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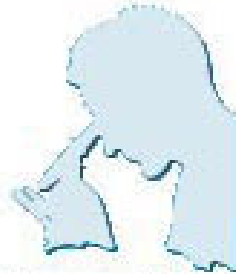
featuring
Low Dose Naltrexone (LDN)
in the treatment of
Multiple Sclerosis

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Case Health
Health
Success Stories

established 2001
Brisbane, Queensland, Australia

1) LDN- My Post LDN MS Story – Jim

story submitted Dec 2005
- story updated Dec 2005
- story updated - no change to report - August 2006
- **story updated July 2007 (3.5yrs on LDN)**

SPECIFICS:

DIAGNOSED - Relapsing Remitting Multiple Sclerosis (RRMS) January 2002

MEDICATION – Beta-Seron – started February 2002, stopped November 2003

MEDICATION – Low Dose Naltrexone (LDN) – started Dec 11th 2003 on 3mg for 1 month then increased dose to 4.5mg taken as close to 11pm at night as possible. Capsule filler is Avicel

DIET - Joined weight watchers and lost 55 pounds, now have 70 lbs more to go. Also attempting to quit smoking (talk about stress) haha.

EXERCISE - Tai-Chi & martial arts, learning to relax, as well as more walking.

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 (now 2yrs on LDN):

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:

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.

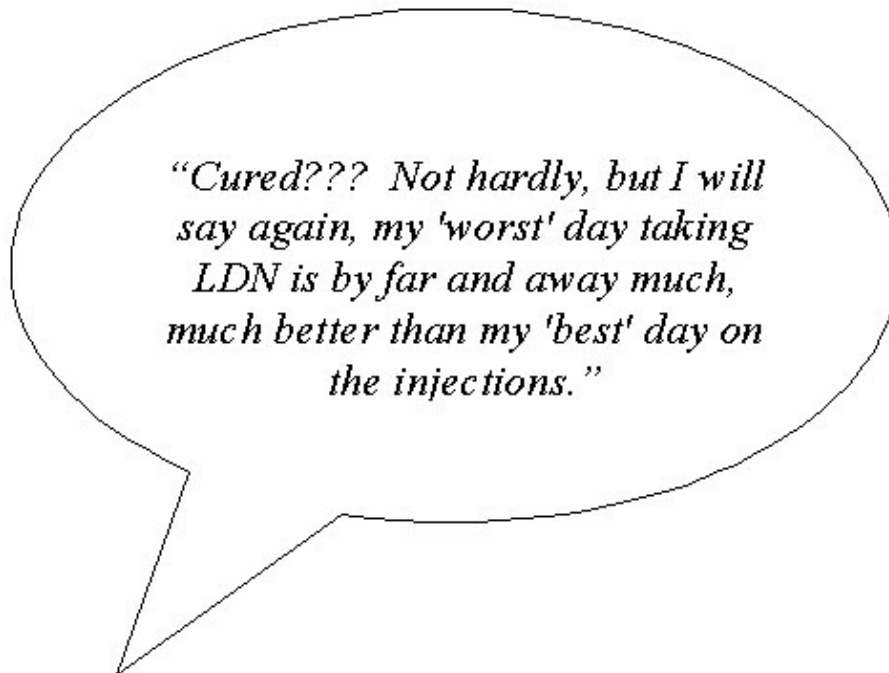
It does help to wear a neckerchief with the 'crystals?' that absorb water and puff up, after it's been in the refrigerator to chill. Using a bottle 'mister' you pump up and spray, plus a small hand held portable fan. They all help 'some' but as with anything, they do have their limits. Keeping stress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

Jim (RRMS)



Jim, December 2005

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

story submitted July 2006

- story updated July 2007 (almost 5yrs on LDN)

SPECIFICS:

LDN - 4.5mg capsule daily - Sept 2002 to July 2007

TOPAMAX: 100 mg for seizures prescribed by my first Neuro in 1999 but ceased May 2006. 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 I felt so much better on LDN 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.

NUTRITION: 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.

SUPPLEMENTS: one multi-vitamin, one Fish Oil tablet daily.

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 choose 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.

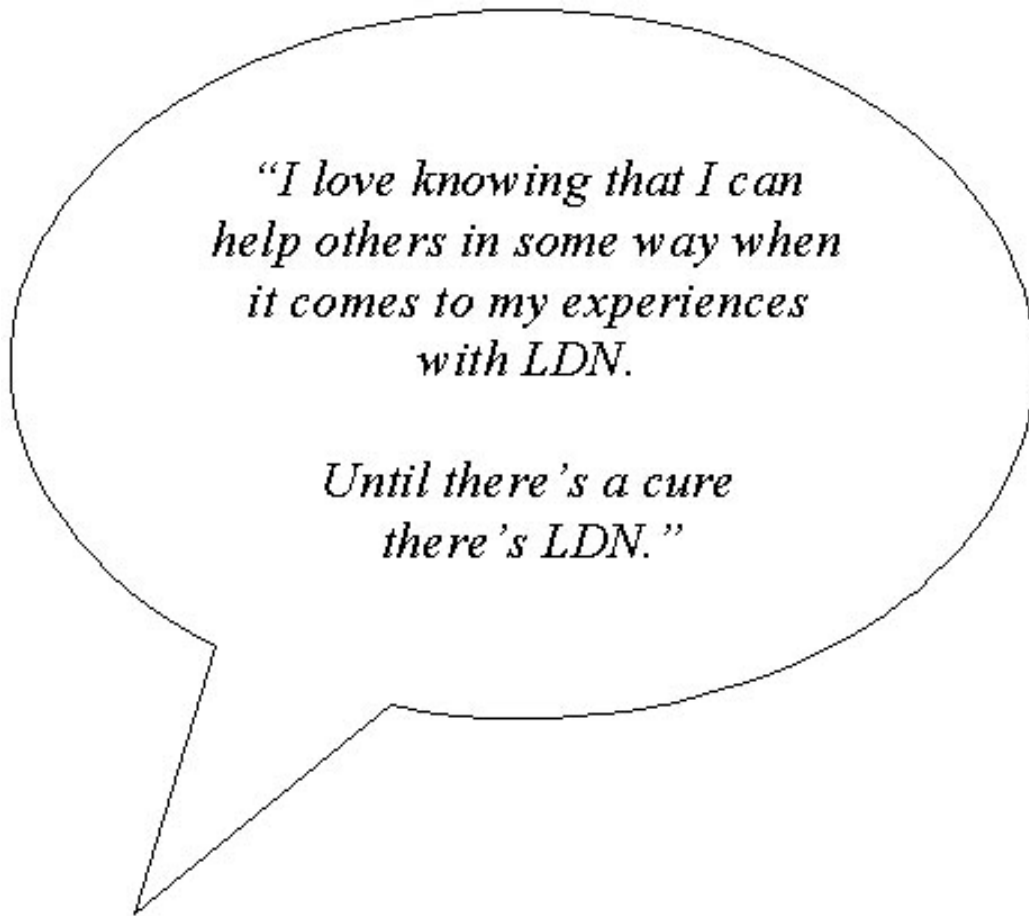
I hope all doctors will take notice of this wonderful treatment option - that the major media will finally acknowledge LDN - that LDN clinical trials for MS and other diseases will happen and will prove LDN to be an effective and economical treatment - and that the FDA will approve it - so everyone suffering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

"Until There's A Cure ... There's LDN"



Carol, July 2006

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

story submitted May 2005
- story updated Jan 2006
- story updated May 2006
- **story updated July 2007 (3yrs on LDN)**

SPECIFICS:

DIAGNOSED - Relapsing Remitting Multiple Sclerosis (RRMS) October 2001

MEDICATION – Avonex then Rebif - started January 2002, stopped July 2004

MEDICATION - Low Dose Naltrexone (LDN) – started 23 July 2004

DOSE & TYPE –

a) Dose – I started on 3mg for 1 month, then 4.5 and have been taking this since

b) Time - I take the Naltrexone at 11pm each day

c) The Naltrexone capsules contain pure Naltrexone powder with Avicil (sp) as a filler.

EXERCISE - aqua therapy at the YMCA three times a week plus exercising at home three days a week

DIET - Swank diet since 1 January 2004

SUPPLEMENTS – Vitamins from 1 January 2004 and since - B-12 shots, Multi-Vitamin, CoQ-10, Beta Carotene, Folic Acid, Ginkgo Biloba, Vitamin D, Fish Oil, Melatonin. From APRIL 2006 - 400 mg Magnesium.

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 – 3 years on LDN

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.

Scott, Ohio, USA



Scott, May 2005

4) I have MS but I'm walking and driving my car again-Bill

story submitted March 2006
- story updated - no change to report - August 2006
- **story updated – July 2007 (2yrs on LDN)**

SPECIFICS:

DIAGNOSED - Relapsing Remitting Multiple Sclerosis (RRMS) 1998

DIAGNOSED – Secondary Progressive Multiple Sclerosis (SPMS) 2002

MEDICATION – Avonex, Copaxone, and Rebif (ABCR drugs), chemotherapy (Cytoxan), plasma exchange, as well as many, many sessions of IV steroids (Solumedrol).

MEDICATION - Low Dose Naltrexone (LDN) – started 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.

DOSE & TYPE –

a) Dose – I started on 1.5mg for 1 week, then 3mg and have been taking this since. I stopped taking the Rebif at the same time.

b) Time - I take the Naltrexone between 10pm and 2am each day

c) The Naltrexone capsules contain pure Naltrexone powder with Avicil (sp) as a filler.

EXERCISE - walking, lifting light weights, and abdominal exercises

DIET – no particular diet

SUPPLEMENTS – no particular supplements

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

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

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

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

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

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

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

While I did not notice any symptom improvement for the first three months, I also had NO flares either. But, after around three months I began to notice small improvements - my breathing was improving - I

could take time off from the oxygen for extended periods of time - the strength in my legs and arms was improving - I began to be able to take short walks with a walker - then was able to take longer walks - then upgraded from my wheelchair to a cane - then actually walked to the bathroom without assistance! My sleep began to improve as well.

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

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

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

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

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

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

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

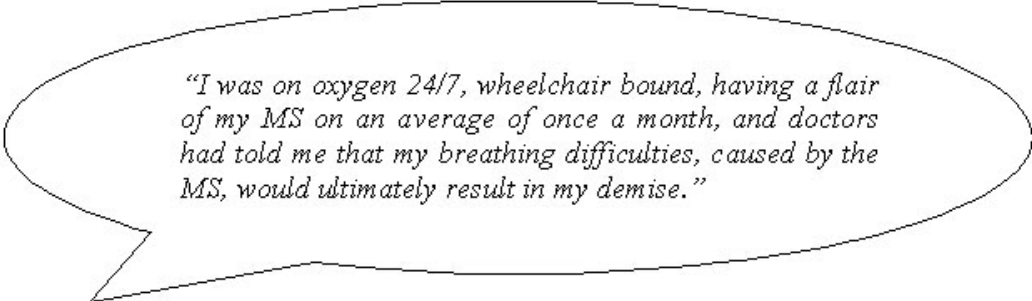
I also do not understand why, if the "Mission Statement" of the National MS Society is to "find a cure for MS," THEY are not funding these studies.

UPDATE: JULY 2007:

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

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

Bill, Alabama, USA



"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."

Bill, March 2006

5) LDN-improvement was gradual and subtle, Julia

story submitted November 2005
- story updated August 2006
– **story updated July 2007 (2 yrs on LDN)**

MEDICATION - LDN - 2.5ml liquid since August 2005
EXERCISE – no particular regimen
DIET – no particular diet
SUPPLEMENTS – no particular supplements

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.

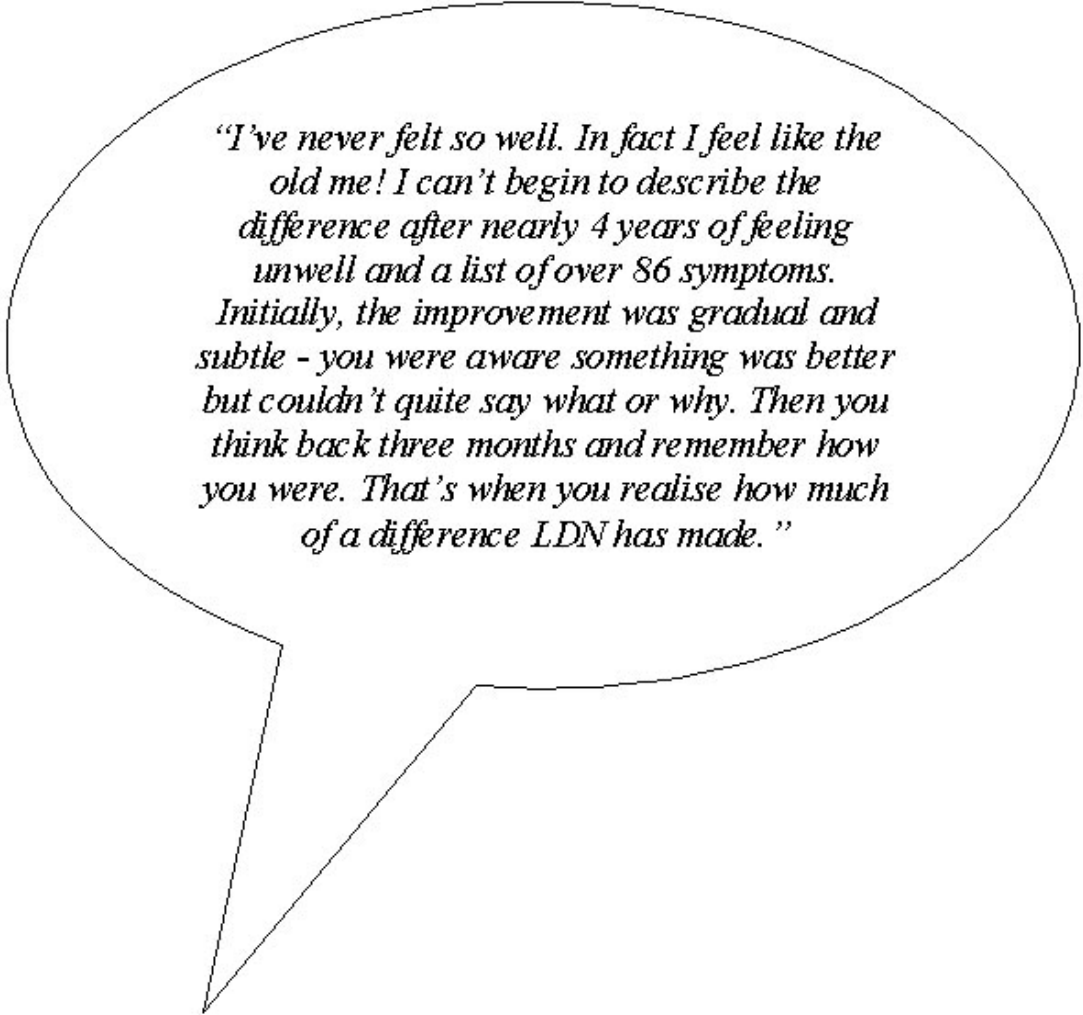
UPDATE: JULY 2007:

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.

Julia (UK)



"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."

Julia, November 2005

Other recently submitted or updated MS/LDN stories you may wish to read ...

LDN-PRMS but no exacerbations-Kathy P – submitted Sept 2006, last updated July 2007 – 3.5 yrs on LDN

' ... I started taking Beta-Seron in 2000 ... I took Beta-Seron for 3 years and felt sick every day ... I went downhill very quickly ... I learned of LDN on the internet ... I took the information to my doctor ... He had no hesitation prescribing it for me in Dec 2003 ... He said it wouldn't hurt me ... I take 4.5mg ... I have not had any new symptoms that were severe or have stayed ... I still have MS but my memory has improved ... can now cook ... my Multiple Sclerosis went from a Secondary Progressive MS (SPMS) profile to a Progressive Relapsing MS (PRMS) profile ... I still take LDN. ... '

LDN-Paul's MS and LDN story began in 2004 – submitted May 2007

' ... The news was completely devastating to my husband (Paul) as he pictured his life in a wheelchair ... being unable to surf, play basketball ... play tennis ... The day after my husband took his first dose he went to work and did not come home until after 5pm ... His feeling of well-being returned and within a week his bladder frequency was gone ... Within a month ... back to 2 sports a day ... 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 wheelchairs, get their vision restored, gain their cognitive skills back or feel like they no longer have the dreaded MonSter ... I believe neurologists that truly care about the health and well-being of their MS patients should first try LDN and move onto the CRAB (Copaxone, Rebif, Avonex, Beta-Seron) drugs only if LDN is not effective for them. ... '

See casehealth.com.au for more ...

LDN is being used for a range of diseases, such as HIV

LDN-HIV viral load down, T-cells up-Matt – submitted Dec 2005, last updated May 2007

' ... I was diagnosed HIV positive ... August 2002 ... I was enrolled in a clinical trial ... September 2002 ... a cocktail of 5 medicines for one year ... HAART (highly active anti-retroviral therapy) taken every 12 hrs ... made me feel consistently unwell ... was able to control the virus for about a year, but then the viral load started to climb ... Dec 2004 ... learned of LDN ... began taking 4.5mg between 9 & 10pm each night ... 2 months ... viral load (VL) went down to below 5000, and my T-cells (CD4) increased by 50% ... 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 ... was start taking LDN twelve months before ... so I am justified in believing it is the LDN that made the difference ... March 2006 -CD4=444, VL=4260 ... June 2006 – CD4=434, VL=5810 ... Oct 2006 – CD4=640, VL=5810 ... Started taking olive leaf extract, then later added selenium ... April 2007 ... CD4 still good at 544, viral load 35,000 – not good but since I had a slight cold the Dr thinks that may have elevated it.

DRUG STOPS MULTIPLE SCLEROSIS BUT SUFFERERS CAN'T GET IT

by Cris Kerr, Administrator & Community Health Researcher,
'Case Health-Health Success Stories' website, October 2005 (revised July 2007)

My name is Cris Kerr and I've been administering the 'Case Health – Health Success Stories' website for the past six years. The site collects and shares success stories (cure or improved quality of life) attributed to any 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 anecdotal evidence

Through my website I became aware of a drug that has stopped the progression of Multiple Sclerosis and enhanced the quality of life of many Multiple Sclerosis (MS) sufferers. The drug is Naltrexone (also known as ReVia) and my 'Health Success Stories' database contains a growing body of compelling anecdotal evidence that it works, and; it works well - BUT, sufferers can't get it.

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

Dr Bernard Bihari (USA), a long advocate and prescriber of Naltrexone has alleviated the symptoms and/or progression of MS sufferers by prescribing **Low Doses of Naltrexone (LDN)**. His groundbreaking work, commenced in the mid 1980s, has resulted in a small but growing number of physicians prescribing Naltrexone to minimize both progression and symptoms of MS for their patients.

Multiple Sclerosis (MS) is not the only disease Dr Bihari has treated successfully with low doses of Naltrexone. LDN is cited as beneficial across a broad range of chronic diseases such as HIV/AIDS, lupus (SLE), Parkinson's, Crohn's disease, Breast and other cancers, arthritis, and even Fibromyalgia. If you're wondering how all these diseases are linked look no further than an errant immune system.

Due to the wonder that is the Internet, word is spreading. A maiden conference dedicated to LDN was held in New York in 2005, followed by a second in 2006. This year (2007), the third (now annual) LDN Conference will be held in October.

MS sufferers whose symptoms or progression have been alleviated by treatment with LDN have formed support groups dedicated to spreading the word. They're striving to help fellow MS sufferers via information-sharing, emotional support, and fund-raising for clinical trials; the first of which commenced this year (2007) at the University of California, San Francisco. Funding was raised by a dedicated support group linked to LDNers.org.

Why are Clinical Trials important?

Naltrexone has not achieved mainstream acceptance as a treatment option for MS due to absence of clinical trial data. Whilst a growing number of doctors will prescribe LDN for MS, most are too cautious to prescribe a treatment they perceive as unproven clinically.

At this time 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) prescribed for the management of MS or other diseases.

Clinical trials answer the 'who, what, why, where, how, and when' questions that must be answered to establish patient profile, efficacy, optimum dose, safety, etc.

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 the safest system to follow, and patients wouldn't want it any other way.

But, where does that leave the promise of Naltrexone?

Health success stories written by patients and attributed to LDN are growing exponentially.

A large body of stories from MS sufferers who've slowed or halted progression of their disease after taking LDN are building a compelling case, but these stories represent only one facet of evidence. Health success stories alone don't provide sufficient evidence for most doctors to prescribe LDN.

A large body of health success stories does, however; provide sufficient evidence to advocate for clinical trials.

Clinical trials cost money and are typically initiated or sponsored by those who expect to recoup the cost outlaid for the trial by commercializing its 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 then they're entitled to view the costs as an investment that will turn a profit.

Naltrexone has long passed its patent protection period. Drugs outside of patent protection are classed as 'generic' drugs because they no longer have a sponsor. A clinical trial therefore, does not present an attractive commercial proposition for those sponsoring organisations that have traditionally initiated clinical trials - because they wouldn't gain exclusive rights (and subsequent profits) from a successful outcome.

What's wrong with this 'system'?

The driving force behind Research, Development, and Clinical Trials is commercial. There's no big profit to be made from a clinical trial of a 'generic' drug such as Naltrexone regardless of the promise it holds, so nothing happens.

How did we discover Naltrexone holds such promise?

Via his practice Dr Bernard Bihari has been trialling Naltrexone since the mid 80s, resulting in a growing body of health success stories linked to low doses of Naltrexone.

Testimonials appear on core LDN supporter sites: 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. An LDN for MS Research Fund, sponsored by the Accelerated Cure Project for MS and initiated by four individuals with a keen interest in LDN is publicised on this site. You'll also find the Foundation for Integrative Research; now known as the Foundation For Immunologic Research (FFIR); founded in 1989 by Bernard Bihari, MD and two colleagues to raise trial funds for the broader range of LDN's promising applications.

In the UK, LDN Research Trust was founded by Linda Elsegood, herself an MS sufferer who takes LDN. Linda's monthly newsletter contains 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 MS sufferers raising funds and contributing to support groups in the interest of helping other MS sufferers learn of the benefits of LDN.

Those that could be helped are not being helped

Whilst there's growing anecdotal evidence that LDN could be the most effective and economic treatment option in the management of MS (for both the patient and the health system), the absence of clinical trial data means the majority of practitioners are still not prescribing Naltrexone. Those that could be helped are not being helped.

What's Disturbing about this Picture of Health?

When you read LDN stories on my website or others I've referenced here; 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. ...'

When you read LDN stories, the second thing you'll notice is the extraordinary difficulty MS sufferers experience when seeking to trial Naltrexone. MS is a debilitating condition with multiple adverse symptoms. People with MS are already suffering. You can't help becoming indignant at the 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. ...'

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

Research, drug development, and clinical trials are commercially-driven by sponsors. That's okay, but there's no recognized 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 is sanctioned to do so.

Most officially recognized specialist 'societies' are sponsored by industries which are, as mentioned earlier, commercially focused and have no incentive to recognize the extended benefits of a generic, unprofitable drug.

The present system is unjust

The present system is unjust. It's inequitable. It doesn't place sufficient value on patient health success stories. It doesn't place sufficient value on advocating for the patient. It doesn't place sufficient value on 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. That makes me feel uneasy and should make you feel uneasy.

A single health success story doesn't register on the public health radar. It is not considered evidence. A growing volume of related health success stories, however, builds a compelling body of evidence that can't be ignored – and that's my goal. 'Proof of concept' equates to proof of the value of health success stories.

The collective LDN story is becoming an excellent example of this through the power of numbers. The collective is greater than the single. Whilst the evidence remains spread far and wide it does not hold weight, it cannot be measured, and it cannot help build a compelling case.

Governments need to acknowledge the value of patient testimony

The collective has a louder voice than the single. Collectively, LDN health success stories provide sufficient evidence to advocate clinical trials; the results of which could help many other sufferers.

The collective LDN story is also an excellent example of why 'the system' needs to change, why we need to rebalance the scales and give more weight and credibility to patient testimony. We need an organisation chartered to act on this type of evidence; an organisation that values patient testimony and can make recommendations (without prejudice or conflict of interest) on behalf of patients from all corners of the globe.

Supporting data for this essay is in the form of untested patient anecdotes of health success. Whilst I firmly believe there is value in what I do, I am but an individual. I do not have the resources to validate patient anecdotes or lobby for action.

Governments worldwide could prove they value and give credence to patient testimony by implementing official bodies and processes chartered to act on compelling evidence in the form of health success stories.

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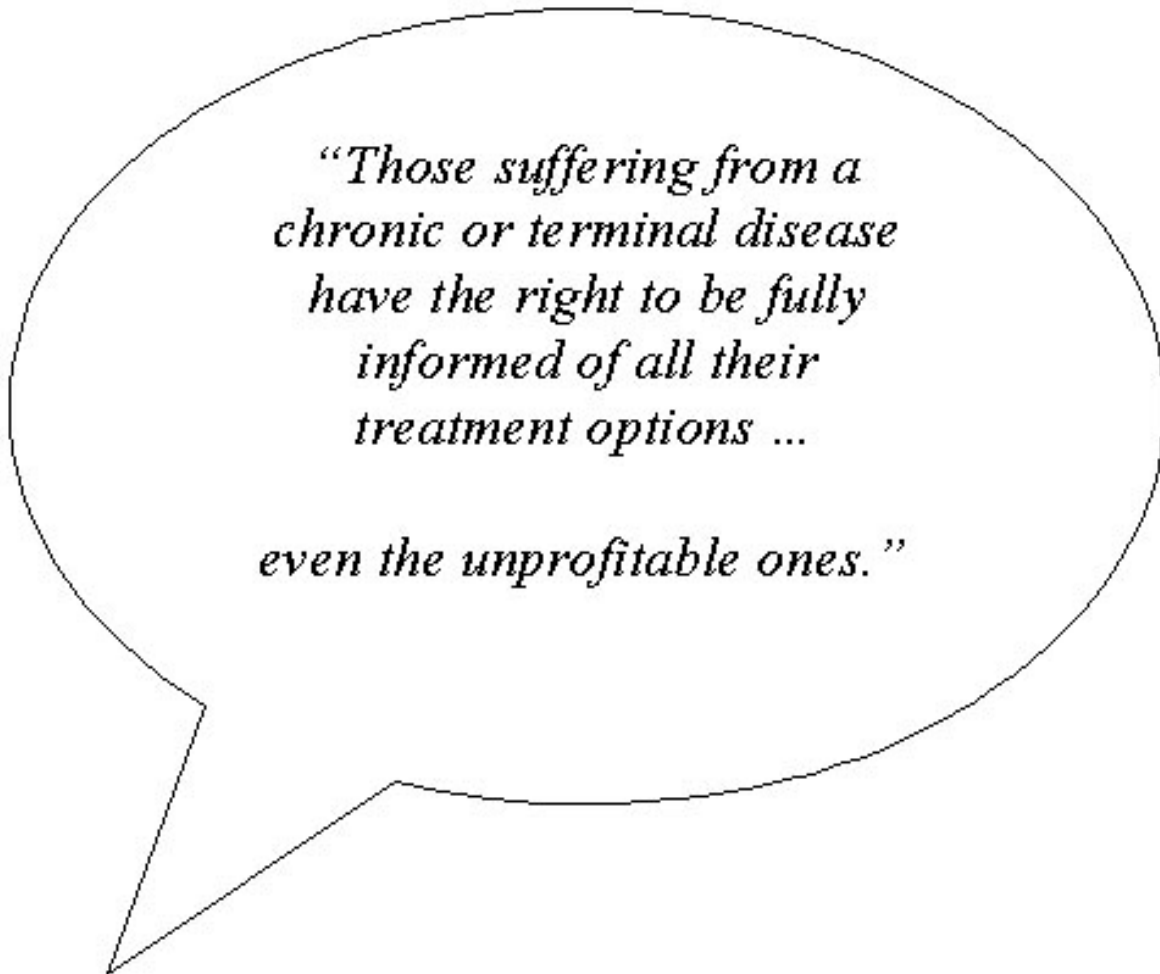
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- (2) LDN Research Trust, UK – Linda Elsegood - ldnresearchtrust.org
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- (19) Dr Phil Boyle - fertilitycare.net/documents/LDNInfo_000.pdf
- (20) Dr Kamau B Kokayi interview with Dr Bernard Bihari – September 23, 2003 - gazorpa.com/interview.html

LDN Advocates:

- (1) LDN Discussion Group - health.groups.yahoo.com/group/lowdosenaltrexone
- (2) LDN Conference Media – LDN Conference 2007 – DVD anticipated Jan 2008 – Cyndi Lenz - skipspharmacy.com/sppress/?cat=8
- (3) LDNers - ldners.org
- (3) Gazorpa - gazorpa.com
- (4) Mary Bradley's Books - marybradleybooks.com
- (5) LDN Diary - LarryGC - larrygc.com/ms
- (6) LDN Discussion - ldn.proboards3.com/index.cgi
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Previously Published:

- a) 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' - news-medical.net/?id=14749
- b) 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
- onlineopinion.com.au/view.asp?article=3905



Cris Kerr, 16 November, 2007

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.

NB *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

Published by OnlineOpinion 23rd October, 2007:
- URL onlineopinion.com.au/view.asp?article=6531

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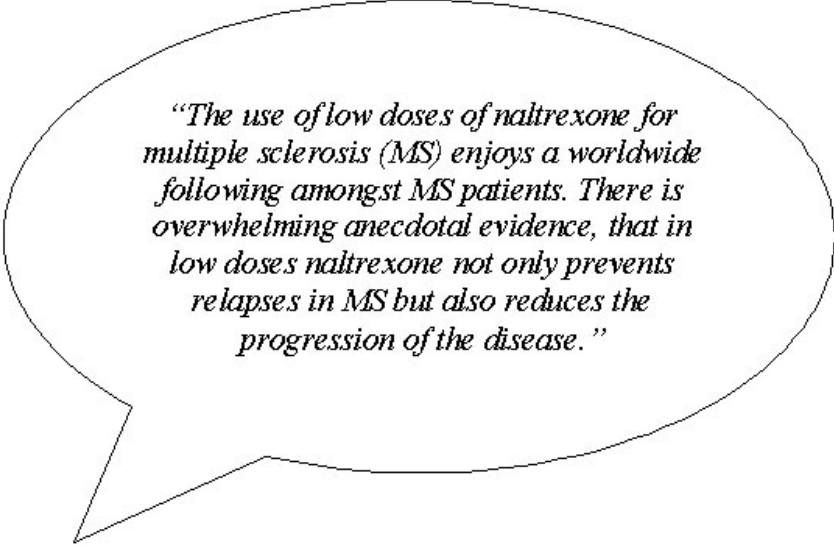
❖ 'Drug stops multiple sclerosis - but sufferers can't get it!' (article only – not stories) 2007, and;

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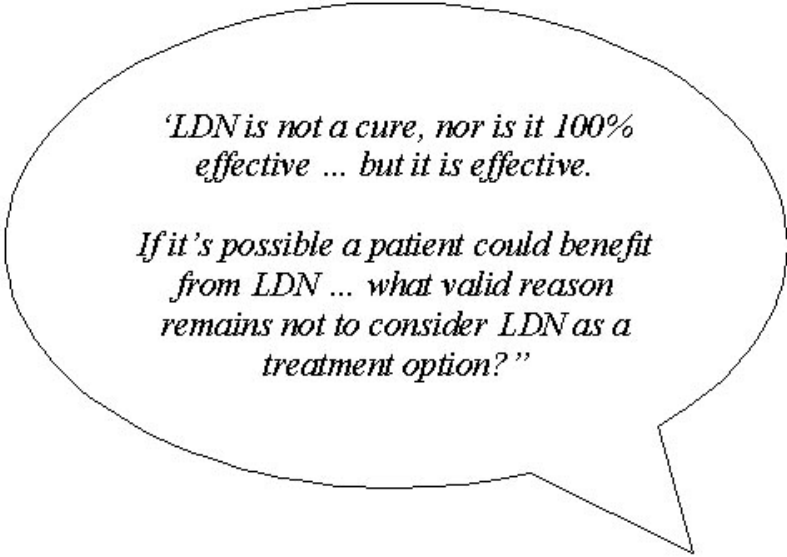
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“The use of low doses of naltrexone for multiple sclerosis (MS) enjoys a worldwide following amongst MS patients. There is overwhelming anecdotal evidence, that in low doses naltrexone not only prevents relapses in MS but also reduces the progression 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