - Omega 3,6,9)
Probiotics
liquid Vitamins/Minerals (includes Vitamin A, B, C, & E, Zinc and other antioxidants)
- Aug 2006 we added the following supplements:
B12
Alpha Lipoic Acid
L-Glutamine (precursor to Glutathione)
N-acetyl-cysteine (NAC) (precursor to Glutathione)
Selenium
- July 2008 - As at July 2008, apart from a short two-month break between Sept 21 and Nov 15, 2007, we've consistently supplemented with all of the above daily.

DIET

- to Jul 2008 - very restricted due to food allergies to dairy, corn, soy, nuts, egg, wheat, and other fruits and vegetables
- from Jul 2008 - Daughter's food allergies have improved dramatically. She can now eat most of the foods she used to be allergic to.

ACTIVITIES & EXERCISE

- n/a

MEDICAL TESTS & LAB RESULTS TIMELINE

- Oct 1, 2004
- ALT/AST 34/39
- HBV DNA, BLD, QL, PCR - 317,000,000/mL (Ref Range <100)*
- Virus DNA, SER, QN - 1,503,400,000 (Ref Range <160)*
- HBeAG - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBeAB (Antibody) - Non Reactive
- HBsAB - Negative

Sept 15, 2005

- ALT/AST 53/51
- HBV DNA (PCR) - not taken

(*Note: My daughter started Liquid Vitamins/Minerals, Essential Fatty Acids, and Probiotics in Summer 2005 to help food allergies and exzema. We added more Antioxidants and Traditional Chinese Medicine/Herbs to our daughter's supplements in Summer 2006. See above schedule of supplements. Adding these supplements may have boosted my daughter's immune system in order to move from the 'Immune Tolerant' stage to the 'Immune Clearance' Stage where her body started to fight the virus. This is normally evidenced by the increasing ALT/AST liver tests, which happened between 15th Sept 2005 and 11th May 2007.)

Dec 21, 2006

- ALT/AST 136/103*
- HBV DNA, BLD, QL, PCR - 26,500,000 (26.5 Million) (Ref Range <100)*
- Virus DNA, SER, QN - 104,700,000 (Ref Range <160)

Feb 7, 2007

- ALT/AST 124/89*
- HBV DNA, BLD, QL, PCR - 59,200,000 (59.2 Million) (Ref Range <100)*
- Virus DNA, SER, QN - 248,100,000 (Ref Range <160)

April 23, 2007

- Liver Biopsy (Prior to initiating LDN treatment)
- The Grade/Scale is based on 0-4 (0 being none and 4 being worst)
- Scarring: 2
 - Inflammation: 2

May 11, 2007

- ALT/AST 196/203*
- HBV DNA (PCR) - not taken

NB July 2007: Low Dose Naltrexone Treatment began mid-July 2007 at 1.0 mg per day.

Aug 10, 2007

- ALT/AST 26/38
- HBV DNA (PCR) - not taken

*Note: After introducing supplementation my daughter's ALT/AST levels started to increase in 2006 (which indicated she'd entered the 'Immune Clearance' stage, or in other words, my daughter's own immune system had begun to recognize the virus and her body had responded by trying to fight the virus). After adding the Low Dose Naltrexone to further help her immune system fight the virus, we saw a dramatic decrease in her liver enzymes and viral load. The doctor's couldn't believe how good the results were, and ordered more tests. Her liver enzymes had returned to the normal range and were the lowest ALT/AST results we'd seen since her diagnosis in 2001.

Aug 17, 2007

- ALT/AST 29/39
 - HBV DNA, BLD, QL, PCR - 53,300 (Ref Range <100)*
 - Virus DNA, SER, QN - 133,225 (Ref Range <160)*
- (*Note: over 99.9% decrease in viral load compared to Feb 2007.)

Sept 21, 2007

- ALT/AST 25/36
- HBV DNA, BLD, QL, PCR - 29,000 (Ref Range <100)*
- Virus DNA, SER, QN - 69,307 (Ref Range <160)*
- HBeAG - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBeAB (Antibody) -Non Reactive
- HBsAB - Negative

Nov 15, 2007

- ALT/AST 22/31
- HBV DNA, BLD, QL, PCR - 170,000 (Ref Range <100)*
- Virus DNA, SER, QN - 462,842 (Ref Range <160)*
- HBeAG - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBeAB (Antibody) -Non Reactive
- HBsAB - Negative

*Note: Between Sept 21, 2007 and Nov 15, 2007 lab results we stopped some of the Antioxidants we were previously using for food allergies and eczema (since those conditions had improved significantly). Because we felt this change may have accounted for the slight increase in Viral Load in Nov 2007 we resumed all supplements and increased the dosage of LDN to 1.5mg nightly.

Feb 8, 2008

- ALT/AST 20/29
- HBV DNA, BLD, QL, PCR - 000,000 Undetectable <100 (Ref Range <100)
- Virus DNA, SER, QN - 000,000 Undetectable <160 (Ref Range <160)
- HBeAG - Negative (Non-Reactive)*
- HBeAB (Antibody) - Positive (Reactive)

- HBsAG - Positive (Reactive)
- HBsAB - Negative

*Note: The above protocol of LDN, antioxidants, and various rotations of Traditional Chinese Medicines proved successful in my daughter's 8th Feb 2008 sero-conversion from HBeAG (e Antigen positive) to HBeAG (e Antigen negative). She also gained the HBeAB (e Antibody positive). These same treatment outcome results only happen in approximately 30% of children on Interferon treatments, so the above treatment may possibly compete with Interferon!

July 11, 2008

- ALT/AST 21/31
- HBV DNA, BLD, QL, PCR - 000,551 (Ref Range <100)*
- Virus DNA, SER, QN - 000,983 (Ref Range <160)*
- HBeAG - Negative (Non-Reactive) **Sero-conversion Maintained!!**
- HBeAB (Antibody) - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBsAB - Negative

*Note: Viral Load has very slightly increased from the undetectable range on 2/8/2008. to 551 on 7/11/2008. While my daughter has done extremely well on the dosage of 1.5 mg at night-time, we are going to increase to the dosage to 3.0 mg a night effective 17 Jul 2008. The 3.0 mg dosage is believed to be the optimal dosage for children. (Note the optimal dosage for adults is 4.5 mg/night).

**Note: We will continue with the above same protocol hoping to also obtain the HBsAG (surface Antigen sero-conversion to HBsAB). While it is very rare (approximately only 5% of Hepatitis B carriers sero-convert to HBsAB), I believe that it can happen. It may take a few years to get there, but I believe in miracles!

MY STORY - July 2008

I'd been waiting for years to become a mother. When I learned that within a few months I'd be flying on a plane to Asia and would finally be united with my new, wonderful 11 month old daughter, I lay awake at 3 o'clock in the morning excited about what the future held, and thinking about how to decorate my future daughter's bedroom. I wanted her to be surrounded with a special room in her new home-to-be, constantly reminded that she is loved and a precious gift from God. I remembered a picture I had just purchased with 3 Angels dancing and rejoicing with the inscription 'The Angels Danced the Day You were Born'.

That message became the inspiration for her bedroom. I wanted to write those powerful words into the wet paint on the walls of her room - symbolic of drawing those meaningful words into the fresh canvas of her heart and life. However, I had never tried cursive writing in wet paint before and did not know if it would succeed. But what did I have to lose, and it could actually work - so why not at least try it and see the results? Well, I tried it and it worked beautifully! My experience with hand painting my daughter's room is something similar to my experience with Low Dose Naltrexone (LDN), as I will share in our story of great 'Grace & Hope'.

After arriving home, my daughter Grace (not her 'real' name), underwent normal adoption blood work to check for HIV/AIDS, Hepatitis, parasites, etc. The doctor called back a few days later and asked me to sit down because she had some news to share on Grace's lab results. She had tested positive for Hepatitis B (Chronic Active). How could that be, I wondered? She had been tested for Hepatitis in the orphanage and had a clean health record. After the initial shock, I realized that she was truly a gift and we would face this disease with hope and prayers for a healing miracle.

While Grace's Hepatitis B had very little impact initially in our lives (besides routine lab results), Grace's food allergies and eczema continued to spiral downwards. From 2002 onwards, she'd developed a new food allergy every few months - and feeding her became very challenging. She became allergic to all dairy, corn, soy, nuts, egg, wheat, and other fruits and vegetables. Additionally, her eczema was so severe that her skin was constantly raw and red. In 2005, I became desperate.

The conventional treatments offered by her Pediatrician, Allergist, and Dermatologist had not delivered improvement, so I started to investigate and use Complimentary and Alternative Medicine (CAM) protocols to see if we could heal the underlying causes of the food allergies and eczema. Based on my research and additional consultations with a Functional Medicine practitioner, we concurred with adding Antioxidants, Probiotics, Essential Fatty Acids (EFA's), and liquid vitamins/minerals to her diet. (Note: Functional Medicine uses both Conventional & CAM approaches to holistically treat patients - (www.functionalmedicine.org).

These combined efforts finally started to improve my daughter's food allergies and eczema, but we also saw another benefit. Her immune system started to recognize and fight the Hepatitis B virus.

In children, due to their immature immune system, the body is often not able to mount a successful attack to totally eliminate the Hepatitis B virus. When the body's own immune system starts to fight the virus, very often the liver enzyme levels (the ALT and AST particularly) begin to rise. This is known as the 'Immune Clearance' Stage because the body's immune system is trying to 'clear' the virus.

If the liver enzymes are raised for an ongoing period of time, it can damage the liver with inflammation and scarring. It's a paradox that the good the body is doing while fighting the virus is also damaging the liver.

My daughter's liver enzymes and viral load started going up in 2006, and her liver biopsy result in Spring 2007 rated both her 'Inflammation' and 'Scarring' scores at 2 (mid-range in the scale 0-4). Her Gastroenterologist wanted to begin either Interferon treatments, or enrol her in a Pediatric Anti-Viral drug trial for a new drug, Entecavir, that was commencing within 6 months. Her doctor contacted Johns Hopkins (Baltimore, Maryland, USA) and together we determined my daughter would be a good candidate for the upcoming Entecavir Pediatric drug trial that was starting in the near future.

While waiting for the Entecavir drug trial to start I went back to the medical professional who had helped us so much over the past two years with Grace's food allergies and eczema (the Functional Medicine practitioner). She was excited about my daughter getting into the Entecavir drug trial, but when I asked her if she could think of anything that might help boost Grace's immune system prior to the trial, she mentioned 'Low Dose Naltrexone' (LDN). She'd recommended LDN for other medical conditions where the immune system needed further stimulation, with success, so she proposed LDN as a possible solution. She said I should research LDN at <http://www.ldninfo.org>, to see if it was something we wanted to try, and left the decision to me.

For approximately 2-3 weeks, I poured over the Ldninfo.org website, which had a wealth of information. LDN had been used by many patients with various conditions; Cancers, Autoimmune Diseases, and HIV/AIDS. All the info indicated it helped the immune system function properly (which is exactly what I was looking for to combat the Hepatitis B virus).

The website briefly mentioned that LDN had been successfully used in Hepatitis C patients. I also reviewed other medical research, including the National Institutes of Health (NIH) PubMed website, into the growing area of research into how opioids and opioid antagonists can positively or negatively affect the immune system (depending upon how they are used and dosage levels). I've included some of those NIH/PubMed studies at the bottom of this story as a reference, particularly those relating to the liver and Naltrexone.

One concern I had was the 'black box liver warning' for Naltrexone. I did further research into the liver warning and found the warning was based on very high doses of Naltrexone, at 300mg per day, where some liver anomalies had occurred in obese patients.

Dr Jaquelyn McCandless and other doctors had been safely administering minuscule doses of between 1mg and 3mg per day (a tiny fraction of the maximum safe dosage) to treat children with Autism. We rationalized that since LDN had been so helpful for other immune related illnesses, and the side affects were minimal (transitory sleep disturbance when starting LDN being the main side affect), and it was so inexpensive (less than a \$1 per day), that we'd like to try it. I grew eager to start LDN before the Entecavir study (to see if maybe the two together would help her).

What did we have to lose in comparison to what we might gain? But, before we started LDN, I wanted to ensure being on LDN would not preclude Grace from getting into the Entecavir Study at Johns Hopkins (because back then, we had no idea how good LDN would actually prove to be).

I spoke with our Pediatric Gastroenterologist in June 2007 to check he was okay with us trying LDN (especially as he was not the prescribing LDN doctor) and to make sure he was aware of our attempt to prime my daughter's immune system with LDN before the trial. While he didn't know if LDN would do any good, he didn't think it could do any harm, since he had other liver patients on a higher dose of Naltrexone for pruritus (severe itching caused by other liver conditions). To maintain eligibility for the trial, we agreed we'd stop the LDN once the Entecavir study actually began. I also consulted my daughter's Pediatrician to ensure she was also aware of our plans. Both doctors concurred with us trying LDN.

In July 2007 we started my daughter on a very minimal dose of 1mg Low Dose Naltrexone (LDN). Within one month of starting LDN, in August 2007, we had liver laboratory tests completed to see if LDN was having a positive result, and it was. The doctors couldn't believe how good the results were, and ordered more tests to confirm.

We were all amazed at the dramatic improvement in her liver since starting LDN in July 2007. We saw a remarkable decrease in liver enzymes, from ALT 196/AST 203 in May 2007 to the normal range of ALT 26/AST 38 in August 2007. Her liver enzymes were the lowest ALT/AST results we'd seen since her diagnosis in 2001.

Additionally, we saw a significant viral load reduction from 59.2 million in February 2007, to 53.3 thousand in August 2007. At that point we no longer even qualified for the Entecavir study - yippee! The Advanced Practice Pediatric Nurse who prescribed the LDN was ecstatic with the results.

Incidentally, I called my daughter's Pediatric Gastroenterologist when we got her lab results in mid-August 07. I said to the doctor, "Isn't this good news"... He responded..."No ... this is GREAT news!" We discussed that LDN appears to be resulting in similar responses as can be achieved with other anti-viral drugs.

The doctor said he had one teenager on Entecavir and this patient also saw dramatic results within the first month (similar to my daughter's impressive viral load decrease). However, the advantage of LDN was that since it wasn't an anti-viral Hepatitis B drug, but instead helped her own immune system to fight the virus, we didn't have to worry about the anti-viral resistance that can be a problem with other anti-viral drugs.

Also, if at any point the LDN stopped working in the future, we always had the option of starting anti-viral drugs (without the worry of her already building up Anti-viral drug resistance). The Gastro doctor was not the prescribing doctor of the LDN, but he said to keep on doing what we were doing because it appeared to be working!

Between the Sept 21, 2007 and Nov 15, 2007 lab results we'd stopped giving Grace some of the antioxidants we were previously using for food allergies and eczema (since those conditions had improved significantly). Because we felt this change may have accounted for the slight increase in Viral Load in Nov 2007, we resumed all supplements, and increased the LDN dose to 1.5 mg nightly.

In February 2008, 7 months into our LDN/Antioxidant protocol, Grace had Sero-converted, going from HBeAG (e Antigen positive) to HBeAG (e Antigen negative), and she'd gained the HBeAB (e Antibody positive). This was an outstanding result! These same treatment outcome results only happen in approximately 30% of children on Interferon treatments, so the above treatment may possibly compete with Interferon!

It is now July 2008. Grace's liver enzymes are still in the great range. She has maintained her HBeAG (e Antigen) seroconversion to HBeAB (e Antibody). Her Viral Load has very slightly increased from the undetectable range on 8 Feb 2008 to 551 (but this is still very, very low compared to the 59.2 Million in Feb 2007).

Over the past year (since beginning LDN in 2007), we've achieved excellent results below the max 3mg dosage level (at 1mg and then 1.5 mg nightly). While my daughter has done extremely well, we're going to increase the dose to 3mg a night, effective 17 July 2008, as she's grown considerably over the past year. The 3.0 mg dosage is believed to be the optimal dosage for children. (Note: For adults the optimal dosage target is 4.5 mg nightly to obtain the maximum benefit to the immune system.)

Besides our blessing of healing for Grace's Hepatitis, we have also seen fantastic results in her eczema and food allergies due to the multi-pronged approach of LDN with the Antioxidants, Probiotics, and Herbs we commenced in 2005. Grace has no more eczema - her skin is now like silk for the first time in her life. Additionally, her digestive tract has been healed, thus eliminating the extreme responses she had to various foods. She is now able to eat every food (in moderation) with no more allergic reaction. That is a real miracle, and as her body is better equipped to absorb nutrition from what she eats, this bonus has contributed to her improved health.

It appears that my daughter's body may have entered into the 'Immune Clearance' stage with the Antioxidants, Probiotics, Herbs, etc. we began in 2005. When LDN was added in 2007, it helped further stimulate her immune system to dramatically fight the virus. In clinical studies, Naltrexone demonstrated an increase in the body's Natural Kill Cells (which fight viruses). Therefore, I believe that LDN might also help jump start the immune system and take a child from the 'Immune Tolerant' stage to the 'Immune Clearance' stage in a safe and effective way!

The LDN website (ldninfo.org) is full of information that you can print out and give to your doctor. Also, the website has a link to the main LDN Yahoo Group where you can learn about other people's success with LDN,

and find out about other 'splinter LDN groups' like mine that focus on specific diseases that LDN has benefited.

Clinical trials of LDN for other diseases (Multiple Sclerosis, Crohn's, HIV/AIDS, Fibromyalgia, etc.) have been completed (or are currently being completed) that indicate the immune modulating effects of LDN. At this point, controlled clinical trials need be undertaken by the medical community in order to prove the efficacy, safety, and dosage recommendations for children and adults. Only when clinical trials are undertaken, will we be able to 'prove' scientifically that LDN really helps to boost the immune system in fighting the Hepatitis virus. However, we need to ask the National Institutes of Health (NIH), FDA, and others in the Medical Community to fund clinical trials for LDN and Hepatitis.

This is one of the end goals of the Yahoo Group that I recently established, 'Hepatitis Children and CAM Alternatives'. Our focus will be on informing other group members, but also documenting our treatment stories in enough detail that we can give it to medical researchers. Our group welcomes both adults and parents of children with any form of Hepatitis (B, C, Autoimmune, etc.) to join us in our journey of healing.

Additionally, we have sent our Case Study to National Institutes of Health, Johns Hopkins, and Pennsylvania State University/Hershey Medical Center in order to further spur interest in LDN and Hepatitis research.

We are truly grateful, appreciative, and awestruck by this miracle and have been blessed by God's mercy in this welcome healing! I personally believe LDN may be a safe, viable alternative to the current limited drugs that are available for children (as well as adults) with Hepatitis and other immune related diseases.

Every day my daughter is reminded when she enters her room (with the hand painted walls) that she is a precious gift and 'The Angels Danced the Day You Were Born'. I'm glad that I was willing to try something different - her room turned out beautifully. Maybe you could say I 'saw the handwriting on the wall', and chose to try something different (LDN) to help her immune system. LDN's results have also turned out beautifully!

Three Cheers for Answered Prayers & LDN! ~~ Joyce

Joyce, USA, Yahoo LDN Group: Hepatitis_Children_and_CAM_Alternatives

(http://health.groups.yahoo.com/group/Hepatitis_Children_and_CAM_Alternatives/)

References:

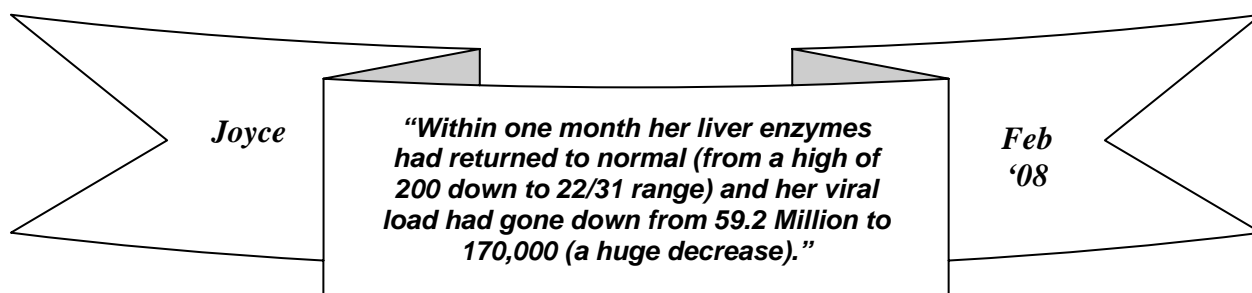
NIH/PUBMed Studies - Naltrexone Benefits the Liver:

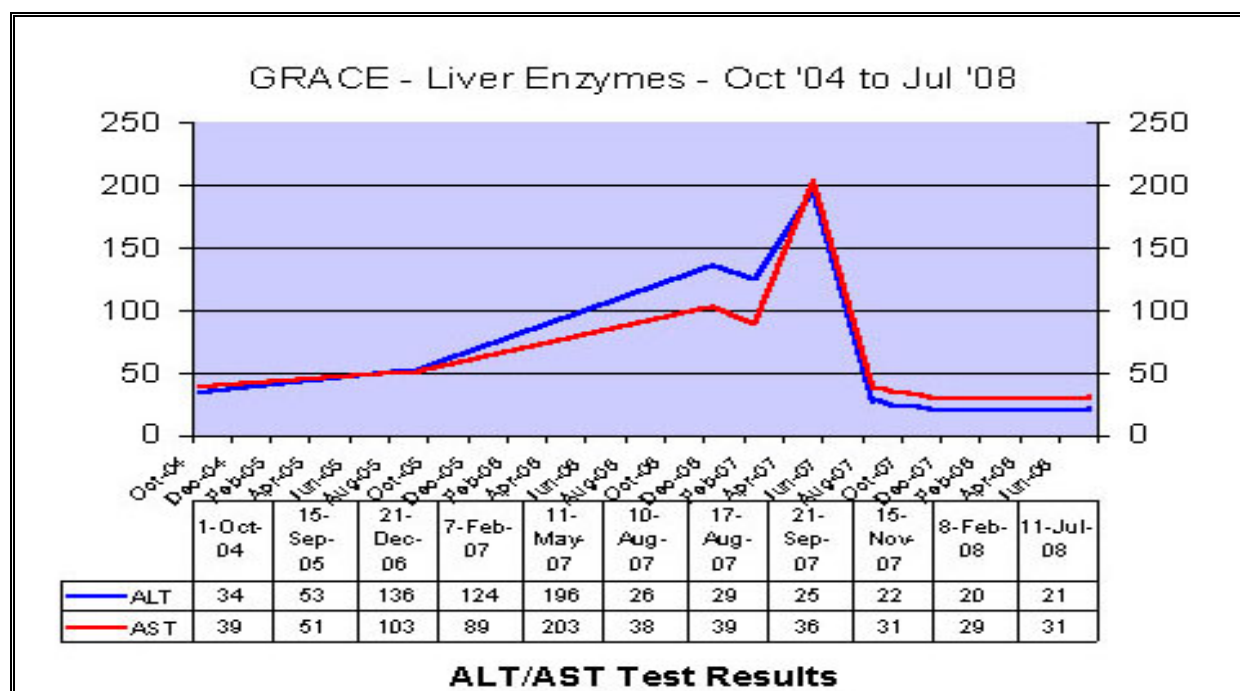
The National Institutes of Health, National Library of Medicine, Pub Med Website include many clinical studies and articles about how opioids and the opioid antagonist (Naltrexone) help both liver conditions and the immune system. The following are nine Clinical Studies (with the corresponding PubMed ID number) which demonstrate the safety and very beneficial effects of Naltrexone to the liver for dosages below 300mg a day. While the below are not specific to Low Dose Naltrexone (which is taken in much smaller doses of up to 4.5 mg a day), the below studies demonstrate the beneficial affect that Naltrexone has on liver disease:

National Institutes of Health, National Library of Medicine, Pub Med Website

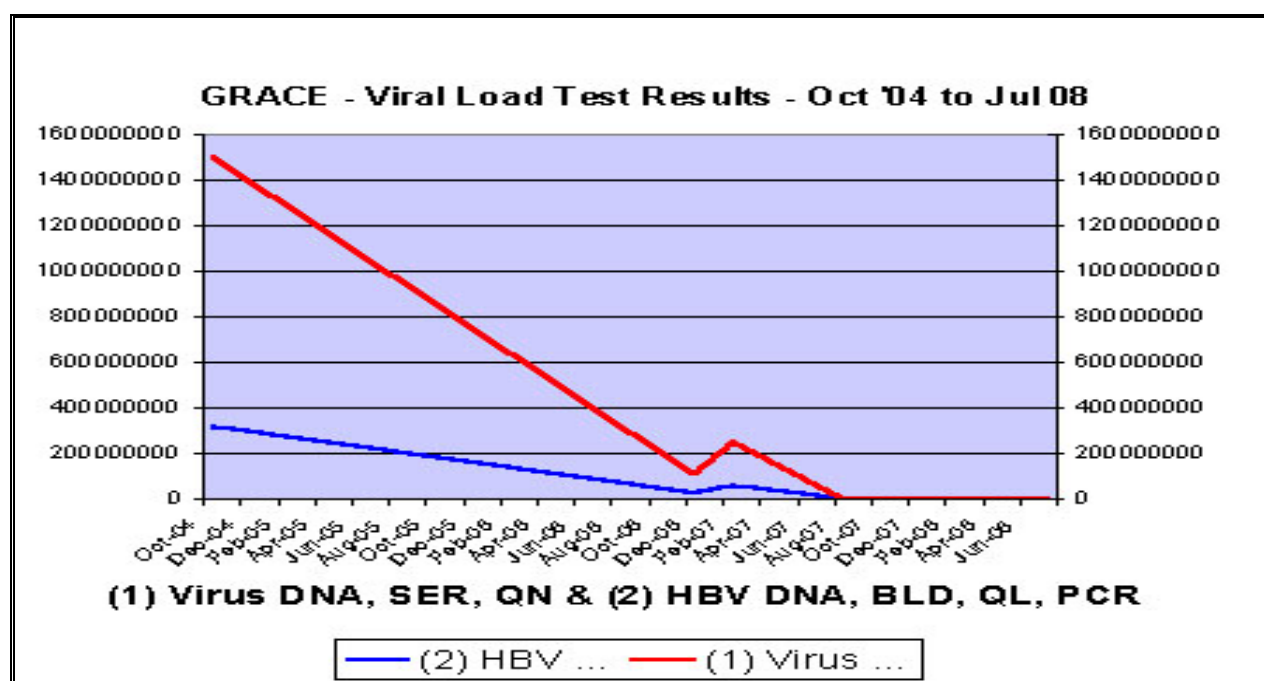
<http://www.ncbi.nlm.nih.gov/sites/entrez?db=3Dpubmed>

1. Reducing Liver Enzymes Levels, including Hepatitis (PMID: 16839858 & PMID: 9411543)
2. Reducing Liver Damage in Hepatitis (PMID: 15389866)
3. Reducing Liver Injury in Cholestasis (PMID: 17295775)
4. Reducing Liver Enzymes in Cholestasis (PMID: 12570015)
5. Reducing Liver Fibrosis (PMID: 16543289)
6. Anti-inflammatory effects & improving hepatic dysfunction (PMID: 15917999)
7. Benefits in Cholestatic Pruritus (PMID: 9322521 & PMID: 15517116)





LDN benefiting daughter's HepB-Joyce C



24) Antioxidants & LDN stabilized my PLS - GaryC

LDN since February 2004

- story submitted July 2008 (over 4yrs on LDN)

SPECIFICS

DIAGNOSIS

- 1993 - Primary Lateral Sclerosis (PLS) based on MRI and clinical symptoms

TESTS

- 1993 - MRI
- 1995 - MRI

MEDICATION/TREATMENT (OTHER)

- prior to 2005 - small doses of Valium, then antidepressant Prothieden

MEDICATION (LDN)

- Feb 2004 to Feb 2004 - 3 mg Low Dose Naltrexone (LDN)
- Mar 2004 to present - 4.5mg Low Dose Naltrexone (LDN)

LDN - DOSE & TYPE

a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone anytime between 9pm and 4am, usually around 3am each night.
c) Type - 4.5mg capsules are compounded by Greens Pharmacy, Adelaide with pure Naltrexone powder and acidophilus filler.

DIET

- 1994 to 1994 - I tried gluten free diet - very restrictive and didn't seem to help.
- 1995 to present - Since then I've tried to eat healthier and a good portion of my diet is organic, however, I do have periods where I tend to eat mainly crap and I know when I do because I get pimples on my face.

SUPPLEMENTS:

- 1998 - These are the antioxidants I began taking daily:
NAC (n-acetyl-cysteine) 1 x 500mg
alpha lipoic acid 1 x 100mg
CoQ10 1 x 30mg
Vit E (mixed tocopherol - apparently better than just d-alpha formula) 1 x 1000 IU
Vit C & E with grape seed extract x 1 (manufacturer discontinued making them)
multi-Vit B tablet (supermarket brands)
Fish oil/EPA 2 x 1000mg
Selenium x 200mcg every second day - bought directly from my doctor - when they've all been used, I'm often without for a couple of months between appointments
- 2005 to present - I added the following to my supplement regimen daily:
Benfotiamine 1 x 150mg
synthetic thiamine (Vit B1) - meant to be good for energy, reduce fatigue
DLPA (DL-phenylalanine) 1 x 500mg - was taken to enhance LDN endorphin effect (but it cannot be taken by people with high blood pressure so I only take this occasionally and will soon check my blood pressure)
St Mary's thistle x 4 tablets - as a liver cleanser as some things I read implicated the liver in PLS/ALS - figured it can't hurt to take it and the more I read the more I think it is valuable. (Liv Pro brand discontinued.)
- Jul 2008 - ceased taking DLPA due to elevated blood pressure

ACTIVITIES, EXERCISE, INTERESTS

- Exercise - none apart from normal walking around (100m at a time would be my absolute limit). Spend half my life on the computer on emails and a car site for people with similar cars to me (I'm an avid petrol head!!).

MY STORY - July 2008 - 4+ years on LDN

I was diagnosed with Primary Lateral Sclerosis (PLS) when I was in my late thirties, after, in retrospect, about a year of symptoms. By then I was feeling very stiff but attributed that to a change of career to computer programmer about 5 years earlier and spending most of my time sitting.

A few months before diagnosis and thinking my symptoms were all due to lack of exercise I tried to start jogging, but the first time I tried I only took a half dozen strides before my legs got confused about what to do. Eventually I built up to the stage where I could manage about 3km down quite a steep hill, along a flat, pot-holed section and back up to home again. (At that stage we were on a 10-acre property out in hilly country.)

However, in other respects I was getting worse so went to see my doctor who decided there was a problem (possible MS or brain tumour) so sent me to see a neurologist who was also an oncologist! My diagnosis was done on the basis of clinical examinations and an MRI. Interestingly PLS and ALS typically don't show on MRIs (except possibly the very newest ones -- MRS I believe). My MRI showed some abnormal signalling in the corticospinal tracts leading me to be diagnosed with PLS. In retrospect it was a very brave call given some people take many years to be diagnosed, although mine did progress pretty rapidly.

There is nothing I have read in over 10 years of communication with other PLSers that has ever caused me to question the diagnosis. I had a follow up MRI in 1995, which was similar, possibly a little more abnormal signalling, but nothing since. I get very claustrophobic and no way they're getting me in one again unless it will lead to a cure!!

For the first 5 years after diagnosis I progressed relatively quickly for PLS, to the point of needing a walker to get around and having very poor speech. I did take various antioxidants (mainly vitamins C and E) at times during those 5 years, but never rigorously or consistently.

I then found a great website as the source of much of my info on antioxidants (<http://home.goulburn.net.au/~shack/>) and based on what I read there I decided to start taking a wide range of antioxidants consistently and rigorously. Steve Shackel, the guy whose site it is has Amyotrophic Lateral Sclerosis (ALS). He had actually improved after starting on all his antioxidants (before I did). The info on his site is oriented towards ALS, but also applies to things like MS and PLS. I worked up my list of antioxidants based primarily on what I found there. There is an almost overwhelming volume of info there now - 10 years ago there was far less.

Within 6 months of starting rigorously on a wide range of various antioxidants my progression stopped and for the subsequent 10 years now has been virtually non-existent, except for my speech which very, very slowly continued to decline, though I feel that is more due to lack of use (because only my family could understand it even 10 years ago anyway). It can be extremely frustrating trying to make myself understood so I probably now only try to say maybe a dozen things per day, hence my speech muscles get little exercise and no practice.

I just wish I had found all the info on antioxidants earlier!! If I could stand beside myself 10 years ago then I would no doubt notice some decline but it has been so slow as to be virtually non-existent from my perspective.

Over 4 years ago I started on LDN after someone on PLS-FRIENDS said how much it was helping her. Within a week or two I was walking a little better (not miraculously better, but noticeably - feet were picking up better) and after about 9 months my urinary urgency (a scourge of PLS for many) dramatically improved. Again, I'd say that in the last four years I have held my slightly improved ground but it's hard to know for sure.

If there has been any deterioration I haven't noticed it. I still drive and until mid 2006 was still working full time. The only reason I am not working now is that my company lost the contract for the work we were doing and most of my group were made redundant.

I attribute the relative stability of my PLS to the antioxidants I started taking about 6 months before my progression basically stopped and the LDN is now the icing on the cake! Based on my own minor improvements with LDN, plus the results I've seen for some others with Motor Neurone Disease (MND), ALS and PLS, I believe 100% in the ability of LDN to help the body and there is no way I'd stop taking it. It's just that four years down the track I don't know how much of my lack of progression is due to the antioxidants, the LDN, or the combination.

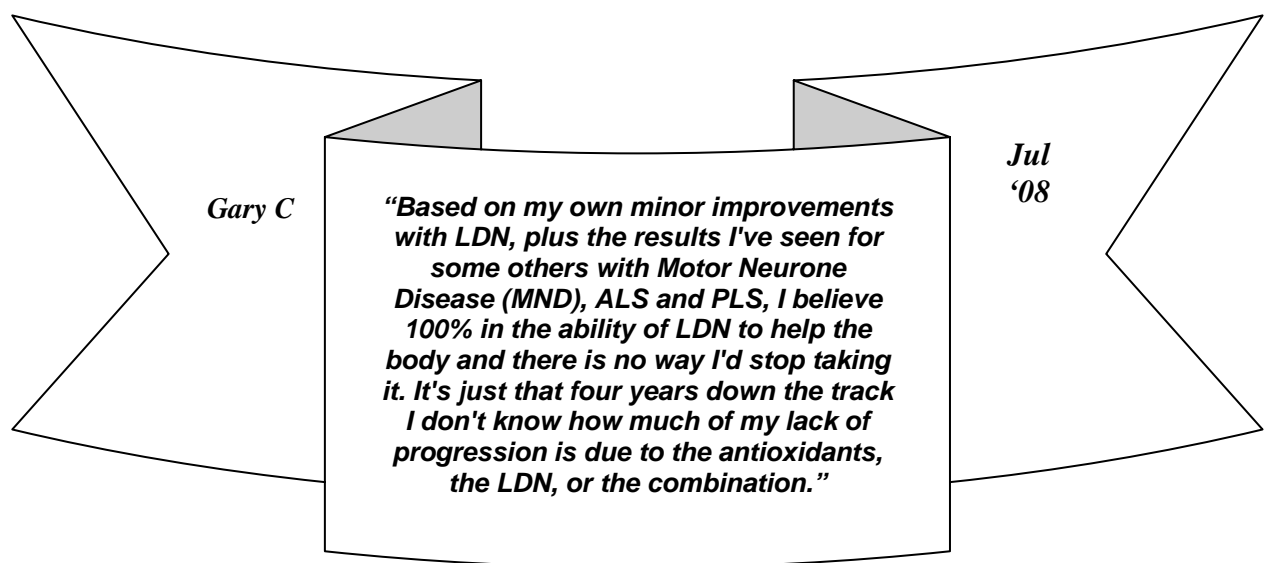
In consideration of the six years before LDN, I have to say that most of it is possibly due to the antioxidants and that the LDN is an extra weapon in my arsenal now. From what I've seen, it's possible I could have achieved a similar result with LDN alone but I'll never know for sure because while I'm stable, I'm not prepared to risk what I've gained to test the theory.

Ten years after beginning on antioxidants and later LDN, I still can't take a step without my walking frame and maybe the distance I could manage is somewhat reduced, but basically I still feel my walking ability is much the same, whereas I feel sure if I hadn't started on the antioxidants I would have been permanently in a wheelchair many years ago. In consideration of the speed at which my PLS was initially progressing, I'd say I was very lucky to find Steve's website, then later LDN, and I wouldn't change either.

One thing I consider very important to point out. I got the impression from things I read long ago now that it was far better to take a wide variety of daily quantities of antioxidants rather than mega doses of just one or two and my results compared to a few people I've known who went the mega dose route would seem to bear that out.

My understanding is that using a wide variety is better; (a) because some work synergistically together so that the effect is greater than the sum of the individual parts, and; (b) and because using a variety allows you to take advantage of the different individual actions of each rather than relying on just one or two ways of working (not putting all your eggs in one or two baskets).

Gary C, Australia



25) LDN is working-Metastatic IVB Cancer - Dee

LDN since 12 February 2007

- story submitted 4 March 2007
- story updated 13 March 2007
- story updated 12 April 2007
- story updated 22 April 2007
- story updated 12 May 2007
- story updated 7 June 2007
- story updated 16 June 2007
- story updated 15 July 2007
- story updated 2 August 2007
- **story updated July 2008 (17 months on LDN)**

SPECIFICS

PRE-LDN TIMELINE – DIAGNOSIS, MEDICATION, TREATMENT, TESTS, SIDE-EFFECTS, OUTCOME

- 26 Oct 2005

Cervical biopsy - Initial results Moderately differentiated (grade 2) invasive squamous cell carcinoma of cervix. I was diagnosed with Cervical Cancer (Adenosquamous Carcinomas), the rarest form, which has features of both squamous cell carcinomas and adenocarcinomas.

- 4 Nov 2005

Surgery - Wertheims total hysterectomy and right salpingo-oophorectomy (removal of right fallopian tube and ovary).

- 7 Nov 2005

Pathology Report - Poorly differentiated Adenosquamous Cell Carcinoma, at least 4 cm in maximum extent with prominent lymphatic permeation, 3 positive Lymph nodes - Comment pT2N1Mx (*TNM System Cancer Assessment).

- 8 Nov 2005

PET SCAN - Status CA cervix with hysterectomy done. No abnormal FDG uptake at the pelvic surgical site or at the vaginal vault to suggest residual tumor. No evidence of distant metastasis to the brain, lungs, liver, adrenal glands, and bone is found.

- 1 Dec 2005

Began concomitant External Beam Radiotherapy (RT) with Cisplatin chemotherapy treatment. This involved 29 RT treatments over a period of 5 weeks, 5 cycles of Cisplatin (one each week for 5 weeks). Blood counts as well as renal and hepatic function tests were performed during treatment. The file located online here details the treatment I received from my Oncologist. I completed the treatment on 9 January 2006. During treatment I experienced the following side effects: fatigue, severe cystitis, severe pain on bowel movements.

(1) Treatment:

<http://www.ldn4cancer.com/files/da-RTChemo-treatment-2006.pdf>

- 14 Sept 2006

A follow-up PET Scan approx 8 months later detected a mildly hypermetabolic nodule in latter part of anterior segment of left upper lobe (LUL), worrisome of a pulmonary metastasis but could be granulomatous nodule, in right lung also 3 eumetabolic subpleural nodules which can be in range of inactive granulomatous nodules but difficult to exclude early small metastases.

- 29 Jan 2007

Follow-up PET scan (2) identified nodules in my lungs suspected as metastatic cervical cancer, and confirmed as metastases with at least 13 nodules, the largest nodule (3) being 1.3 cm. Reclassified cancer to Metastatic Stage IVB (based on TNM System Cancer Assessment).

(2) Pet Scan: <http://www.ldn4cancer.com/files/da-070129-PET-scan.pdf>

- 3 Feb 2007

CT Scan further confirms metastases of at least 13 nodules, largest one being 1.3cm with a calculated 'doubling time' of 33 days. My oncologist said the 'gold standard' of treatment for my cancer type, Taxol/Carboplatin, would not be responsive. He offered palliative chemotherapy and gave me 4-9 months survival, which I refused. Advised to get affairs in order.

(3) CT Scan: <http://www.ldn4cancer.com/files/da-070203-CT-scan-thorax.pdf>

(4) Doubling Time: <http://www.chestx-ray.com/SPN/DoublingTime.html>

POST-LDN TIMELINE – MEDICATION, TREATMENT, TESTS, SIDE-EFFECTS, OUTCOME

- 12 Feb 2007

I started taking 4.5mg Naltrexone (LDN) nightly, between 10pm and 11pm. The capsules are compounded with avicel filler. I took no other medications. After starting on LDN I experienced the following side effects: In the first month I had some difficulty with sleeping. I also experienced intermittent but high levels of anxiety which would last all day.

- 13 Jun 2007

My follow-up CT scan showed a slowing of the largest nodule growth, now 2 cm in size and no further metastases, extending the growth rate to 70 days. After only 4 months, the LDN had prevented further metastases and slowed the 'doubling time' (growth) of the existing nodules.

(5) CT scan:

<http://www.ldn4cancer.com/files/da-070611-CT-scan-thorax--lowdose.pdf>

- 1 Aug 2007

CT Scan revealed no significant growth for any of the metastatic nodules, the largest nodule now 2.0cm x 2.1cm. LDN appears to have halted the growth of the largest nodule and continued to stop further metastases. Calculated growth rate since previous scan has extended to 232 days.

(6) CT scan: <http://www.ldn4cancer.com/files/da-070801-CT-scan-thorax.jpg>

- 15 May 2008

CT SCAN shows the nodules still growing slowly which gives me time to try other treatments which will target the largest nodule directly.

(7) CT scan:

<http://www.ldn4cancer.com/files/da-080515-CT-scan-thorax-lowdose.pdf>

- 13 Jun 2008

I underwent Radio Frequency Ablation (RFA) to destroy the largest nodule in my left lobe. I've now reset the 'clock' on the largest tumor growth, expecting that the LDN will continue to hold down the growth of the other existing nodules, and extending my high quality of life. Apart from early on, LDN has had no side effects for me, and anyone seeing me would never believe I have cancer since I feel and appear healthy.

(8) RFA: <http://www.cancernews.com/data/Article/612.asp>

(9) RFA report:

http://www.ldn4cancer.com/images/RFA_report_LT_lungtumor_080613.pdf

- 21 Jul 2008

Low dose CT thorax scan, post RFA (Radio Frequency Ablation)

Result: Successful treatment with RFA to one of the larger tumors in Left upper lobe. Multiple metastatic nodules are shown but some are showing calcifications.

LDN DOSE & TYPE

a) Dose - 4.5mg

b) Time - I take my Naltrexone between 10pm and 11pm each night

c) Type - my naltrexone capsules are compounded from pure naltrexone powder and Avicel filler by Skips Pharmacy.

DIET

- I have a normal diet - fresh vegetables and fruits - Japanese.

SUPPLEMENTS

- none

EXERCISE, INTERESTS

- I work, travel, and use a gym. I'm an advocate for LDN and administer my own website at ldn4cancer.com.

MY STORY – 4 March 2007

In December 2005 I had External Beam Radiotherapy (RT) and Chemotherapy with Cisplatin, completing that regimen on January 9, 2006. The PET Scan after that treatment was clear.

Just over twelve months later, on 29 January 2007, I had a follow-up CT scan and my Oncologist confirmed metastatic cancer with 13 nodes in the lungs, Stage 4B. There is virtually no hope of long-term survival using a conventional regimen involving Carboplatin/Taxol chemotherapy. My Oncologist had nothing else to offer and his prognosis was dire.

On 7 February 2007 I was notifying my friends of my hopeless situation when a close friend living in Florida, suggested I contact a Dr Bernard Bihari who'd developed a treatment using a drug called naltrexone.

I phoned Dr. Bernard Bihari in New York and had a phone consultation. He agreed that Low Dose Naltrexone would be helpful because he had discovered benefits of LDN for MS and cancer patients, and had experienced some success in applying LDN to ovarian cancer patients.

It gave me hope that my rare form of cervical cancer (adenosquamous), which had metastasised to my lungs, might also be responsive. I was lucky to be in a position to start this controversial treatment straight away

because I wasn't experiencing any serious effects from the lung nodules, and was therefore not taking any strong medications for pain or inflammation. I also wasn't taking any immunosuppressants.

Dr Bihari faxed a prescription for a 90-day supply of 4.5mg LDN capsules to Skip's Pharmacy in Boca Raton that same day, and my friend in Florida picked up the LDN and had it couriered to me. I started taking the LDN on 12 Feb 2007, taking one 4.5 mg LDN capsule between 10pm and 11 pm each night.

As at 4 March 2007, I've been on the regimen 21 days and will wait for at least another month before having another CT scan to see if the regimen has had any effect on my lung nodules.

UPDATE 13 March 2007

Today is the 28th day since I started taking LDN. I'm still feeling good and going regularly to the gym and doing vigorous workouts on a cross-trainer.

I had some trouble sleeping, but no trouble sleeping now and my appetite is good. I'm keeping my original lifestyle, which involved regular dinners out and drinking wines (red & white) and champagne. My LDN prescribing Doctor, Dr Bernard Bihari, said no need to curtail normal life activity.

My Oncologist had expected my medical situation to have taken a turn for the worse by now, and that I'd be beginning chemotherapy as a last effort to slow down the growth of the metastatic cancer.

Chemotherapy has no track record of success in treating cervical cancer metastatic to the lungs, so going that route is an admission of defeat. I've chosen to use LDN exclusively for the moment, because chemotherapy will not work and will destroy my existing immune system while doing nothing against the existing cancer.

I'll be posting again in 2 weeks, when I'll have been on LDN for 6 weeks, and getting closer to the time when I will begin to find out whether LDN is working because if it isn't, symptoms of the metastasis will become noticeable.

UPDATE: April 12th, 2007 - Month 2 Status

This is now the second month that I've been on LDN. By this time, my oncologist was certain that I would be experiencing serious effects from the rapidly growing cervical cancer metastasis to my lungs. PET scans taken prior to beginning LDN showed a doubling in size of the lung nodules about every 4 weeks. I'm delaying a follow-up scan until I've been on LDN for at least 3 months, since reality is that if LDN isn't working, there are no alternatives anyway. The 2nd line protocol would be Taxol/Carboplatin, which has zero record of success for my cancer cell type.

My previous LDN prescribing doctor, Dr. Bernard Bihari (discoverer of the benefits of low doses of naltrexone), has retired from his medical practice and I've now moved to one of his referrals, Dr Martin Ehrlich in New York. I had a telephone consultation with him on March 30th when he accepted me as his patient. I've now gotten the first prescription from him for my next 6-month supply.

UPDATE: April 22nd, 2007 - Spreading the word

I spent the Easter holiday in Hawaii with my father and his wife. He's 82 and his wife, Mary, is 75. She's had Rheumatoid Arthritis for many years now, and rarely gets through the night without pain and stiffness.

On April 4th, I suggested she try LDN for her RA and gave her a 4.5mg tablet from my prescription. She continued taking it nightly for the next 7 nights. The 2nd day after starting LDN, she did not experience the usual arthritic pain she was accustomed to, and some other minor ailments she had also disappeared.

She returned to her home in Arizona on April 11th with an 8-day supply from my prescription, and went to her GP for her own prescription on the 17th. He was reluctant to give one, but she persisted and he wrote the prescription on the 18th. An order was placed with Skips Pharmacy in Boca Raton, Florida. It was shipped out and arrived in Arizona on the 21st.

Before her own prescription arrived, the 8-day supply I gave her on the 11th ran out and for 2 days she was without LDN. By the 2nd day, the pain and stiffness from her arthritis had returned, so she was glad to get

back on LDN on the 21st. The return of the arthritis after only a short time off LDN was proof positive to her that LDN works.

Now she's convinced of the benefits of LDN for arthritis. She's living in a retirement community with a large population of seniors and she's become an advocate for LDN and is now 'Spreading the Word'.

UPDATE: May 12th, 2007 - Month 3 Status

It's now the 3rd month since I've been on LDN exclusively for my metastatic lung cancer. I have experienced no changes to my overall well-being and have not been curtailing any of my usual life activities (fine dining, fine wines, travel). I will wait one more month before scheduling a CT scan to measure the changes in the lung nodules that were identified in my last CT scan on February 6th.

UPDATE: June 7th, 2007 - Scheduling next scan

I've been trying to contact my Oncologist for an updated scan and he finally replied questioning "Which region do you want scanned?" I have metastasis to my lungs duh??? I requested in my email a CT scan but he thinks since I have had no treatment in 4 months the cancer must be all over the place.

Now I am not "counting my chickens" here but just goes to show that Oncologists don't care about alternative medicine even though I have sent him all the LDN literature and published paper by "his peers". They only want to give chemo knowing it won't do any good. I will see today if he responds back with my request for a "thorax CT scan" and get on with it. Will be posting the results shortly thereafter, but in the meantime, I am feeling good.

UPDATE: June 16th, 2007 - Month 4 Update

Received the results of my CT scan taken June 13, 2007 and the results, though still ambiguous, gave me hope. The largest nodule had increased from 13mm to 20mm (compared to the previous scan taken on Feb 3, 2007, around 4mths ago).

The largest nodule was still growing, however; the growth rate appeared to have slowed. The 'doubling rate' evidenced in previous scans was 33 days, but the growth rate (no longer doubling) of the largest nodule has slowed to 65 days. (The 'doubling rate' was based on the growth of a nodule between two scan dates.)

Looking for more silver lining, there were NO NEW metastases found. When compared to previous scans, my last PET Scan (Jan 29, 2007) showed the largest nodule was doubling in size every 33 days. Based on that projection the largest nodule should have grown to 30mm in size (and I assume would have, had I not taken this course of intervention). Instead, it measured 20mm. I started taking LDN on Feb 12th, 9 days after my last CT scan.

Dr. Bihari's clinical studies show that LDN needs around 6 months to begin seriously impacting the growth of many cancers so I think the fact that the largest nodule was only 20 mm instead of the expected 30 mm over the 4 months, represents around 50% reduction in the expected growth rate (from 33 days to 65 days).

So if LDN started slowing the growth, then it would be a gradual effect as we're dealing with human tissue and immune systems not poisons, so it won't happen overnight. Taking this reality into account and assuming that any reduction will be gradual, I have created a model to track the projected and actual growth rate based on pre and post-LDN scans. Based on this model and focussing on the beginning and end points of nodule growth, the largest nodule appears to have either slowed or stopped.

Before I go on summer holiday, I'm curious to know if my assumption of slowed growth is real. I'll be having a follow-up scan in Aug 2007, a couple of months away. If the nodule growth increases only marginally, say by only 1 mm, this will mean the rate of growth has slowed down to greater than 240 days (based on my model). I'm not expecting a reduction in the tumor size, but if that occurs, all the better.

UPDATE: July 15th, 2007 - Alkaline, pH, and cancer

My new GP asked me at my last visit (my oncologist dropped me) if I was alkaline? Well I knew a bit about this topic but not nearly enough. So I have been researching diet, pH and cancer relationship. Many alternative

cancer treatments (DMSO, coral calcium, etc.) are essentially based on raising the alkalinity of the body because cancer cells cannot survive long in an alkaline environment.

I thought there must be some safe and easy methods to do this without the expense and complications of those alternative treatments. First I bought pH test strips at the local pharmacy to check my urine pH balance. Cost about US\$10 dollars for 5.5 meters (18 feet) of tape which will last a long time. I tested myself and was happy with the results – 'in the green' - so pH was over 7 and approaching 8.

From my other readings I thought of baking soda as a way to raise the body's alkalinity safely and found on the internet that many are drinking a small amount of baking soda dissolved in a glass of water twice a day. They claim it works wonders. One doctor in Italy, Dr Tullio Simoncini (specialist in oncology) has even used a cancer treatment regimen based on administering bicarbonate salts orally, through aerosol, and intravenously. There is one case he describes where he treated a man for lung cancer using bicarbonate salts.

He says the man survived for over 20 years. Since keeping the body's pH balance is fundamental to overall health, making it more alkaline is not that unusual and if it does prevent many of the things that ails the body, that would seem to be a complementary approach to the LDN that I'm taking now.

LDN boosts the immune system, while making a more alkaline body makes an inhospitable environment for the cancer cells to survive for long. Makes sense to me and I'll add this to my lifestyle.

UPDATE: August 2nd, 2007 - Its Official - LDN is working

Had a CT scan on August 1st and received the results today. Wonderful news as the results showed stability with no significant increase in tumor sizes or any new metastases. LDN has apparently almost stopped the largest tumor growth plus all the smaller ones that were noted in the previous scan on June 11th.

My last scan was June 13. At that time the growth rate had slowed to 140 days. My scan on August 1 was 51 days later.

Recalculating the growth rate of the largest tumor since previous scan has now resulted in a growth rate of 242 days versus 140 days from the previous scan on June 11th, and the scary 33 day 'doubling rate' before I started LDN on February 12th.

Since Dr. Bihari found in his studies that 6 months is the point where LDN has been known to show positive benefits, I'm glad that I fit the typical profile. It means that there's hope the next scan in November will continue following Dr. Bihari's experience - which is that the nodules begin to decrease in size after around 6 months.

Now that would be a great Thanksgiving that I'll be looking forward to.

UPDATE 15 May 2008

CT SCAN shows nodules still growing slowly which gives me time to try other treatments, which will target the largest nodule directly.

UPDATE 13 Jun 2008

I underwent Radio Frequency Ablation (RFA) to destroy the largest nodule in my left lobe. I've now reset the 'clock' on the largest tumor growth, expecting that the LDN will continue to hold down the growth of the other existing nodules, and extending my high quality of life. Apart from early on, LDN has had no side effects for me, and anyone seeing me would never believe I have cancer since I feel and appear healthy.

UPDATE July 2008 – 16 months on LDN

On 13th June I underwent successful treatment with Radio Frequency Ablation (RFA) to one of the larger tumors in my Left upper lung lobe. Multiple metastatic nodules were evident, but some of them were showing calcifications. It wasn't reported on the scans. My oncologist noticed the calcifications when he viewed the scans during our appointment.

It's now been 16 months since diagnoses with metastatic lung cancer, and well beyond the 10 months my oncologist had given me, even with chemotherapy. LDN has been successful in controlling the cancer growth with no side effects, a success beyond anything I'd hoped for, or that conventional medicine has been able to offer or achieve for my cancer type.

I'll continue with my current LDN protocol and have another follow up in coming months.

Dee, HK

MY PERSONAL WEBSITE: <http://www.ldn4cancer.com>

1) *The TNM System is a cancer assessment system that classifies stage of disease according to its anatomical extent. Three factors are assessed; the primary tumor T, the nodule N, and the extent of metastasis M; based on a combination of pathological (pTNM) and clinical (cTNM) tests.

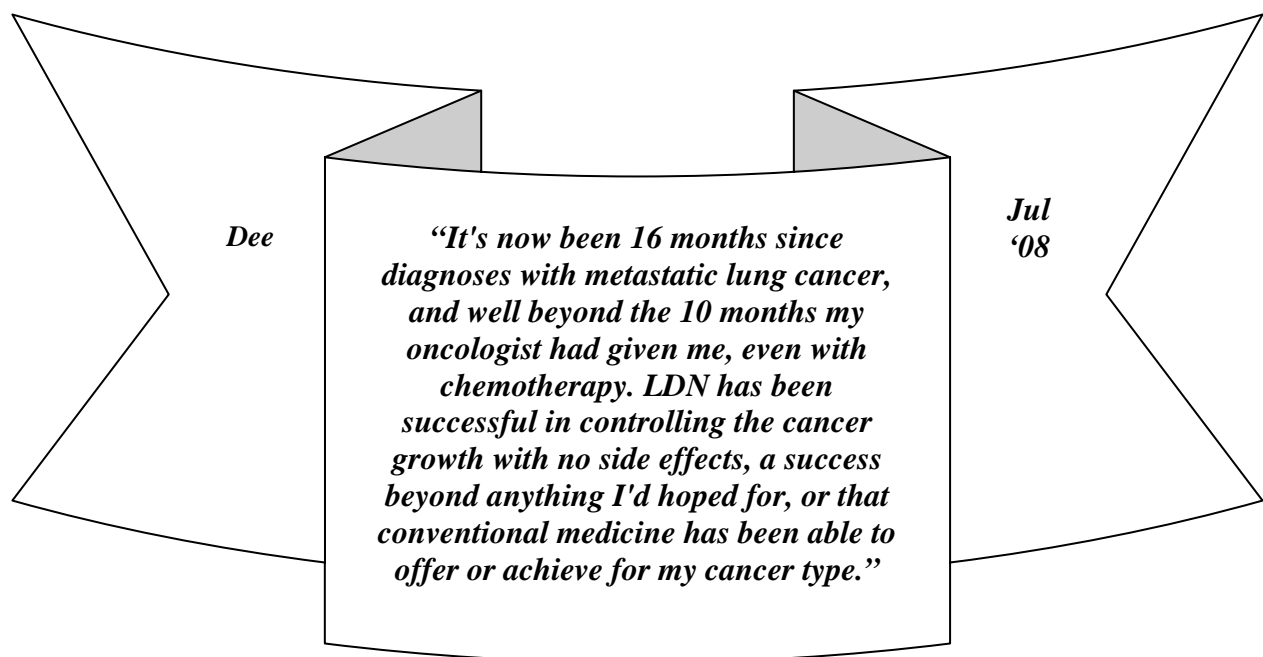
Ref: <http://www.upmccancercenters.com/cancer/headneck/staging.html>

2) The long-term survival of a patient with pancreatic cancer with metastases to the liver after treatment with the intravenous alpha-lipoic acid/low-dose naltrexone protocol.

Ref: http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=PubMed&list_uids=16484716&dopt=AbstractPlus

3) Carbonic anhydrase inhibitor suppresses invasion of renal cancer cells in vitro - ' ... Acidification of the extracellular milieu of malignant tumors is reported to increase the invasive behavior of cancer cells. ... '

Ref: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=15781>



26) LDN-Four years breast cancer free - Lola

LDN since 21 April 2004

- story submitted July 2008 (4+ years on LDN)

SPECIFICS

DIAGNOSED

- 21 Apr 2004 - Breast Cancer Stage IIA

Recommended Treatment Plan

Chemotherapy: 5-FU--Intravenously every 3wks along with

Adriamycin--Intravenously every 3wks along with

Cytosin--Intravenously every 3wks

for six treatments

Then

Radiation Therapy for approx 6 weeks daily x 5 days, Monday through Friday

(No Anti-hormonal (anti-estrogen) therapy possible)

TESTS (pre LDN)

Copied from the Medical Report, April 2004:

Size of tumor 2.8cm, location 12 O'Clock.

Type Grade III, Poorly Differentiated, Infiltrating (Invasive) Duct Cell Adenocarcinoma

Hormone receptors Estrogen-Negative, Progesterone-Negative

HER-2-NEU Oncogene Negative Over-expression

Flow Cytometry (strands of DNA) Diploid-two

Rate of Growth (percentage of cells dividing) S-Phase Of-13.6% (High-Fast)

Sentinel Node Axillary Lymph Nodes, none of two were positive

Staging Negative for Metastases Stage IIA (T2 NO MO)

Percentage chance of relapse: 33% over 5-10 years with no further therapy

- 21 to 29 Apr 2004 - No biopsies were done prior to or during surgery

MEDICATION (pre LDN)

- prior to Apr 2004 – none, apart from birth control pill

MEDICATION (post LDN)

- 21 Apr 2004 to present – 4.5mg Low Dose Naltrexone (LDN)

SURGERY (post LDN)

- 29 Apr 2004 - Surgery - Right Partial Lumpectomy

TREATMENT (post LDN)

- May 2004 to Jun 2004 - Radiation Therapy for 6 weeks, daily x 5 days per week, Monday through Friday

TESTS (post LDN)

- July 2008 – To-date bone scans, blood work, mammograms, CT and PET scans have all come back negative for cancer

LDN DOSE & TYPE

a) Dose - 4.5mg Low Dose Naltrexone (LDN)

b) Time - at 10pm every night

c) Type - compounded capsules using pure naltrexone powder and lactose filler

SUPPLEMENTS

- prior to Apr 2004 - none

- Apr 2004 to present, as follows:

DL-Phenylalanine 500mg x 2 capsules per day

Tart Cherry Juice – one glass daily

Vitamin D3 15mcg (600 IU) x 1 daily

Fish Oil capsule 1000mg x 2 daily

COMPLEMENTARY THERAPIES

- none

DIET

- 1973 to 1990s – Low Carbohydrate diet

- 1990s to 2002 – off and on Low-Carb diet

- 2008 – Commenced Suzanne Somers diet

EXERCISE OR INTERESTS

- Apr 2004 to present – normal, no particular restrictions

MY STORY – July 2008 – over 4 years on LDN

I was in my mid 60s when diagnosed with Breast Cancer in April 2004.

Before the diagnosis, I'd only ever been admitted to the hospital once in my lifetime, and that was to give birth to my wonderful daughter in 1963.

I've always been healthy - never had blood pressure problems, nor cholesterol problems. I've never been on any medications except for many years of birth control pills. I seldom even took aspirin. I did smoke, but only until my mid thirties, then I quit for good. I'm 5ft 1in tall and have always weighed around 110lb.

At the time of diagnosis my daughter was taking Low Dose Naltrexone (LDN) for her Multiple Sclerosis (MS), and was doing really well, so she immediately put me on 4.5mg of LDN the night of 21 April, 2004.

I decided to go ahead with the recommended surgery, a Right Partial Lumpectomy, on 29th April, then have the radiation therapy, but I also wanted my daughter to schedule a consultation with Dr Bernard Bihari, to give me a second opinion on the chemotherapy.

On June 9th 2004, during the time I was undergoing radiation therapy, I had a phone consultation with Dr Bihari, after I'd faxed all my medical reports in advance.

After consulting with Dr Bihari I decided not to undertake chemotherapy, but instead continue taking the 4.5mg of LDN each night.

Dr Bihari told me that, as I was taking LDN before the lumpectomy, any cancer cells that may have escaped during surgery would have been destroyed like pac-men by the immune system.

At Dr Bihari's suggestion, I've also been taking two 500mg DL-Phenylalanine capsules, Solaray brand, every day on an empty stomach - to keep my endorphins up throughout the day. (NB This is not for everyone. There are cautions on the label. For example, if you have high blood pressure or PKU, you cannot safely take this supplement.)

It is now July 2008, and ALL of my bone scans, blood work, mammograms and other scans have come back negative for cancer.

I continue to take 4.5mg LDN at 10pm every night, adhering to Bihari's LDN treatment protocol.

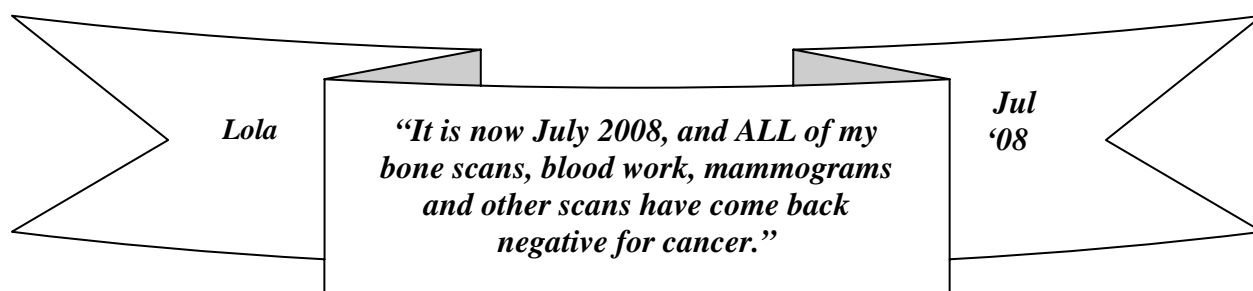
I have now been cancer free for 4 years.

Lola, USA

Reference:

' ... As a fat-soluble vitamin, vitamin D requires some dietary fat in the gut for absorption. ... Very few foods in nature contain vitamin D. The flesh of fish (such as salmon, tuna, and mackerel) and fish liver oils are among the best sources ... '

<http://ods.od.nih.gov/factsheets/vitamind.asp>



27) LDN-Crohn's and Me - Peter B

LDN since October 2007

- story submitted July 2008 (9mths on LDN)

SPECIFICS

DIAGNOSED

- 1996 to 2003 - health deteriorated steadily, many emergency trips to hospital, but no diagnosis. I began to lose weight quite quickly, and during this period I was rushed to hospital 11 times by ambulance and one by car. I was at my wits end. The last time I was picked up in an ambulance I insisted to be taken to the Carlisle hospital instead of Dumfries hospital.

- 2003 - admitted to Carlisle hospital and diagnosed with Crohn's Disease

MEDICATION (pre LDN)

- 1996 to 2003 - no medication

- 2003 to 2003 - during a few weeks in Carlisle hospital - IV morphine & IV steroids

- 2003 to 2006 - Prednisolone (steroids) x 40mg (stopped taking them 2 years ago)

- 2006 to Apr 2008 - no medication

TESTS (pre LDN)

- 1996 to 2003 - approx 12 endoscopies, colonoscopies and barium follow-throughs

SURGERY/HOSPITAL TREATMENT

- 2003 - a section of my intestine, and part of my small bowel was removed

MEDICATION (post LDN)

- Oct 2007 to Oct 2007 - 4.5ml LDN (stomach problems led to reduced dose)

- Oct 2007 to Dec 2007 - 1.5ml LDN

- Dec 2007 to Jan 2008 - 2.5ml LDN

- Jan 2008 to Feb 2008 - 3.5ml LDN

- Feb 2008 to present - 4.5 ml LDN

TESTS (post LDN)

- none

LDN DOSE & TYPE

a) Dose - 4.5ml Liquid LDN

b) Time - I take my LDN at bedtime each night, usually between 10pm and 12pm

c) Type - Liquid (the label says '135 naltrexone')

SUPPLEMENTS

- 1996 to 2008 - I tried lots of herbal supplements.

- Mar 2008 to present - Aloe Vera oil every 3 days and

- May 2008 to present - I now start each day with a chamomile, marigold, primrose tea blend. (I use the actual leaves and buds, soak them in hot water for ten mins, then strain and drink - from a health food shop. It tastes like crap, but seems to set me up for the day and makes me feel good.)

THERAPIES

- 2003 - 2008 - Acupuncture - I'd recommend acupuncture highly to anyone suffering from Crohn's. It had no real effect the first time I went, but by hell it did every other time.

DIET

- 1996 to 2008 - very restricted

- 2008 to present: No spices, eggs, or bread. Fruit was off the menu but I now find I can eat it in moderation without adverse consequences. Believe it or not, lucozade was bad news, and red bull a killer. I used to start with black tea but it'd give me a bad gut. Thankfully, my diet is a little less restricted these days: I can have the odd drink of alcohol, very occasionally. If I have an alcoholic drink, then it has to be vodka. Long ago, I used to drink jack daniels but it's a gut rot, as is whisky. All ales and lagers make me feel bloated and ill.

EXERCISE OR INTERESTS

- 2008 - I'm getting more exercise and can go for a walk without wondering where the next bathroom is.

MY STORY - June 2008

I've had Crohn's Disease for some 12 years now. Soon after diagnosis, I had a section of my intestine and a part of my small bowel removed. They then put me on steroids that seemed to ease the pain and make life a little more bearable, but the problem was still there.

I was first ill in 1996 when rushed to hospital on Boxing Day with chest pains. I was worried it was a heart attack, but I was a fit person who was playing 2, sometimes 3 games of football a week. I was checked and they determined it wasn't a heart attack. They had no idea what it was but kept me in for 5 days and kept an eye on me. I was put on an IV drip and given morphine injections to help with the pain. I have to admit I was fine after that for a few weeks, then it happened again and the same process was carried out at the hospital.

I began to lose weight quite quickly, and during this period I was rushed to hospital 11 times by ambulance and one by car. I was at my wits end. The last time I was picked up in an ambulance I insisted to be taken to the Carlisle hospital instead of Dumfries hospital. At Carlisle's I was dealt with in a professional way and had endoscopies and colonoscopies. I was introduced to a gentleman called Mr Palmer who was a cancer specialist. He quickly discovered what the problem was - and a good job too as I had dropped from 12 1/2 stone to 7 stone in a month.

My family never said it, but they all thought I had cancer and were ready to call my brother in from Australia because they were worried I wasn't going to make it. I'd had endoscopies, barium follow-throughs, and colonoscopies by the load before this, but Dr Palmer was the first one that managed to see what the problem was.

Not long after being diagnosed I had surgery - within a matter of days. I have a nice zipper scar that goes down my belly past my belly button. At least he managed to cut out 2 sections that were badly diseased.

I was then put on prednisolone steroids, 40mg, and was on this dosage for at least 3 years (1997-2000), before being told I should have reduced it years before. I steadily reduced the dose and began to feel a bit better, but my whole life changed from the day I first fell ill.

As you know there is no cure for this Crohn's Disease and it is the most intrusive disease known. It affects your whole way of life, no more going out and relaxing, having a drink or going to a restaurant and eating what you want. It's a case of let's plan every trip based on; "are there toilets nearby?", or "sorry, we can't attend that restaurant as they do not serve suitable food". There is also the embarrassing side of the illness that all of us with digestive disorders know about, but I won't touch on it in this story.

I could not go out for meals and drinks when I wanted. I found going anywhere a potential disaster, as I found myself needing the toilet and would be in it for ages so it put a stop to doing things I used to do. I had to change my diet completely. I found foods I usually ate would make me ill and it got to a stage where I was frightened to eat anything because I knew it could result in a day of being ill and camped in the toilet.

Yes there have been times when I felt better – usually those times when I stopped taking the steroids completely as I knew they were not helping but only masking the pain and causing me more illness.

I don't understand why doctors can just so easily say 'take a steroid and go home' - to what I think is a death sentence. Taking steroids did help the spasms in the gut and ease the pain, but do we really know what the drugs are doing to our bodies? We put on weight in a rapid style, and no matter what we do it's hard to get the weight back off. People cannot live that way as the steroids have so many side effects that the public do not know about, such as; mood swings, depression, temper tantrums, brittle bones, kidney damage, and the list goes on ... yet, I was given them like they were smarties.

I took steroids for years, and any time I was ill the doctors put me into hospital, stuck me on a drip, starved me of food and water, and pumped me full of steroids and morphine. That's no way to live, but it was the only way I could get relief.

The last straw for me was 2 years ago when I sneezed and cracked 2 ribs. Don't get me wrong, it wasn't a huge sneeze, it was just a normal, every day, run of the mill one. Why had this happened? Steroids, I'm sure, played a part - so I decided there and then to bin them for good.

I tried other herbal things and even acupuncture, which incidentally, I'd recommend highly to anyone suffering from Crohn's. It had no real effect the first time I went, but by hell it did every other time. In the end I took nothing for the illness, had acupuncture, but just lived with the bad gut and pain and put up with it ... that is, until October 2007.

I was first introduced to LDN by a friend who suffers from MS and read all about the tests that have been done, and the outcomes of Crohn's patients being on the drug. Tests showed that the scarring and blisters go

away, the redness of the intestine walls were a thing of the past and the lining returned to pink. To others who read this story, this will make little sense, but to the worst-hit cases of Crohn's, this is like having 6 numbers in the lottery.

A close friend, Steven, who is fundraiser for LDN, has MS - and he called me to say he had something that would help me. He gave me a number to call so I could speak with a lovely lady called Linda Elsegood.

I called Linda, and within 5 mins she'd convinced me LDN was worth trying. I ordered it online. It was easy to do and I got a bottle of red medicine that didn't taste too good, but hey, if you drink Guinness you'll know what I mean. So anyway, I tried the medicine. I didn't want to get my hopes up, but I have to admit I was surprised at how I felt.

Since starting LDN I've noticed a vast improvement in my well-being. I have more energy and drive in the morning. I've also started to eat much better, and I'm finding I can eat fruit again without having to run to the bathroom. I've rediscovered the freedom of walking again without the worry of my stomach playing up. My moods are much better and I feel friendlier towards people: I've even been out to a bar and had a couple of drinks.

Don't get me wrong. It's early days yet, but so far, I'm being positive. There are a few side effects when starting to take the new medicine. I started taking 4.5mg LDN but had stomach problems, so I dropped the dose down to 1.5mg for 1 month, then took 3mg for 1 month, then took the optimum dose of 4.5mg.

You have to build up slowly with the dosage, because if you start at the maximum 4.5mg, you'll find yourself with a bad stomach and you'll feel like rubbish (I found that out the hard way) - so start at a low dose and build it up slowly. Like every drug it takes time to notice improvement, especially as this is such a low dose. It took a few days for me to notice the first beneficial changes, but there were changes, and so far they've been sustained.

I always take my LDN when I am just getting into bed. I go to the fridge where it's kept, take the liquid, then straight into bed and read for a short while before I am off to sleep. I never used to be able to sleep very well, but since I've started taking LDN I find I can get the rest my body needs.

I don't hide my illness. I make sure people at work and my family are aware of what the illness is ... it's nothing to be embarrassed about. Talking to people helps them understand your feelings. They're not mind readers and they don't know what you're going through unless you talk to them and help them see they can help.

I have work friends that know there are days that everything is not great with me and they accept that there may be times I will be in the toilet a while. My family always makes plans if we are going on journeys. We make regular stops without me having to plan the route myself and worry if I'm going to need the toilet. It's nice to hear them say 'ok let's stop here for a sandwich', or any other excuse they can find without making me feel like I need to ask them to stop. It makes a big difference.

On family birthdays, when we all go out for a big meal, they always chose somewhere that they know will have ordinary food that will agree with me rather than booking an Indian meal where everything on the menu will kill me.

I've had emails from people all over the world asking me for advice, and I can say it's been a pleasure to help people. I like knowing I'm helping them move on to something less damaging to their bodies than steroids.

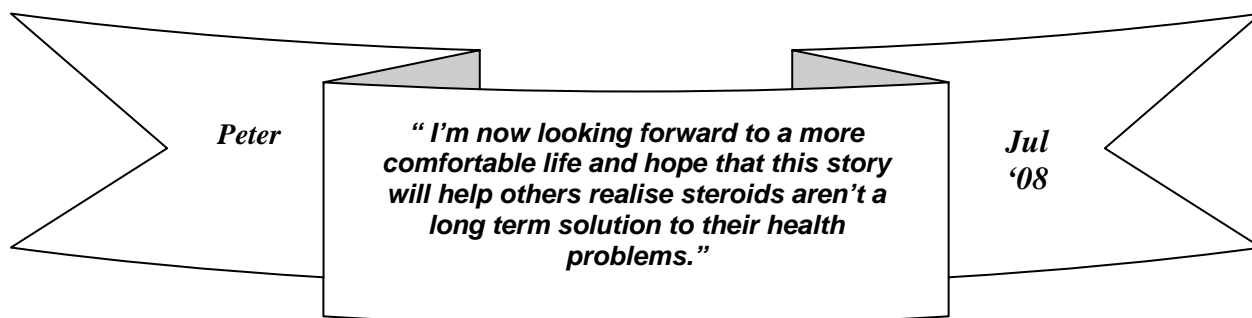
I walk out the front of my house along the sea front knowing that if I was to feel ill, I can always go back home, but at least it's a start - and it comes with a renewed sense of freedom I haven't felt a long time. I recommend others do the same. Don't push it, but try to get some exercise - slowly but surely - and take up a hobby to relax yourself. I find fishing very therapeutic, and when I'm fishing, my body just seems to automatically relax.

Last year, I went on holiday to South Africa to see my mother and father-in-law. They're aware of my illness and were really considerate to my needs - and I'll tell you what ... the 2 weeks I was away was the best relief I've felt in years ... until now, with LDN.

I'm now looking forward to a more comfortable life and hope that this story will help others realise steroids aren't a long term solution to their health problems.

Cheers,
Peter, UK

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health in June 2008.



28) LDN-Crohn's best it's ever been - Claudia

LDN since February 2008

- story submitted July 2008 (5 mths on LDN)

SPECIFICS

DIAGNOSIS

- Jun 2004 - Crohn's Disease

MEDICATION/TREATMENT (pre LDN)

- Jun 2004 to Jul 2004 - Cipro, Flagyl, Prednisone
- Jun 2004 to Nov 2004 - Bentyl, Colazol
- Nov 2004 to Feb 2005 - Asacol, Bentyl
- Feb 2005 to Oct 2005 - No medication due to pregnancy (doctor approved)
- Oct 2005 - Mar 2006 - Asacol
- Mar 2006 to Feb 2007 - No medication
- 16 Feb 2007 - phenergan and vicodin for abdominal pain - Hospital Emergency Room (ER)
- Feb 2007 to May 2007 - Asacol, Chromagen (iron)
- May 2007 to May 2007 - Pentasa (not tolerated)
- May 2007 to Aug 2007 - 6 mercaptopurine, Asacol (continued until April 2008)
- Aug 2007 to Apr 2008 - Asacol
- May 2007 to May 2007 - 6-mp, Asacol, Prednisone x 40 mg taper dose for 6 weeks (post hospital admission)
- Nov 2007 to May 2008 - In Penn State Clinical Trial. Unknown at this time whether LDN was started in November 2007 or in February 2008.

TESTS & PROCEDURES

- Jun 2004 - CT Scan with barium contrast diagnosed Crohn's Disease (in local hospital ER), followed by colonoscopy w/biopsies by a GI to confirm diagnosis (2 days later, still hospitalized)
- Jun 2004 - Colonoscopy Results: Colonoscopy revealed a 'normal looking colon with what appeared to be a fissure or possible Crohn's disease involving the anal canal.' No biopsy from this area was taken. 'The rest of the colon was unremarkable until one got to the cecum. At the cecum, a stenotic ileocecal valve could be seen with some ulcerations surrounding it. The scope was able to be manipulated through this somewhat stenotic area into the terminal ileum. The terminal ileum contained the findings characteristic for Crohn's disease. There was marked fissuring ulceration, induration, cobble-stoning, erythema and edema. Biopsies and photography were obtained.'
- Sept 2004 - CT Scan of abdomen - CT Scan Results: Terminal ileum at the ileocecal valve extending proximally for several cm is abnormal. The wall appears thickened. There is inflammatory change in the adjacent fat. A few small soft tissue nodular densities adjacent to the abnormal terminal ileum likely represent lymph nodes. This appearance is most compatible with an exacerbation of her Crohn's disease.
- 4 Dec 2006 - Blood work: Iron 33 MCG/DL, %SAT 10.7
- 1 Feb 2007 - Colonoscopy Results: Internal non-bleeding, mild hemorrhoids were found. One nodular area was found at 22cm proximal to the anus. This looks like a site of previous fistula with scarring. No active inflammation or ulceration. An area of congested mucosa with polypoid-appearing tissue (likely granulomatous tissue) was found at the ileocecal valve. Narrowing of the IC valve was noted. A diffuse area of mucosa in the terminal ileum was moderately erythematous, nodular and edematous. Tissue was very friable. Unable to advance beyond 5 cm proximal to the IC valve due to luminal narrowing. Biopsy results: Non-specific chronic active ileitis. Chronic inflammation with focal active cryptitis.
- 15 Feb 2007 - Upper GI/Small Bowel Follow-through Results: Showed disease at the terminal ileum but no signs of fistulas or strictures.
- 4 Apr 2007 - Blood Work: Iron 61 MCG/DL, %SAT 18.5
- 16 Apr 2007 - Capsule Endoscopy: 'There is patchy segmental inflammatory segments throughout the small bowel suggestive of active Crohn's disease. The distal portion of small bowel was obscured by stool. It appears that the capsule time elapsed while still in the small bowel. A possible avm was incidentally noted in the proximal small bowel.'
- 11 May 2007 - CT Scan and later admission into hospital with lower-right quadrant pain. CT Scan Report Results: 'A long segment of abnormal terminal ileum with marked thickening of the wall and narrowing lumen. It also showed that there was mild to distal portion of the appendix which had enlarged up to 9 millimeters in size with some inflammatory changes at the tip of the appendix. Further surgical consultation was advised particularly considering that the appendix had changed in caliber.'
- 11 May 2007 - Had low white blood cell count - apparently due to 6-mp.
- May 2007 - Received surgical consult: Non surgical at this time
- May 2007 - Gastro consult advised resection, which Family Physician and Surgeon did not advise.
- 27 Sept 2007 - Blood work: SED Rate 31 MM/HR
- 13 Nov 2007 - Colonoscopy w/biopsy: Polyp removed from ileocecal valve during procedure.

Colonoscopy Results:

Ileum: Erythema present, vascular pattern absent, erosions present, granularity present, bleeding present, ulcers present, edema present, deep ulcers present.

Sigmoid Colon: Vascular pattern absent. Pseudo polyps present, Granularity present, bleeding absent, ulcers absent, Stenosis, non-ulcerated. Fistula with suspected opening.

Biopsy results:

Ileum: Active chronic inflammation

Right Colon: No pathologic diagnosis
Transverse Colon: No pathologic diagnosis
Left Colon: Active chronic inflammation, severe
Rectum: No pathologic diagnosis
Polyp ileocecal valve: Submucosal lipoma, lymphoid hyperplasia

'The biopsies from the ileum show small intestinal mucosa with villous atrophy, increased lamina propria chronic inflammation and active inflammation involving the surface epithelium and immediately subjacent crypts. The biopsies from the right colon and transverse colon are unremarkable. The biopsies from the left colon contain three unremarkable mucosal fragments and a fourth fragment with marked active chronic inflammation. The rectal biopsies are unremarkable.'

- 15 Feb 2008 – Colonoscopy Results: Ileum: Erythema, granularity, bleeding, ulcers, edema and stenosis present. Activity level severe, Deep ulcers present. 30 cm fistula - Ileum to sigmoid.
- 13 May 2008 – Colonoscopy Results: Ileum: Erythema, erosions, pseudo polyps, granularity, bleeding, ulcers, edema present. Fistula healed.

MEDICATION/TREATMENT (post LDN)

- Nov 2007 to April 2008 - Asacol
- Feb 2008 to present – 4.5mg Low Dose Naltrexone (LDN)

LDN - DOSE & TYPE

a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my LDN at bedtime, usually around 10pm.
c) Type - capsules compounded with pure Naltrexone and unknown filler

DIET

- 1998 to present - Vegetarian
- Jun 2004 - Jan 2005 - low residue diet
- 2008 to present - Currently no dietary restrictions, but I do not tolerate artichokes or corn

SUPPLEMENTS

- Feb 2005 to Jun 2007 - Iron

ACTIVITIES, EXERCISE, INTERESTS

- Yoga, some Pilates, and I play the Wii :-). Keeping up with my almost 3 year old takes a lot of exercise! I enjoy spending time with my family, shopping, reading and helping in my community.

MY STORY – July 2008

I lived in Florida for the first 25 years of my life. I had been experiencing 'stomach problems' since my late teens, but thought nothing of it. I moved to West Virginia in 2003 and began working at a domestic violence shelter shortly after I moved.

In June of 2004 I began experiencing debilitating abdominal pain after each meal. I still went to work and tried to ignore the pain. Luckily one of my co-workers was formerly a nurse. She saw me doubled over in my office and asked what was wrong. When I pointed to my lower right abdomen as the location of the pain, she insisted that I leave and see the doctor immediately. After arguing with her briefly, the pain became overwhelming and I drove myself to a local clinic. I did not have health insurance and was trying to avoid a hospital bill. The doctor at the clinic pushed on my lower right abdomen and my vision went black.

He immediately sent me to the Emergency Room. I drove myself there. I called the girls at work on my drive to the ER and one of my co-workers met me there shortly after I was seen. They gave me pain meds which made me incoherent. They ran blood tests and had me drink barium for a contrast CT Scan. After several hours of waiting, the results came back and an Emergency Room doctor asked if I knew I had Crohn's disease.

Not only did I not know I had it, I had never heard of it and was not 'with it; enough to understand what he was telling me. I was handed a print-out from the Internet to explain what this diagnosis meant. I was also told that I was going to be admitted to the hospital for further testing. I was given pain medication for the next day and not allowed to eat until I had a colonoscopy which was scheduled for Monday (I was admitted on a Thursday). I felt miserable, weak, drugged, tired and confused. All this and without health insurance.

I had the scope Monday and my blood pressure dropped to 60/40 afterwards. About an hour after the procedure was done, the representative from the local Department of Health and Human Resources came by to gather my financial information to see if I would qualify for help from the state to cover the medical bills - still

groggy from sedation, I gave him information and I was denied for help. I was given antibiotics and steroids, as well as Bentyl and Colazol to treat the Crohn's and was released on Wednesday.

The medications were extremely expensive. My fiancé and I decided to move up our wedding date so that I could access his health insurance. We were married in August of 2004 in Las Vegas. I saw the gastro that performed my scope. I was extremely unhappy with him and so was thrilled when I switched to a provider in my insurance network. The new provider took me off the Colazol and informed me that it was only treating the colon, which was not the part of my intestines with the disease.

I had been spending 500 dollars a month on a medication that wasn't even treating the diseased area! This gastro put me on Asacol to better treat the affected area. I saw him a few times over the next year. He advised me that it would be fine to go off the Crohn's medication (Bentyl and Asacol) while I was pregnant (Feb 2005 - October 2005).

While pregnant, I worked full-time until June 2005, but then had to make a trip to the Emergency Room due to severe dehydration. I received IV fluids and phenergan.

In July 2005 I went to the hospital, again while pregnant, and had an ultrasound to rule out kidney stones. The final conclusion was 'round ligament pain'. After I delivered a happy and healthy little boy in October of 2005, I had a monstrous flare, but did not go to the doctor for it - rather I just went back on the medications.

I was working full time again between November 2005 and July 2006, then found part-time work, due in no small part to the Crohn's disease. During the same period I changed gastroenterologists, then became anaemic and was put on Chromagen to help with the iron deficiency.

In January 2007 I enrolled in graduate school to obtain a Master's Degree in Special Education. (I'll graduate in May 2009, after I complete a 12-week internship.)

In February of 2007 I decided to switch gastros again because the one I had did virtually nothing to help me and took very little time with me. My new gastro came very highly recommended and lived up to their reputation. Before I was even seen in the office, I was scheduled for a colonoscopy (as I had not had one since 2004 and was experiencing a lot of bleeding and pain).

We tried Pentasa to better treat the ileum, but I did not tolerate it well. I was placed on 6-mp and a week later was hospitalized again with what they believed was appendicitis. While in the hospital, I received a surgical consult, saw my family doctor and got a consult from a gastro ... the one I left in 2006. He insisted that my ileum needed to be resectioned, but the other two doctors disagreed. I was given steroids, put back on the 6-mp and discharged after 2 days in the hospital.

During my time on the 6-mp, I was more miserable than I had ever been. I had constant headaches and developed gout in my hands from a build up of the uric acid from the medication. The steroids had their typical side effects and I put on weight as well.

I called my gastro and informed her that I was going to take myself off the 6-mp, as I'd rather deal with the disease than feel as awful as I had been feeling. There were days that I couldn't even get off the couch to take care of my son. I missed out on playing with him, cuddling with him and being a mom to him for 3 months because of the medication. That's when I knew there had to be something else out there.

My gastro wanted me to consider Remicade or Humira. I did my own research and found an article by Dr. Jill Smith about low-dose naltrexone (LDN) and the clinical trial she had completed regarding its use in Crohn's patients.

I took the literature to my gastro who stated that she didn't know enough about it to prescribe it, but that I was the second person that month to ask her about it. I showed her a list of doctors that prescribe it, but she could not be persuaded. I called doctors on the list, but none prescribed for Crohn's. So, I called Penn State and arranged to meet with Dr. Jill Smith about the study and to see if I would qualify.

In November 2007, I drove 4.5 hours to Penn State in Hershey, PA where I filled out paperwork, had a physical, got lab work and scheduled a colonoscopy. I qualified for the trial. For the next 6 months, I drove to Hershey EVERY month, 4.5 hours each way, for a 1 hour appointment. The exception was the three scopes I received when I would go down the night before with a friend and prep for the scope in a hotel room and ride home after the procedure.

The trial changed my life. The medication changed my life. Without the compassion, education and determination of Dr. Jill Smith and her nurse, Sandy Bingaman, I would likely be dealing with an active and oppressive disease, and taking toxic medication with horrid side effects.

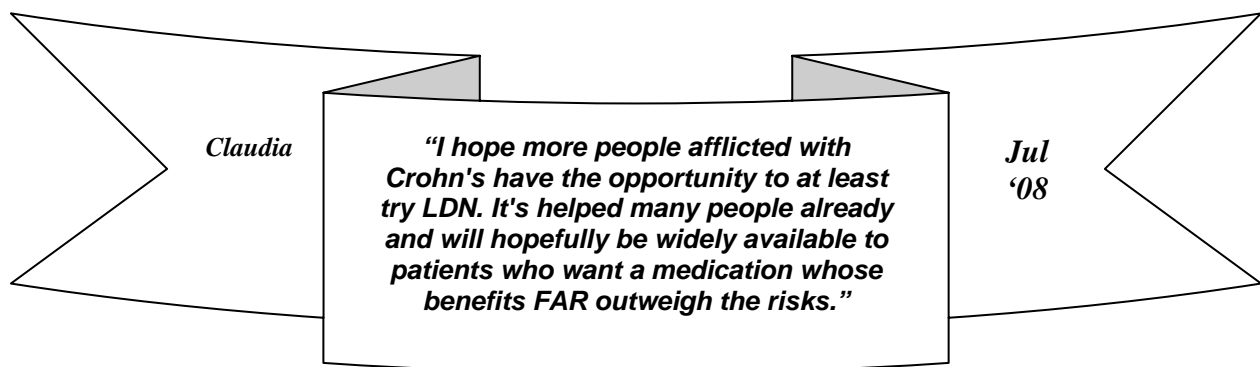
Instead, I take one pill before bed and experience only odd dreams - which really are quite entertaining. My intestines are not healed and naltrexone is by no means a miracle cure for Crohn's. However, it healed the 30cm fistula I had, and has significantly reduced the bleeding and pain I experienced on a daily basis.

On a side note, I've dropped 20 lbs in the last 4 months while on LDN. This is a positive aspect for me, as I put on a significant amount of weight from the other medications I had taken.

It's now July 2008 and I feel better than I have in years. I'm still on the LDN under the care of Dr. Smith, even though my part in the trial is over. I definitely don't miss that drive every month, but I truly miss the staff at Penn State, who went out of their way to make sure I was comfortable and cared for.

I have a prescription for Bentyl to take 'as needed', which is rarely. I hope more people afflicted with Crohn's have the opportunity to at least try LDN. It's helped many people already and will hopefully be widely available to patients who want a medication whose benefits FAR outweigh the risks.

Claudia, USA



29) LDN-Every condition has improved - Celia

LDN since November 2007

- story submitted July 2008 (7mths on LDN)

SPECIFICS

DIAGNOSIS

- late 1960s – hyperthyroid resulting in partial thyroidectomy in 1971
- 1990 – osteoarthritis
- 1994 - chronic fatigue
- 2003 – high cholesterol
- 2004 - IBS with rectal bleeding (so bad sometimes I did not dare go out)
- 2004 - intestinal diverticula
- 2005 - high blood pressure
- 2005 - mild Systemic Lupus Erythematosus (SLE)
- Jan 2006 - abdominal aortic aneurism
- 2006 – chronic obstructive pulmonary disease (COPD)
- 15 May 2006 - Lung cancer (no tumour, just metastases to the chest), prognosis with treatment 6-12 months. Palliative care of chemo and radiation resulted in No Evidence of Disease (NED) but told the cancer would come back, with less than one per cent chance it wouldn't.
- Jan 2007 – COPD flared after chemo & chest radiation - chest x-ray showed inflammation due to infection but clear of cancer
- Jun 2007 - hiatus hernia and gastric ulcer - no sign of cancer in stomach.
- Jan 2008 - Temporomandibular joint dysfunction (Tmj)
- May 2008 – No Evidence of Disease (NED) for lung cancer, and abdominal aortic aneurism had ceased growing

TESTS (pre LDN)

- late 60s – thyroid problems
- 1990 - osteoarthritis
- 2003 – T4 test re fatigue - hyperthyroid – went back on Levothyroxine thyroid med
- 2004 – colonoscopy - IBS
- 2005 - positive ANA test detected mild Systemic Lupus Erythematosus (SLE)
- Jan 2006 – ultrasound detected abdominal aortic aneurism, size 3.5cm
- May 2006 – Mediastinoscopy detected enlarged lymph nodes in chest (Lung cancer)
- approx July 2006 – ultrasound - abdominal aortic aneurism had grown to 3.8cm
- Sept 2006 – CT scan for Lung cancer revealed 'No evidence of disease' (NED) following palliative chemo & radiation
- Jan 2007 – chest x-ray showed inflammation due to infection – clear of cancer
- 14 Mar 2007 – X-ray re back pain found thinning of thoracic spine due to radiation and steroids - thus started Adcal D and Alendronic Acid to build bone.
- 3 May 2007 - CT scan - 'No evidence of disease' (NED)
- Jun 2007 – Gastroscopy revealed hiatus hernia & gastric ulcer, no sign of cancer in stomach
- 5 Jul 2007 – X-ray – hip - re future surgery.
- Aug 2007 - Spirometry re breathing and to assess for surgery - I think the result was a FEV1 of 42%.
- 1 Oct 2007 - CT scan of chest prior to hip replacement - NED, abdominal aorta aneurism had grown to 4.5cm

TESTS (post LDN)

- Dec 2007 – blood pressure lowered (after commencing LDN)
- 17 Dec 2007 - CT scan – NED for cancer but abdominal aorta aneurism had grown to 4.8cm
- May 2008 – X-ray of chest - NED for lung cancer, ultrasound - abdominal aortic aneurism has not grown any further and remains at 4.8cm
- August 2008 – CT scan - NED for cancer, X-ray of chest - NED for lung cancer, ultrasound - abdominal aortic aneurism has not grown any further and remains at 4.8cm

SURGERY

- 1971 - partial Thyroidectomy
- 10 Oct 2007 - total left hip replacement

MEDICATION/TREATMENT (pre LDN)

- 1971 to 1972 – 1 x 100mcg daily Levothyroxine following partial Thyroidectomy (ceased taking as I felt well)
- 2004 to Oct 2007 – 2mg x Loperamide, 135mg x Mebeverine (for IBS - ceased after improvement on LDN)
- 2005 to Nov 2007 – Plaquenil (for SLE)
- 2005 to Dec 2007 – Rampiril (blood pressure improved 2 mths after starting LDN so I ceased taking these meds)
- Jun 2006 to Aug 2006 – palliative care - 8 doses x chemotherapy (Cisplatin & Carboplatin) over 2 months.
- Aug 2006 to Sept 2006 – palliative care - 12 doses x radiation over a period of 2.5 weeks
- Jan 2007 - I had a very bad exacerbation of COPD, which landed me in the hospital. I came out on oxygen, a nebuliser (Atrovent 500mcs per 2ml), steroids (Prednisolone tablets), and Flixotide inhaler (also contains prednisolone).
- Feb 2007 - steroid injection in left hip for pain

MEDICATION/TREATMENT (post LDN)

- Jan 2007 to July 2008 - Flixotide in nebuliser (prednisolone)

- 2003 to present - 1 x 100mcg daily Levothyroxine
- 2005 to present – 1 x 20mg Lipitor (statin) – (Jul 2008 - when I remember to take them)
- 2006 to present –Atrovent in nebuliser daily (Jul 2008 for COPD, though rarely used now)
- 2006 to present – Salamol Inhaler as needed
- 2006 to present – 1 x Mucodyne capsule 2 or 3 times per day
- Jun 2006 to present – 10mg to 20mg daily of Temazepam (since cancer diagnosis)
- Jun 2006 to present – 2mg x Valium as needed (since cancer diagnosis)
- June 2006 to present - Adcal D3 daily (since radiation thinned thoracic spine)
- June 2006 to present – 70 mg x Alendronic Acid – once weekly (since radiation thinned thoracic spine)
- Jan 2007 to present - 10mg Amitriptyline (for pain in Temporal mandibular joint)
- Apr 2007 to present – Iscador (series 2) daily – a derivative of Mistletoe - homeopathic hospital referral
- Jun 2007 to present – 20mg to 40mg x Omeprazole (for Hiatus hernia and Gastric ulcer)
- Nov 2007 to present - 4.5mg Low Dose Naltrexone (LDN)
- Jul 2008 to present – Spiriva in inhaler – once daily

LDN - DOSE & TYPE

- a) Dose – 4.5mg Low Dose Naltrexone (LDN)
- b) Time - I take my Naltrexone at bedtime, usually around 9.30pm.
- c) Type – 4.5mg capsules were initially compounded with pure Naltrexone powder and calcium carbonate filler, but filler was changed to lactose soon after starting (after I learned calcium carbonate can slow the release).

DIET

- May 2006 – I changed my diet but not radically. I now eat mainly eggs and fish, vegetables and fruit, 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.

SUPPLEMENTS

- late 2006 to present – I began taking the following:
Vitamin C
Vitamin E
Vitamin B
Magnesium
B17 (in the form of 20 Apricot kernels daily - 3-4 at a time during the day, with a day off once or twice a week as per Phillip Day's guidelines)
- July 2008 – The following were added:
Selenium
Alpha lipoic acid
L. Acetyl Cysteine
Milk thistle

ACTIVITIES, EXERCISE, INTERESTS

- Since improvement I'm able to get around a bit more and am walking more now. Feel much more alert.

MY STORY – June 2008

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.

Of course I went on the usual supplements (but knew this was not enough), changed my diet (but not radically), 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 then learned about Iscador, a derivative of Mistletoe, and fortunately, as there is a homeopathic hospital not too far from me, I got a referral and now use Iscador (Series Two), on a regular

basis. Still, I searched the Internet, and, lo and behold, came across Low Dose Naltrexone (LDN). I had never heard of it before, but it seemed like a miracle drug. I had to have it. 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. Although I felt great, I had some disturbed nights, but not too many strange dreams (which happens with some people). I have now determined when it is best for me to take it. This is usually about 9:30 pm, and, as I take sleep aids an hour later, this seems to be working for me. 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, as did '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 abdominal aortic 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.

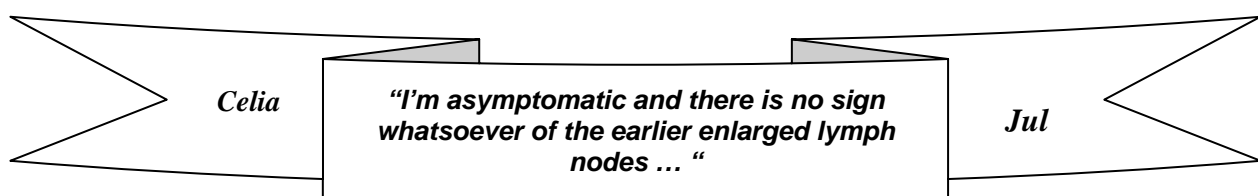
UPDATE July 2008 – 7 months on LDN

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 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. I told him right off ... 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 good 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.

Celia, Scotland



Dr Gluck

We're all curious. When, and under what circumstances did you first meet Dr Bernard Bihari?

David G *His family moved into my family's neighborhood in Queens (NYC) when we were both in the 5th grade of public school.*

Cris *How did you first learn of Bihari's Low Dose Naltrexone (LDN) protocol?*

David G *We continued seeing each other socially over the years, even after our medical training. In 1986 he told me about the positive results in the clinical study he had done of LDN in patients at Downstate Medical Center. The patients had ARC (later called HIV infections and AIDS).*

Cris *Have you ever prescribed LDN, and if so, what were the circumstances and the outcomes?*

David G *Since I have been retired from active medical practice for many years now, I have recommended it to many, many people but only prescribe it for members of my family. There, the purpose in most cases is for preventive use (either primary or secondary prevention).*

Cris *What led to the setting up of the lowdosenaltrexone.org and ldninfo.org websites?*

David G *In 1999, I was no longer in the active practice of occupational medicine, and having heard of the continued excellent results Dr Bihari was having with LDN in his private practice, and having shared that information with my son Joel, who is an experienced programmer, my son and I decided to launch the website in order to let physicians and the general public know about LDN.*

Cris *Most of your fellow medical practitioners aren't even aware of Low Dose Naltrexone as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

David G *Detractors? I am blissfully unaware of it, if I do. I have certainly encountered many, many doctors who were dismissive.*

Cris *What helped you maintain your sense of purpose, your resolve, through adverse times?*

David G *As I told Bernie Bihari, when he first told me what results he was seeing from LDN, "This needs to be shouted from the rooftops!" After a lifetime in Internal Medicine, where one had to deal with insufficient medications for serious illnesses, the discovery of this new and harmless method of upgrading the immune system and thus enabling one to draw on the body's own powerful potential to fight disease, seemed to me a godsend!*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views are largely ignored. Why do you think that is?*

David G *For many reasons ... Doctors become inured to dealing with apparently preposterous and unscientific claims that patients bring them. Physicians' long professional training deeply ingrains the understanding that the scientific method, and only the scientific method, of testing proposed therapies by double-blind clinical trials can hope to yield reliable information. These trials are very costly and generally require the support of large pharmaceutical companies.*

Cris *In your opinion, what will it take for the medical community, scientists, politicians, and journalists to apportion value to patient testimony?*

David G *In my opinion, if it's only 'patient testimony', the chances are that they won't. Even if a celebrity or major politician were to become ill with a disease that could be well-handled by LDN, these people are shielded by their VIP status, and thus are restrained to use only the medical hierarchy's traditional treatment models.*

I believe that the pathway to recognition for LDN is open to us in the form of continued successful outcomes in repeated small clinical trials run at academic centers. Each one of these that is published in a respected peer-review medical journal becomes another weapon in forcing the groups you mention to pay attention.

My hope is that the grassroots movement, which has brought LDN this far, will mobilize behind a collection of such medical journal reports (and there may be sufficient of them within the next year to act upon) and use them to bombard every governmental health-related committee to insist that 'Attention Must Be Paid!'. Should government be willing to listen (and perhaps LDN's cost-saving potential may do the trick), at that juncture, patient testimony may have its chance.

Cris *Dr Gluck, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... After receiving my first two LDN health success stories in 2003 and deciding to research further, I discovered your website. Since then I've often wondered, if not for your website, your credentials, and your son Joel*

behind the scenes, if I would have learned the true depth, breadth, and inequity of the LDN story.

I want to take this opportunity to thank you sincerely for having the good grace, the courage, and the fortitude to freely share what you've learned with the rest of the world in what must, at times, have been an unwelcome or even hostile environment.

(1) Dr David Gluck, Editor, ldninfo.org & lowdosenaltrexone.org

(2) Cris Kerr, Administrator, casehealth.com.au

Dr Gilhooly

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further??

Dr Gilhooly *A patient with MS in my NHS practice asked for LDN four years ago, in 2004, and I promised to at least look into it. I soon found out that there was little of the usual research and clinical support for the use of the drug. My experience in addiction medicine, where I had used the full-dose version of naltrexone, gave me the confidence to at least try the low-dose version. Fortunately this patient had a good experience and had a significant improvement in her hand tremor, so I was intrigued and wanted to look into it more.*

Cris *You've prescribed LDN for Multiple Sclerosis and have reported on successful outcomes. What's your overall observation of the likelihood of LDN benefiting MS patients?*

Dr Gilhooly *A significant proportion of patients with MS improve with LDN, but the main benefit is preventing deterioration. This is actually quite hard to prove but as part of our work on the LDN trial, we have developed a blood test, which helps determine who will respond and how well they have responded. We are still working to validate this test, but we are confident that LDN represents a major step forward for MS.*

Cris *Have you prescribed LDN for any other diseases, and if so, what was the outcome?*

Dr Gilhooly *I have used it in some Chronic Fatigue patients with good effect but with the advent of the blood test, I plan to use it more widely. I have also managed to get a patient with severe rheumatoid arthritis off steroids using LDN, which is pretty impressive.*

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Dr Gilhooly *I have not really had many bad reactions from my colleagues although they will not usually prescribe it for various reasons. One of our aims is to increase the numbers prescribing LDN substantially, and this can only be done through increased research and training for doctors.*

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Dr Gilhooly *LDN has really been kept alive by the patients worldwide who have derived a benefit, and of course it is very rewarding to help patients who have been to lots of clinics and had no improvement. We now feel that our understanding of how LDN works is improving, and it is less of an art and more of a science.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Dr Gilhooly *LDN has not emerged from the usual pharmaceutical company route, and there is a tendency among doctors to be conservative and to distrust anything that has not been through the various stages of development that most drugs have. LDN is effective across a broad range of conditions but proving that is complicated and time consuming.*

Cris *Dr Gilhooly, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

(1) Dr Gilhooly, MB ChB, MRCP

(2) Cris Kerr, Administrator, casehealth.com.au

Interview with
Dr Jaquelyn McCandless
July 2008

Dr McCandless

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Jaquelyn M *In early 2005 the lab director of Immunosciences, Dr Ari Vojdani, mentioned to me that the immune panels I was conducting on children with autism very much resembled the panels on MS patients he was finding in his laboratory. Soon after that I happened to come upon a website about patient-reported treatments and noticed LDN being high on a list of therapies being used to help MS patients.*

I looked up LDN on the www.lowdosenaltrexone.org site and also read in the autism literature about studies that had been done with varying doses of naltrexone a decade before with varying but some success, the researchers hoping that naltrexone might obviate the necessity to put the children on a casein free/gluten free diet to combat the opiates thought to be from the undigested large peptides going to the brain as caseo-opioids and gluteo-opioids. Naltrexone did not satisfy their desire for that outcome, and compliance was very bad in their studies because of the terrible taste of this opioid antagonist for children who for the most part could not swallow capsules.

The main thing that came out of these few earlier studies was that naltrexone could be helpful for some self-injurious children. (Note: We now know that the main cause of self-injury in autism is extreme pain in inflamed guts but children who cannot speak cannot convey the source of their pain.) Nothing was noted then about any immune benefit, and I am not sure anyone knew yet at that time about the importance of endorphins to immunity. I thought, "Maybe this could help my autistic patients".

I tried it for my granddaughter Chelsey and a few others who did not like it because of the bitter taste. I asked Dr Tyrus Smith at Coastal Compounding in Savannah, GA if he would help me create a transdermal carrier that would be effective, and he came up with a cream made with oil from the emu. I found it to be odorless, hypoallergenic, and extremely effective, and parents could apply it to the bodies of their already sleeping children when they, the parents, went to bed.

Parents began reporting, sometimes the very next day or within a few days, a lifting of mood when their children awoke in the morning, calling it the 'happy cream'. The thing they loved the most was that the children started being more sociable, playing with their siblings and relating to their fathers for the first time. I have received many such reports since starting to prescribe LDN for children with autism.

Cris *You've prescribed LDN for Autism and have reported on successful outcomes. What's your overall observation of the likelihood of LDN benefiting patients with Autism?*

Jaquelyn M *I have a large database that collected over 200 reports from patients until I finally stopped collecting them, with 75% showing a positive response to LDN. For autism, a very complicated and multi-factorial disorder needing varying therapies, this is considered a high benefit rate.*

LDN is by no means a sole treatment for autism, but ideally accompanies dietary restriction, healing gut problems, nutrient protocols, and detoxification protocols. Parents like knowing that it is helping their children's immune system, though this benefit does not show up for awhile; but they particularly report liking the mood elevation, the socialization, and better cognition and language that occurs in many children. It is also very easy to apply and is inexpensive, which they also like.

I routinely require all of my own patients with autism to be on the casein/gluten free diet, but when I did a study on a larger group that had children who were not on dietary restriction, I began seeing hyperactivity and insomnia as a side effect to LDN in about 15% of the children. Since one of the aspects of autism is gut inflammation and ineffectiveness of the DPP-4 enzyme which is necessary for proper breakdown of the large peptides into amino acids, I see this side effect as a clue that the children would benefit from dietary restriction, and when parents agree and implement the diet often these side effects are ameliorated, but not always. Some children have had to stop LDN because the interference with sleep was intolerable for the parents and the rest of the family.

Giving an opioid antagonist even in a tiny dose to children who may have opioid-like substances in their brains from their diets can apparently cause a withdrawal reaction that manifests as hyperactivity. Sometimes cutting the dose down would help, sometimes enforcing the diet would help, and sometimes the kids just got used to it and began calming down and some just had to stop its use. Even in the face of severe insomnia and hyperactivity, many parents were reluctant to stop it because of their pleasure at seeing their child be sociable for the first time. This actually became an incentive for some to finally tackle the restrictive diet, which brought even more health benefits.

One year ago I queried the three pharmacies most known for compounding for autism and learned that over 10,000 prescriptions had been compounded for LDN just by those three in the two years since being introduced by me to the

autism community. Dr Smith who created the transdermal cream had generously given out his formula for the cream to at least 50 pharmacies, including firms located in Hong Kong, Scotland, and Israel where I had gone to teach doctors the bio-medical approach to autism, including the knowledge of LDN.

Cris You're presently in Mali with your husband, Dr Jack Zimmerman, trialling LDN for HIV. How is that progressing and are the results to-date in-line with or outside your early expectations?

Jaquelyn M I performed a series of immune tests on a group of children with autism, and discovered that 90% of them raised their CD4+ cell count in that 16-week period, and thought, "This has to go to Africa." I made some enquiries and learned that Dr Bernard Bihari, the discoverer of the clinical benefit of LDN in AIDS patients in 1985, had written a protocol and attempted to implement a research study in Mali Africa a few years before. This study could not get adequate funding and had been laid aside.

I was led to Mr. Seyni Nafo from Mali who had spoken of this attempt to do a study in his country in one of the early annual LDN conferences and who was very desirous of it being resurrected. With Mr. Nafo's invitation to come to Mali to look into the research possibilities and meet the professionals there in Bamako who might conduct the proposed study, and my husband's willingness to conduct a social/communication study alongside the medical research with me; we went in the winter of 2006, liked what we saw and the people we met, and proposed the revival of that study.

The challenges have been major, one of them being the language and distance problem, but phones, faxes and internet have been powerful tools in working together between the two countries and to carry this project forward. Another challenge has been finding groups or persons to contribute to funding for the study: We were certainly surprised at the difficulty raising funds for what we deem as a very important project.

However, with a substantial amount of our own funds along with help from many others it is actually currently in process with adult male and female participants in each of the three groups, one with LDN and placebo, one with LDN and HAART drugs, and one with HAART and placebos, and we are still gathering our total number of recruits needed with present hopes that the study will be fully recruited by the end of July and will probably complete around March or April of 2009, about 4-5 months later than we had hoped.

The stigma associated with this disease makes those infected extremely reluctant to come forward for testing until they are already very ill, particularly the women, and this has made recruiting very slow, as by then it is too late for them to participate in the research we are doing, which is to try to show that LDN can prevent the inevitable loss of CD4+ cells until the patient finally has full blown AIDS leading to their demise.

We have had to go back to the drawing board several times for any changes; Mali has strict IRB regulations based upon US IRB regulations. We have found that many Africans are fearful of American drug studies that in the past have hurt their citizens by inadequate informed consent and other inhumane or negligent practices by large drug companies working there to get AIDS and other drugs accepted through research studies on their people. Their people are quite suspicious of drugs in general, and people have been found deceased from AIDS there with their cabinets full of HAART drugs which they were given but did not take.

With a literacy rate of 17% in this country, and much less than that for women, the counselling and education aspect is paramount and is the challenge that my husband has undertaken as his part of the study to help men and women communicate better. He has trained counsellors to work with groups, now ongoing, consisting of women only, men only, and men and women together. Anyone in the study taking the drugs can invite their partners to participate in the counselling and communication groups even if they are not in the medical part of the study.

Cris *Have you prescribed LDN for any other diseases, and if so, what was the outcome?*

Jaquelyn M *I have worked with crohn's (mostly adolescents and children and a few adults), multiple sclerosis, chronic fatigue syndrome, fibromyalgia, parkinson's, and cancer patients. Everyone to whom I currently prescribe LDN, feels positive about the results, some ecstatically so. Some were disappointed that their illness was not reversed, particularly the MS patients, but eventually grateful that they felt stronger and better generally and were no longer progressing.*

My husband and I have been taking it for three years now and we love it; we think it is one of the best anti-aging agents around, and it definitely helps mood and libido as well as immunity. I have all my friends on it and some swear they never get ill anymore even with extensive travelling schedules, and wouldn't give it up for anything.

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Jaquelyn M *Actually most of my fellow practitioners happen to be autism specialists and alternative or anti-aging doctors, and are for the most part grateful to have another therapy in their armamentarium to treat difficult populations. I've heard a lot of stories about patients having difficulty even getting a prescription, however, and the ignorance of my colleagues to even investigate the situation is very disheartening.*

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Jaquelyn M *Primarily what has helped me the most is the support and love in a wonderful marriage of 33 years to a rare man who has actually gone beyond patriarchy and truly honors and enjoys having an empowered woman for a partner. And needless to say it has been especially heartening to see children previously thought to be untreatable getting better and being enabled to have much more independence in their lives than ever thought possible with the knowledge and treatments now available, including LDN.*

Writing a successful book on the biomedical treatment of autism 'Children with Starving Brains' that has sold 50,000 copies and been translated into three and soon to be five different languages has also given me a lot of satisfaction, inspired by the love for my wonderful granddaughter with autism who though not completely recovered, has definitely benefited from my efforts.

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Jaquelyn M *For one thing, autoimmune conditions are extremely complex and poorly understood by even most medical professionals, much less the lay public. Fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities are a few of these disorders that have up until quite recently been considered 'psychosomatic' and not 'real' illnesses by many in the past who had no idea what was causing the illnesses, or any knowledge of how to treat these kinds of patients. The sheer increase in these disorders has brought much more knowledge and understanding currently, so there is hope that these kinds of views will be more honored and investigated now than in the past.*

Secondly, LDN being made from a generic drug that no one can own creates a situation where large research studies that can only be conducted by wealthy drug companies will never happen, as corporate profits are not a motivation.

This is why I have gone to Africa to get a study done. Also, that country stands to benefit the most from an inexpensive non-toxic remedy that could help millions of unfortunate persons there with HIV+ status to survive if our study proves it to be effective, and especially if we can get it manufactured there. As more studies are conducted, I believe the situation will change.

Unfortunately, I believe that many busy doctors after starting practice get their primary continued medical education from drug reps, and drug reps are not about to talk about (or give samples of) a cheap generic drug that might compete with the profits being made by pharmaceutical companies.

Cris *Dr McCandless, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the*

investigation of a treatment with much potential to alleviate suffering, but as yet very little support.

Jaquelyn M *You are very welcome; I hope many people take advantage of the knowledge and experience you are offering them.*

(1) Jaquelyn McCandless, MD, Certified by the American Board of Psychiatry & Neurology, Autism Specialist and Physician Trainer, Author, '*Children with Starving Brains, a Medical Treatment Guide for Autism Spectrum Disorder*' and '*Flesh & Spirit, the Mystery of Intimate Relationship*' both by Bramble Books.

(2) Cris Kerr, Administrator, casehealth.com.au

Skip

How and when did you first discover the potential benefits of low doses of naltrexone (LDN)?

Skip L *A patient called the pharmacy in 1999. He'd heard of this new drug and wanted to know if I knew anything about it. I contacted Dr Bihari and had several conversations with him prior to us dispensing it. Several months and several dozen patients later, we started to hear of very positive effects.*

Cris *The compounding of low doses of naltrexone needs to be exact and of the highest possible quality and consistency. Were there any early lessons learned when you first began compounding LDN, and if so, what effect did that have on your compounding procedures?*

Skip L *We started compounding using the commercial tablet, but we found the patients taking capsules compounded from commercial tablets were not getting the same benefits as the patients who took capsules compounded with naltrexone powder. It's now 2008 and we've learned a great deal since then. We now add food coloring to ensure the naltrexone is distributed evenly through each compounded capsule, and we now have our capsules assayed. The additional checks and balances we've introduced have resulted in an average distribution range of 99.7% to 100.3% of active compound in each capsule, exceeding any accuracy range published to-date.*

Cris *At what point did you realise you wanted to learn more about LDN?*

Skip L *Within the first few months of hearing about it, in 1999.*

Cris *How many patients are presently using Skips Pharmacy to fill their prescriptions, and what is the degree of positive or negative feedback you've received? Have you recorded and measured that feedback to share with others?*

Skip L *At present we're filling prescriptions for over 10,000 patients. We felt it was very important to track and measure feedback, and as a result we've recorded that 83% of patients using our pharmacy have a positive response to LDN.*

Cris *Since becoming more outspoken on the benefits of LDN and devoting more of your time to supporting patients taking LDN, what have you learned or experienced?*

Skip L *Each patient is different, so each time we dispense LDN we conduct an N=1 study. The power of the internet is extreme when it comes to any untoward effects; that is to say, there is a reverse-placebo effect that is inevitably highlighted through the internet. When one patient has an unexplained untoward effect, the first thing they blame is the filler. At the New York Academy of Science, an issue was raised that Calcium carbonate was not a good filler. The next year, at the National Institute of Health, I presented a paper on the disintegration profile of Calcium Carbonate and suggested that because of its inherent compact-ability, it was inappropriate to use as a filler. We then suggested Avicel would be the best filler because its hypo-allergenic and releases immediately, which is a highly desirable characteristic for this particular protocol. Subsequently an urban myth has grown around the use of Avicel, suggesting a large proportion are allergic to it. This is not true, yet it is still perpetuated.*

Cris *With regard to LDN, what aspects, if any, are you most concerned about?*

Skip L *I'm concerned about the uncontrolled growth of patients using LDN without any concern for the science. We are getting more and more enquiries about LDN for diagnoses that do not have an auto-immune vector. Subsequently, if they begin LDN and the product fails, the medical establishment can point to LDN as another example of quack medicine.*

Cris *Are you aware of the range of diseases suffered by patients who fill their prescriptions through your compounding pharmacy, and if so, what are some long-term successful examples?*

Skip L *Our primary focus has always been MS. We have patients that have had no exacerbations in over 5 years. The longest time between exacerbations has been 9 years. This is significantly longer than any published data on any other MS drug.*

Cris *With regard to LDN and the knowledge you've gained through patient support, what do you believe are key factors in successful patient outcomes or failures?*

Skip L *Realistic expectations most definitely improve outcomes for those starting on LDN. Over the years there've been hundreds of stories on the internet suggesting LDN is a miracle cure for many diseases. But, when patients are encouraged to slow down and do some research first, they learn what they can and can't expect from LDN. They learn LDN is not a miracle cure, but that it can reduce their exacerbations and decrease the rate of their progression. Those who know what to expect are those most likely to continue with the therapy, and subsequently benefit from it.*

Cris *You provided sponsorship for a couple of the now annual LDN Patient Conferences, and your wife Cyndi and son Adam have been heavily involved in videotaped records of those conferences. What first prompted this extended family involvement, and how has that impacted on your family?*

Skip L *I was going to the NIH conference and Cyndi asked to come along. At the time she was a film student and wanted to test her ability to create a documentary on LDN. Adam was also studying digital media at UCF and was our AV guy. After each conference we've filmed, there has been a coming together of the family around getting this information out.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Skip L *The scientific establishment holds anecdotal data as invalid. Physicians have become afraid of litigation stemming from the prescribing of novel drugs. We have forgotten that the vast majority of drugs available in the world are the result, not of well controlled placebo double blinded cross over studies, but of empirical experimentation by physicians.*

Cris *Skip, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you for everything you do to support patients, and thank you for continuing to provide a consistently high quality compounding service that's so integral to success with LDN - and is ultimately, a key partnering factor in the alleviation of suffering.*

- (1) Dr Skip Lenz, Pharmacist, Skips Pharmacy, Florida, USA
- (2) Cris Kerr, Administrator, casehealth.com.au

LDN Research Trust - Fact Sheet 2008

Telephone: 0871 989 9666

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www.ldnresearchtrust.org

Low-dose Naltrexone in the Treatment of Multiple Sclerosis Dr Bob Lawrence MRCS; LRCP

Naltrexone is a class of drug known as an opiate antagonist. Its normal use is in treating addiction to opiate drugs such as heroin or morphine. The dose used for this purpose is usually between 50 and 150 mg each day.

Low-dose Naltrexone (LDN) has been used in the treatment of MS in the USA since 1985, but is relatively new in the United Kingdom. Despite the fact that the drug is used at a very low dose, the occurrence of significant introductory or long-term side effects cannot be excluded.

This method was devised and subsequently developed by Dr Bernard Bihari, a neurophysician in New York, USA. Dr Bihari is qualified in Internal Medicine, Psychiatry and Neurology, but has recently retired from practice. The main website is www.lowdosenaltrexone.org

The introductory dose is just 3 mg for the first month of treatment. It has been reported that those receiving this drug in the treatment of MS experience a range of benefits, including reduced spasm and fatigue, and improvements in bladder control, heat-tolerance, mobility, sleep, pain, tremor and others. After this period (in the absence of any introductory side effects), and for greater therapeutic response, the dose can be increased to the current maximum recommended dose of 4.5 mg per day, to be taken between 9 at night and 3 in the morning. LDN only stays in the system for 4 hours. For those unable to tolerate even the 3 mg dose, lower doses of 1 or 2 mg are available. Such doses are intended to introduce the therapy more slowly, allowing more time for the necessary endorphin response to develop.

How Naltrexone Works: The benefits of the drug are apparently due to the temporary inhibition of endorphins (a natural pain-killer, produced in the brain). This results in a reactive increase in the production of endorphins, which should result in a reduction of painful symptoms, and an increased sense of wellbeing.

Increased levels of endorphins should be expected to stimulate the immune system, promoting an increase in the number of T lymphocytes. This effect was observed in Dr Bihari's research. This increase in T-cell numbers apparently restores a more normal balance of the T-cells such that the effects of the disease process are significantly reduced. It has been observed that in those suffering the relapsing-remitting form of MS the number of relapses is reduced, and the rate of progression of the disease is diminished. In chronic progressive MS (either primary or secondary) there seems to be a similar reduction in the progression of disease symptoms.

Dr Bihari's research suggested that no one receiving this treatment as a regular therapy has experienced a relapse while actually on the treatment. Occasionally however, there may be a short-term increase in symptoms during, for example, periods of infection or stress. This arises from previously active lesions already present in the brain or spinal cord.

Despite these promising findings it must be emphasized that a positive beneficial response to this treatment cannot be assured or guaranteed.

The Use of Low-dose Naltrexone in MS, and the Occurrence of Side Effects Introductory Symptoms

When starting LDN there might be a temporary increase in MS symptoms such as weakness, changes in sensation, muscle spasm, pain, fatigue or tiredness. These initial symptoms may also include changes due directly to the altered level of brain endorphins, such as disturbed sleep, occasionally with vivid, bizarre and disturbing dreams. These symptoms usually disappear within the first week of treatment, and are replaced by improvements in specific symptoms.

The initial increase in symptoms can also be explained when we consider the manner in which the drug works. Contrary to the common belief that MS is due to over-activity of the immune system, MS actually

occurs due to a reduction in immune system activity. Specifically, it is the reduction in the number of the suppressor T-cells within the immune system that allows CD4 helper T-cells to do damage. Thus, during an acute relapse the overall number of T-cells is reduced, the normal balance of helper and suppressor T-cells is disrupted, and helper T-cells tend to predominate. This is most pronounced during an acute relapse, but a similar situation occurs although perhaps to a lesser extent, in chronic progressive MS.

It has been demonstrated that in the presence of LDN, the numbers of T-cells may increase by more than 300%. Therefore, when the number of T-cells is initially increased, the predominance of CD4 helper T-cells may increase the intensity of the MS, temporarily increasing some symptoms. However, as the number of T-cells continues to increase the normal balance of suppressor to helper T-cells is restored, the activity and intensity of the disease process is reduced, and symptoms once again diminish.

In less than five percent of cases treated, increased introductory symptoms may be more severe or more prolonged than usual, lasting sometimes for several weeks. Rarely, symptoms may persist for two or three months before the appropriate beneficial response is achieved. In this situation, an ultra-low dose may be introduced to provide a gentler introduction to the drug.

Symptoms Related to the Endorphin Response

If the endorphin response is rapid and significant, there may also be some additional symptoms related to the increased level of endorphins, including nausea and constipation. The nausea usually fades within a few days, and can be minimized by taking a lower dose of the drug until the symptoms lessen. The constipation may take two or three weeks to resolve, during which time additional supportive measures may be required.

If constipation has been a symptom prior to LDN treatment, this might be related to the MS itself, or it could be due to the consumption of foods known to cause sensitivities, such as cow's milk or wheat. Such food sensitivities are known to promote a range of symptoms collectively referred to as irritable bowel syndrome (IBS). IBS symptoms can include abdominal bloating, flatulence, gastric or abdominal pain, diarrhoea or constipation, or a condition alternating between the two. IBS can also increase urinary symptoms of frequency or urgency.

If constipation has been a problem in the past, it is vital that measures should be taken to minimize this before starting LDN. You should eat plenty of fresh or dried fruit, and fresh vegetables. In addition, food sensitivities should be avoided by excluding foods most likely to cause the problem, that is, cow's milk and wheat.

Stool softeners such as Lactulose, Codalax, Docusate sodium (Diocetyl or Docusol) may be used. Bowel stimulants such as Dulcolax or Senokot may be more effective, but should be used only occasionally or avoided if possible, as there will be a tendency to become dependent upon them. Bulking agents such as Celevac, Fybogel, or Normacol may be useful, but tend to be less effective than stool softeners.

Commercial laxative bought over the counter at the chemist's often contain phenolphthalein. These products should be avoided completely, as the substance is highly addictive with a rapidly acquired dependency. They appear to solve the problem initially, but continued use of such products will make the constipation much worse!

Symptoms Related to the Inclusion of Lactose Filler

It has become apparent that some patients using LDN with lactose filler have experienced increasing muscle stiffness and/or joint pain after a few weeks of therapy. This delayed increase in symptoms is believed to be due to an increased sensitivity to the lactose filler used in the LDN supplied by some pharmacies.

Symptoms Related to Prior Use of Opiate Analgesics

Occasionally, other transient symptoms have included severe pain and spasm, headache, diarrhoea or vomiting. These additional symptoms appear to be associated with previous frequent use of strong analgesics, which create addiction and dependency, thus increasing the body's sensitivity to pain.

Therefore, it is vital that all strong analgesics, including opiates such as codeine, co-hydromol, co-codamol, dihydrocodeine, tramadol, morphine, pethidine, and diamorphine should be avoided for at least two weeks prior to treatment with LDN.

Symptoms Related to the Intrinsic Toxicity of the Drug

From toxicity studies of naltrexone in the early 1980's, reversible liver changes were found to occur only in those receiving doses higher than 300 mg per day. This is on average one hundred times the dose used in LDN; that is, the dose of LDN is just 1% of that shown to cause even reversible liver changes. The possibility of adverse side effects due to drug toxicity cannot be entirely excluded, but the likelihood of damaging side-effects is believed to be minimal, as the drug is used at such a low dose. Long-term use of LDN has not yet been evaluated by a trial. However a trial is planned, and it is hoped that it will be conducted in 2008 when adequate funding has been found.

In the meantime, due to possible toxic effects of long-term use of LDN on the liver and kidneys, it is required that anyone suffering previous liver or kidney problems should report this condition before starting therapy. The risk is believed to be minimal, however, as the dose of the drug is extremely low, and it is expected to be metabolized and excreted from the body within three or four hours of ingestion.

Suggested Method of Therapy

Take 3 mg daily for the first month, then 4.5 mg daily thereafter. If the 3 mg dose is hard to tolerate, doses of 1 or 2 mg may be used instead until your body adjusts. If you notice an increase in symptoms when taking 4.5 mg, it might indicate that this dose is too high for you. In this case lower the dose, and improvements should become apparent.

Contraindications and Special Precautions:

LDN stimulates the immune system, whereas many of the drugs routinely used by the NHS in the treatment of MS suppress the immune system. Therefore, LDN cannot be used whilst taking steroids, beta-interferons, methotrexate, azathioprine, mitoxantrone or any other immune-suppressant drug. If there is any doubt, please submit a full list of the drugs you are presently taking so that their compatibility can be assessed. Note: LDN can be taken with copaxone, as this is not an interferon.

LDN Dosage update

We receive some phone calls from people that are experiencing problems adjusting to LDN. Here are a few guidelines.

Starting dose

- Normally 3 mg
- If spasms or stiffness are a symptom before starting, then a lower starting dose of 2 mg should be used.
- In severe cases a starting dose of 1 mg should be used.

Increasing dosage

- LDN can usually be increased from 3 mg to 4.5 mg after a month.
- In the case of side effects or spasms it is best to increase the dosage 0.5 mg at a time, normally in 2-week stages.
- If the higher dose has an adverse effect at any time, it is best to reduce the dose and try again when the side effects have gone.

Continuing Dose

With LDN the dosage is subjective. Some people find a dose as low as 2 mg works best for them. Many men cannot tolerate a dose higher than 3 mg as it worsens symptoms.

LDN in the UK

LDN is available in liquid form, either privately or on the NHS, from Dickson's Chemist in Glasgow. The liquid suspension cost £15 a month, and is sent by monthly recorded delivery to your home. There are no problems with fillers; it keeps for 28 days at room temperature, 56 days in the fridge. Capsules are also available at £27 monthly with Avicel filler. Further costs are involved if you live outside the UK. To find out more call Paula at Dickson's in Glasgow on: 0141 647 8032.

SHARED VISION FOR HEALTH

by Cris Kerr, Administrator & Community Health Researcher
'Case Health-Health Success Stories' website, 23rd October, 2007

Health systems should be recording and sharing successful health outcomes ... because success breeds success ... and because when the path to success is shortened, people suffer less and productivity from the same limited health resources is enhanced.

Premise

When you want to achieve success in any field the first thing you do is research how others have achieved success.

In the standard western medical system, successes and failures should be recorded and shared within a framework - alternately referred to as Evidence-based or Outcome-based Medicine - with the primary goal being the application of best long-term practice in diagnosis, patient care, and treatment outcomes.

Such a framework has obvious merits but historically, the patient's perspective hasn't been sought and included as corroborating evidence. Typically, the health system;

- 1) doesn't place sufficient value on confirming success or failure via the patient perspective, and;
- 2) doesn't record or recognize success or failure when/if it occurs outside the standard medical system.

Who is in the best position to provide evidence of health success or failure? Arguably, it's the patient.

Advocacy

The Case Health online database was created to fill this gap in the health system, and advocate the value of patient testimony. I encourage individuals to freely share information on health success in the hope of making the path to health success shorter and less stressful for others.

The website collects and shares health success stories (personal or research) through an online database. Keywords are attributed to each story and this framework serves a dual purpose:

The database can be searched by symptom, condition, or treatment so patients can discuss what they've found with their doctor. The database also collects significant research findings, so analysts can gain 'insights' into cause and effect and develop theories for curiosity-driven research, or gain insight into public health statistics, benefits, or risks.

There are many ways people can contribute to their communities but most haven't considered information as one of those ways. They can help improve another person's health by sharing detailed information on how they achieved their own health success - and if they do that they contribute something more valuable than cash to their community.

Optimum health is a universal goal. Challenges and resources differ between countries - but we are all human and we all share the same desire - to acquire and employ knowledge that results in the least invasive and least expensive path to optimum health.

My Case Health website recorded its first controversial Low Dose Naltrexone (LDN) treatment health success story in November 2003. A significant increase in LDN linked success stories prompted me to write the article; * 'Drug Stops Multiple Sclerosis - But Sufferer's Can't Get it'. The article highlights the growing number of LDN health success stories linked to many auto-immune based diseases, the absence of mainstream recognition of patient testimony, and; advocates for health framework reform.

The Case Health website remains at concept stage, however; the article *'Drug Stops Multiple Sclerosis - But Sufferer's Can't Get it' represents an inaugural proof-of-concept document.

'Case Health - Health Success Stories' is a free worldwide community health service website that collects

and shares patient anecdotal evidence of success and news of significant research results. The site was created in 2001 and is located online at casehealth.com.au and casehealth.com.

Proposal - Vision for Health Reform

With governments around the world presently considering or developing new health frameworks, I hope you'll agree the timing is right for visionary reform:

Our health systems should be recording and sharing health successes and failures (learnings), including patient perspectives because;

- a) success breeds success and when the path to success is shortened, people suffer less, and;
- b) because 'learnings' can alert us to risks associated with failure, consequently reducing risks.

What would a 'Shared Health Accomplishments and Research Environment' look like?

1. A robust, secure health IT infrastructure sharing successes so they can become repeatable and sustainable, and; sharing failures so they can be avoided.

1a. A new Medicare rebate would be paid to all Health Professionals who're prepared to spend time documenting and sharing detailed patient histories of successes and failures (learnings) through a central database. Implementing this type of framework not only acknowledges quality patient care and treatment but ensures success is repeatable and sustainable, and; guards against treatment failure.

To substantiate the integrity of submissions, the patient would confirm or counter-sign. The database would build slowly, with integrity, and therefore grow more valuable with time, delivering ever-increasing dividends for the future.

A 'weighting' would be applied to each submission, depending on the qualification of the Health Professional. Submissions by less qualified allied health professionals would initially be assigned a lower 'weighting' but would attract a higher 'weighting' as the volume of corroborating testimonies increases.

1b. In acknowledgement that any person who's achieved success or experienced failure has information of value to share, the database would accommodate all health successes and failures; including those that occur outside the standard health system. Any individual could opt to submit their health story details, that is; how they achieved success or how they failed (what they learned) - so they may contribute to the volume of knowledge. Submissions would be 'weighted' accordingly but would attract higher 'weighting' with regard to public health benefits or risks, or when the volume of corroborating testimonies increased.

1c. The framework would be governed by systems and processes that promote equity and quality, and guard against infiltration of conflict of interest, commercialisation, or bias to maintain database integrity and protect this valuable investment in the future health of all.

1e. Database searches (non-personalized details only) would be freely accessible to all, including health researchers, analysts, and the general public. Names and addresses would be protected by law, secured, and shielded in a separate database - and would therefore not be accessible via search, however; special dispensation could be given for a rare event - such as research or analysis that indicates a major public health benefit or risk necessitating deeper analysis, evaluation or validation.

When Health Systems are documenting and freely sharing all successes and failures, including patient contributions, quality and productivity from the same limited health resources will be dramatically enhanced and people will suffer less.

(1) *Alternate version entitled 'Anecdotal evidence points to relief for MS sufferers' was published on ONLINEopinion Australia's e-journal of social and political debate, 3rd January, 2006
- URL onlineopinion.com.au/view.asp?article=3905

(2) Published by OnlineOpinion 23rd October, 2007:
- URL onlineopinion.com.au/view.asp?article=6531

Bad things Happen When Good People do Nothing

by Cris Kerr, Administrator & Community Health Researcher
'Case Health-Health Success Stories' website, July 2008

The Low Dose Naltrexone (LDN) Treatment Protocol developed by Dr Bernard Bihari first came to my attention around five years ago, in 2003. I learned of LDN, because I valued what patients themselves said was working for them.

I'm not a qualified health researcher, but what I've learned from the patients themselves through collecting and sharing their health case studies has been invaluable.

I've learned, for example; that you're unlikely to hear of a treatment option that has potential to halt or slow progression of a range of diseases linked by immune system dysfunction. LDN is not a cure, and not everyone achieves success with LDN ... but it does work, and it's been working for patients since the 1980s.

*"No one would have crossed the ocean
if he could have gotten off the ship in the storm."
Charles Kettering*

As with most medications, there can be side effects to contend with. From observations, the most common is initial sleep disturbance, and; in the case of some diseases such as progressive forms of Multiple Sclerosis, there's also a possibility of exacerbation in the first six months of treatment.

I've also learned from observations that those who don't succeed with LDN often have a long and recent history of medication reliance, or have deferred making complementary lifestyle changes. In particular, abrupt cessation of opioid-based (narcotic) pain medications, steroids or other immune system suppressants following a lengthy period of reliance can result in withdrawal symptoms or rebound effects, and hence, abandonment of LDN as a treatment option.

This is an understandable 'catch 22'. We want the 'high impact' health fix for many reasons: We can't afford time off work or for our boss to discover our health's been compromised, or we have families relying on us to care for them – and so we lean on the health solution that helps us get on with our day-to-day lives with the least interruption - but not necessarily in the least invasive way.

*"The world hates change,
yet it is the only thing that has brought progress."
Charles Kettering*

Just as it takes more time and more precision to drive in a nail with a hand-held hammer than it does a sledgehammer, there's far less scope for error with LDN, and hence, a greater need for patient research and preparation, protocol precision and patience. Yet surprisingly, clinical trials of low doses of naltrexone have diverted from Bihari's well-established and successful protocol; as did a German clinical trial that switched to morning doses in response to patient sleep disturbance, and hence, did not achieve the same degree of successful outcomes.*

"The good we secure for ourselves is precarious and uncertain until it is secured for all of us and incorporated into our common life."

Jane Addams

Clinical trials of LDN are needed, but as some would need to run for six to twelve months or longer, they'd be costly. Naltrexone has long been 'off-patent', so the pharmaceutical companies that initiate clinical trials are unlikely to perceive this particular unmet market need as potentially profitable and worthy of investment.

Commercialism can benefit markets - but there are distinct areas where commercial markets should not dominate, infiltrate, conflict, or otherwise influence to the detriment of the greater public good. Indeed, the story behind LDN infers the health market scales have long been tipped too far in favour of commercialism and are in need of re-balancing.

'Optimum quality of life' is a basic human right that should stand tall, above all other rights. It is sacrosanct and must therefore be protected from the taint of 'conflict of interest'. Societies thrive in an environment of fair play and balanced needs, and there is no greater need for fair play and balance than in health.

*"Man Cannot Discover New Oceans
Unless He Has the Courage to Lose Sight of the Shore"*

Andre Gide

Meanwhile, a low-cost treatment with a reasonable safety profile and reasonable potential to alleviate human suffering is still being disregarded and summarily dismissed. Our fellow humans - our mothers, fathers, partners, children, friends, and neighbours – have been, or are still being denied a treatment option that might improve their quality of life or prolong their life – are being denied a chance where there may otherwise be none – a situation that is unjust, senseless, sad and haunting if you dwell, as I do, on its implications.

*"We should all be concerned about the future
because we will have to spend the rest of our lives there."*

Charles Kettering

We know patients are being denied a treatment with potential to enhance their quality of life or alleviate suffering, and we know this is being justified by 'unproven efficacy', and in the interest of 'patient safety'. We also know denial of this treatment option has sometimes been weighed against the possibility of litigation.

Well, there are many ways to do harm. You can directly harm by doing something, and you can indirectly harm by doing nothing. Through a brilliant piece of satire, the final episode of the Jerry Seinfeld series confronts us with four observers who indirectly cause harm to another human being by doing exactly that, nothing.

*"Never doubt that a small group of thoughtful, committed citizens
can change the world. Indeed, it is the only thing that ever has."*

Margaret Mead

Most current knowledge of LDN efficacy and safety remains limited to a handful of small clinical trials and patient testimony, which is spread randomly from one patient interest group to another, making it easy for the scientific community to ignore, disregard and summarily dismiss

as they would a single grain of sand. To divide is to conquer, and while this continues, nothing will change.

Case Health has been striving to bring the evidence together in one central database, and has created this free e-book to help build awareness of the collective 'volume value' potential of patient testimony as case studies. The collective is greater than the single, and a grain of sand can become a beach stretching as far as the eye can see.

It's my greatest hope Case Health's increasing volume of patient testimony will result in the scientific community acknowledging presently held tenets are not static or absolute, and that a central store of corroborating patient testimony;

- has immense potential to provide valuable public health 'insights and learnings';
- can help validate successful health outcomes, and;
- can attain 'volume value' in its own right.

*"In ancient China, the doctor was only paid when the patient was well.
In modern health systems, perhaps your visible success
should depend on health outcomes ... ",*

HRH The Prince of Wales, Prince Charles

I maintain faith our inherent human capacity for compassion and fairness will influence those who can help overcome resistance and progress the return of patients to their rightful place at the core of our health systems, in acknowledgement of the value they can add through their testimony.

*"Through our scientific genius
we have made of the world a neighborhood;
now through our moral and spiritual genius
we must make of it a brotherhood."*

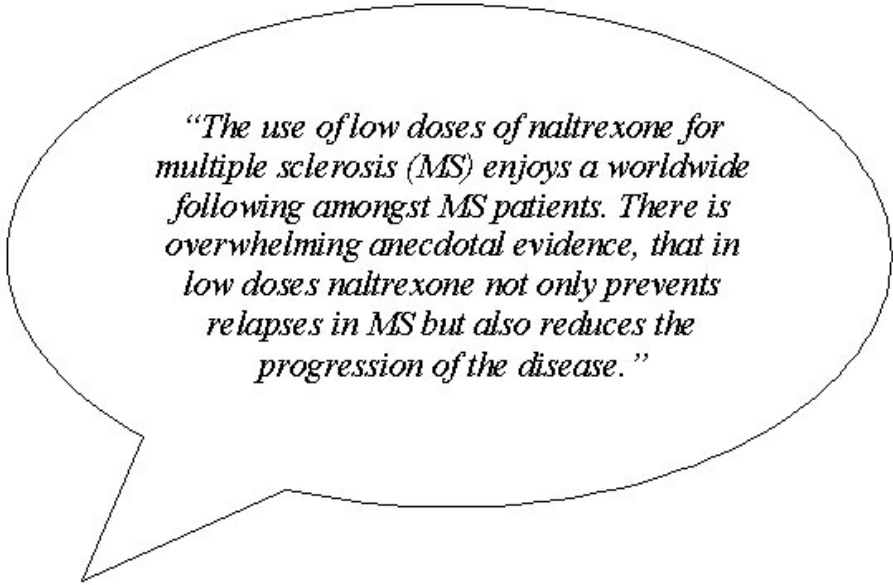
Dr. Martin Luther King, Jr.

It's my greatest hope governments around the world presently reviewing and implementing long-term visions for improving population health will welcome, accommodate, and integrate patient testimony as a valued, protected, and integral part of their public health IT systems.

*'A society grows great when old men plant trees
whose shade they know they shall never sit in.'*

Greek proverb

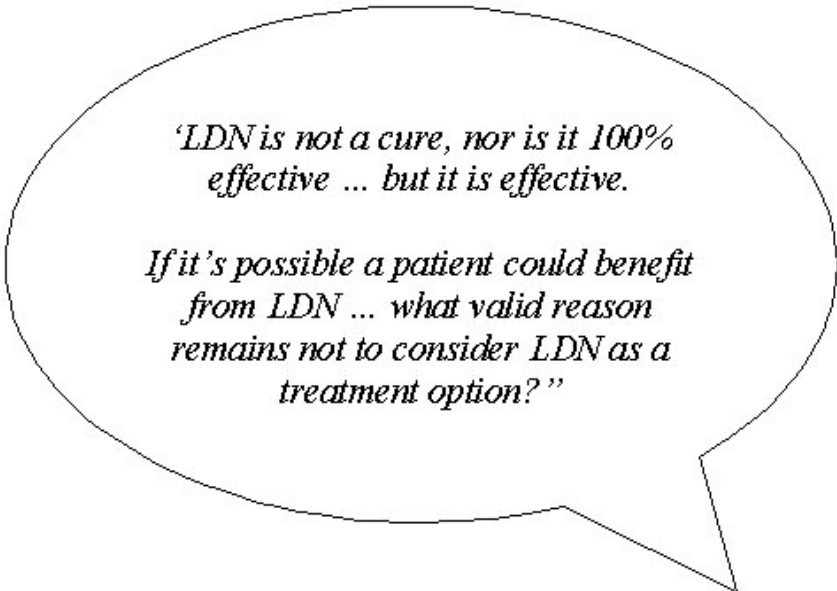
*Ref: Dr. Evers Trial in Germany for Multiple Sclerosis (MS)
http://www.lowdoseofnaltrexone.org/ldn_trials.htm



"The use of low doses of naltrexone for multiple sclerosis (MS) enjoys a worldwide following amongst MS patients. There is overwhelming anecdotal evidence, that in low doses naltrexone not only prevents relapses in MS but also reduces the progression of the disease."

Dr David Gluck

Source: ldninfo.org



'LDN is not a cure, nor is it 100% effective ... but it is effective.'

If it's possible a patient could benefit from LDN ... what valid reason remains not to consider LDN as a treatment option?"

Cris Kerr, November 2007

Media

Video News & Testimony

Video News

'Wonder drug?'

Health Check - Article & Video by Ali Gormon, R.N.
Featuring Crohn's patient Pam Sweigart and Dr Jill Smith
Thursday, May 22, 2008 | 10:16 AM
Penn State College of Medicine, Hershey, Pennsylvania
LDN clinical trial for Crohn's Disease
ABC6 Action News, Philadelphia, Pennsylvania USA
http://www.abcclocal.go.com/wpvi/story?section=news/special_reports&id=6156884

'Wonder drug?'

Health Check - Article & Video by Ali Gormon, R.N.
Featuring Multiple Sclerosis patient Lori Miles
CBS47 News, Jacksonville, Florida (on Youtube)
<http://www.youtube.com/watch?v=Kz52KK5lhOc>

'Drug Addiction Medication May Treat Other Diseases'

Health Watch - Article & Video by Dr Max Gomez
Featuring MS patient Ronnie Raymond and Dr David Gluck
May 26, 2008 7:33 am US/Eastern
CBS WCBSTV News Report, USA
<http://wcbstv.com/topstories/lo.dose.naltrexone.2.732830.html>

Video Testimony

Vox Pops

Second Annual LDN Conference: 'The Future is Now'
National Institute of Health Campus, Bethesda Maryland
2006
produced By Cyndi & Adam Lenz (tdgr2productions.com)
Main: LDN Conference 2006 - 'The Future is Now' DVD

'The Future is Now 2006' DVD Montage

Pat Crowley, Dr Phil Boyle, Dr David Gluck, Mary Boyle-Bradley, Dr Jaquelyn McCandless,
Dr Skip Lenz-Skips Pharmacy
<http://www.youtube.com/watch?v=aA7VihTWBMU>

Third Annual LDN Conference: 'Breaking Down Barriers'
Vanderbilt University Campus - 20 October 2007
produced By Cyndi & Adam Lenz (tdgr2productions.com)
Main: <http://www.youtube.com/user/TropicalDawg>

'LDN Doctor Advocates Speak 2007'

Dr Jill Smith, Dr Terry Grossman, Dr Joseph McWhirter, Dr Burt Berkson, Dr David Gluck
<http://www.youtube.com/watch?v=DAZ1fQKdOC8>

'Dr David Gluck Speaks 2007'

Progress of Dr Mira Gironi's MS clinical trial, Italy
Progress of Dr Bruce Cree's MS clinical trial, Univ of California, San Francisco
<http://www.youtube.com/watch?v=ctnm7cv-EXY>

'Dr David Gluck Speaks 2007'

Dr Gluck presents Dr Jaquelyn McCandless clinical results in Autism, and planned HIV trial in Mali, Africa
<http://www.youtube.com/watch?v=1N3o4ggTnUI>

'Dr Patrick Crowley Speaks 2007'

Dr Crowley is in Private Practice in Scotland
He shares his survey results on 50 MS Patients
<http://www.youtube.com/watch?v=kclMin66Sf4>

'Dr Phil Boyle Speaks 2007'

Dr Phil Boyle is a Family Physician & Infertility Specialist
Dr Boyle shares his clinical experience in prescribing LDN
<http://www.youtube.com/watch?v=1sZGQqYTVBg>

'Dr Terry Grossman Speaks 2007'

Dr Grossman presents a case study: Treatment for Stage 4 Renal Cell Cancer, Claudia Feb04
<http://www.youtube.com/watch?v=XbYC0R5uKzE>

'LDN Patient Advocates Speak 2007'

Janet Kunselman, Susan Benz, Fritz 'Goodshape' Bell, Anon
<http://www.youtube.com/watch?v=D0HsgCgboGk>

'LDN Patient Advocates – Conference Opening 2007'

Susie Sedlock and Brenda Powell opening the Third LDN Conference
<http://www.youtube.com/watch?v=CND5sp2ErDg>

'Noreen Martin Speaks 2007'

Noreen Martin, Author, Surviving Aids & Cancer
http://www.youtube.com/watch?v=_Nh-t3LA6e4

'Mary Boyle Bradley Speaks 2007'

Mary Boyle Bradley, Author, 'Up the Creek with a Paddle'
<http://www.youtube.com/watch?v=WCTwLbRX2Ys>

Documentaries

LDN Documentary

This earliest known documentary includes an interview with Dr Bernard Bihari prior to his retirement
Dr Patrick Crowley, County Kilkenny, Scotland
http://www.lowdosenaltrexone.org/_conf2006/P_Crowley1.mov

Media Other News

News Articles

'Telling the world how it feels'

Sydney Morning Herald, online, 24 April, 2008

<http://www.smh.com.au/news/science/telling-the-world-how-it-feels/2008/04/23/1208743039836.html>

'The Drug that gave me back my life'

by Sarah Spediff, Independent, Ireland, 5 May, 2008

<http://www.independent.ie/health/case-studies/the-drug--that-gave--me-back--my-life-1367070.html>

'Low Dose Naltrexone (LDN) and MS'

Article by Ronald Hoffman, MD, and Skip Lenz, Pharm D FASCP

Magazine of the United Spinal Association online, January 25, 2008

<http://www.unitedspinal.org/publications/action/2008/01/25/low-dose-naltrexone-ldn-and-ms>

'Firefighters help one of their own'

By Denise Sinclair, Daily Home online, Sylacauga, USA, 13 September 2006

<http://www.dailyhome.com/news/2006/dh-sylacauga-0913-dsinclair-6i12v2419.htm>

Addiction Remedy Studied For Crohn's Disease Relief

By David Wenner, staff writer for The Patriot-News of Harrisburg, Pennsylvania USA

<http://www.newhouse.com/addiction-remedy-studied-for-crohns-disease-relief-2.html>

References

- (1) Low Dose Naltrexone Org – edited by David Gluck, MD - <http://www.lowdosenaltrexone.org> & <http://www.ldninfo.org>
- (2) LDN Research Trust, UK – Linda Elsegood - <http://www.ldnresearchtrust.org>
- (3) Case Health - Health Success Stories – Cris Kerr - <http://www.casehealth.com.au> & <http://www.casehealth.com>
- (4) Dr M R (Bob) Lawrence, Dietary Research Ltd, Wales, UK - <http://www.msrf.co.uk/index.cfm?fuseaction=show&pageid=651&CFID=4799847&CFTOKEN=68687005>
- (5) LDN Clinical Trial in Multiple Sclerosis – patient-funded - <http://www.mscenter.ucsf.edu/research.htm>
- (6) All LDN Clinical/Animal Trials - http://www.lowdosenaltrexone.org/ldn_trials.htm
- (7) Oral Presentation at the IV International AIDS Conference in Stockholm , June 1988 - http://www.lowdosenaltrexone.org/ldn_aids_1988.htm
- (8) Jill Smith, Professor of Gastroenterology, Pennsylvania State University, 'Low Dose Naltrexone Therapy Improves Active Crohn's Disease, American Journal of Gastroenterology, Jan 11 2007 - http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&list_uids=17222320
- (9) The long-term survival of a patient with pancreatic cancer with metastases to the liver after treatment with the intravenous alpha-lipoic acid/low-dose naltrexone protocol - http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=16484716&query_hl=1&itool=pubmed_docsum
- (10) Burton Berkson, MD, PhD – presentation, National Cancer Institute meeting – April 2007 - http://www.lowdosenaltrexone.org/mm/Berkson_Presentation_Apr_2007.pdf
- (11) Autism – dietary considerations – gluten & casein - Kalle Reichelt, M.D. 1991 http://en.wikipedia.org/wiki/Gluten-free,_casein-free_diet
- (12) Agrawal YP – Low-dose naltrexone in multiple sclerosis – Med Hypotheses 2005;64(4):721-4 – Science Direct (Elsevier) - http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6WN2-4F3FDWS-3&_user=10&_coverDate=01%2F01%2F2005&_alid=767767282&_rdoc=2&_fmt=high&_orig=search&_cdi=6950&_sort=d&_docan=chor=&view=c&_ct=2&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=2bfd6c6cf74df22fc041c216f05caa24
- (13) Bernard Bihari, MD – Curriculum VITAE & papers - http://www.lowdosenaltrexone.org/bbihari_cv.htm
- (14) Ian S. Zagon, PhD - Professor of Neural and Behavioral Sciences, Pennsylvania State University – <http://www.fred.psu.edu/ds/retrieve/fred/investigator/isz1>
- (15) Jaquelyn McCandless, MD, Jack Zimmerman, PhD – HIV clinical trial Mali - http://www.lowdosenaltrexone.org/developing_nations.htm
- (16) Experimental Evidence for Immunomodulatory Effects of Opioids, Landes Bioscience - <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=eurekah.section.10979>
- (17) Role of nitric oxide in inflammation mediated neurodegeneration – PMID: 12076984 - http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=PubMed&list_uids=12076984&dopt=AbstractPlus
- (18) Dr Pat Crowley, County Kilkenny, Scotland – LDN Documentary http://www.lowdosenaltrexone.org/conf2006/P_Crowley1.mov
- (19) Dr Skip Lenz, Skip's Pharmacy, Florida – Survey 2006 - <http://www.ms-people.com/forum/index.php?s=dfe1764bb0265b16d51eff70e4a97fa5&act=Attach&type=post&id=14480>
- (20) Dr Phil Boyle - http://www.fertilitycare.net/documents/LDNInfo_000.pdf
- (21) Dr Kamau B Kokayi interview with Dr Bernard Bihari – September 23, 2003 - <http://www.gazorpa.com/interview.html>
- (22) Hughes Syndrome - The blood disease that mimics MS - Hughes Syndrome <http://www.msrf.co.uk/index.cfm?fuseaction=show&pageid=736&CFID=579952&CFTOKEN=15420960>
- (23) Wikipedia 'low dose naltrexone' entry - http://www.en.wikipedia.org/wiki/Low_dose_naltrexone
- (24) Pediatric MS Center: 'Promising MS Research' www.pediatricmscenter.org/Newsletter/Pediatric%20MS%20June%202008%20Newsletter.pdf

LDN Advocates:

- (1) LDN Discussion Group - <http://www.health.groups.yahoo.com/group/lowdosenaltrexone>
- (2) LDN Conference Media – LDN Conference 2007 – Conference DVD – Cyndi Lenz - <http://www.skipspharmacy.com/sppress/?cat=8>
- (3) Gazorpa – <http://www.gazorpa.com>
- (4) LDNers - <http://www.ldners.org>
- (5) Mary Bradley's Books - <http://www.marybradleybooks.com>
- (6) LDN Diary - LarryGC - <http://www.larrygc.com/ms>
- (7) LDN Discussion - <http://www.ldn.proboards3.com/index.cgi>
- (8) LDN Forum, Germany - <http://www.f27.parsimony.net/forum67727>
- (9) LDN Info – Crystal – <http://www.crystalangel6267.webs.com>
- (10) LDN & Cancer – Dee - <http://www.ldn4cancer.com>

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