

**ROUND-UP of The Inaugural
International LDN Awareness Week**

19-25 October 2009

by Cris Kerr

Advocate for the value of patient testimony



(media list follows further below)

Outcomes

It's too early to celebrate all outcomes as the ILDNAW project hasn't been attempted before.

Did we progress the mission of 'Raising Awareness' during the ILDNAW?

YES, tangibly, undeniably.

Did outcomes meet all expectations?

YES and NO.

NO... if we had unrealistic expectations of major stories in every major news outlet and every doctor agreeing to prescribe LDN.

Thankfully, we didn't.

On this first attempt we knew the best we could hope for was to punch holes in barriers, broaden the audience, and raise awareness of LDN in a way that fueled ripples that radiated... ensuring more of those who need to hear of LDN, do hear of LDN.

Did we achieve that?

YES, though there was less media attention given the designated week than we'd hoped, awareness was definitely raised and more patients are now asking about LDN.

Importantly, good contacts were made, and lessons were learnt regarding the media news cycle and timing that will stand us in good stead going forward.

YES, because activities associated with the week heightened pressure on Multiple Sclerosis Societies to recognize patients are taking LDN and benefiting, and therefore, moved these societies one step closer to recognizing LDN as a treatment option.

YES, because due to fluctuations in the news cycle and insufficient lead time ahead of ILDNAW... in many international locations, promising contacts and communications are continuing. There is more to come.

YES, because it has prompted beneficial professional papers:

(a) 'What is the evidence for low dose naltrexone for treatment of multiple sclerosis?', Medicine Q & As, Ref No 69.3, October 2009 NHS - Prepared by UK Medicines Information (UKMi) pharmacists for NHS healthcare professionals
Expiry: 31st Oct 2011

(b) 'Introduction to Low Dose Naltrexone' by Dr Ian S. Zagon, October 2009

What all this means is that the week was successful, but that it is too early to assess all outcomes as word is still spreading, promised articles are still to be published, and activities are continuing.

LDN GOING FORWARD

A rough overview/thoughts on preparations for next year's ILDNAW follows, but only to throw some ideas around before seeking broader input.

Going Forward

We're all short of time and energy and awareness activities should not present a burden, exhaust people, or risk their health (as it has for some this year)... so, if we're all in agreement, we could begin discussions around the bigger picture first, up-front, THEN work toward that big picture over the next ten months as a much larger group in unison... in bite size pieces... molehills instead of mountains... activities anyone can manage as time and health permit.

This will spread and ease the onus so no one individual is burdened.

It will also gain the widest possible support going forward... because more hands make light work.

We now have an International LDN Aware website www.ldnaware.org where a group of us from around the world are working together to raise awareness globally.

We will be working on raising funds for "Virtual" LDN conferences, this will enable everyone worldwide to participate.

We need to seek nominations for LDN advocates - those who through the kindness of their hearts are already active or want to be, and want to contribute to the Mission and Goals through a larger committee of representatives from each country... so the result is a fair and equitable representation.

Identifying our common goals is important, and it's equally important to acknowledge and utilize the wealth of expertise and various skillsets that exist throughout the LDN population.

Sometimes it may seem that as an LDN population, advocates can be at odds.

Not so... we have far more in common than most, and it's these common goals that unite us all and will help keep all our eyes firmly fixed on the LDN horizon that we all want to reach.

As LDN advocates we can all be on the 'same page' contributing to the same equitable goals, principles, and outcomes - even when tactically operating on different activities.

Beyond that, a SWOT analysis may be beneficial in helping us plan and develop strategies and tactics going forward - covering the 'who, what, where, how and when'.

Some examples...

STRENGTHS

LDN patient advocates united in their mission = patient power, professionals are also advocates, patients with years of experience in LDN use and support are invaluable, evidence of efficacy and safety detailed in case studies and stories can continue to build, research to-date, etc

WEAKNESSES - high PR costs, science writers rejection of patient testimony based on lack of 'scientific' evidence, media news cycles, health/safety regulatory environment and its limitations, etc

OPPORTUNITIES - build on media and other contacts already made, gain more non-patient advocates to boost energy and activism, make more efficient use of resources, minimize PR costs, change mindset of science writers, etc

THREATS - because advocates using LDN are patients their activism is

dependent upon their health and strength which could be compromised, LDN mission could be compromised by health/safety regulatory environment if it is perceived that words such as 'wonder drug' are perpetuated, risk of being discredited, industrial infiltration and competitive tactics have been escalating, divide and conquer/factions and fractions, etc

A core committee could further develop a SWOT analysis, could then develop a general Forward Plan containing agreed strategies and tactics that enhance collaboration and help everyone work in unison toward;

- (a) building on strengths;
- (b) taking advantage of opportunities;
- (c) managing weaknesses, and;
- (d) minimizing threats.

Or in other words, a core committee of united voices would be in collective agreement with an LDN Mission and Goals, would work in unison on the same forward plan, strategies and tactics, and would with fellow advocates implement those strategies and tactics to take LDN forward.

All input and thoughts are welcome on this or anything else you feel might help the LDN population of advocates work better together and further define their united purpose, enhance consistency, improve communications and actions, and ultimately, enhance the likelihood of others benefiting from LDN.

Of one thing I am certain, working together always achieves far more than working in isolation, and we owe it to those who haven't heard of LDN to look beyond our differences and focus on our common goals - that which first brought us all together in the first place - 'Patients benefiting from LDN who want to see others benefit from LDN as they have'.

YOU HAVE THE KNOWLEDGE AND SKILLS

WE WANT TO WORK WITH YOU

AS AN LDN ADVOCATE FOR YOUR COUNTRY

TO BENEFIT YOUR FELLOW COUNTRYMEN AND WOMEN

We look forward to receiving your nomination as an official LDN advocate:

- (1) FULL NAME
- (2) FULL ADDRESS
- (3) EMAIL ADDRESS
- (4) TELEPHONE NUMBER

Following nominations, we hope representatives from each country will form

representative committees to contribute to international meetings on 'LDN Going Forward'.

Resources

These four free resources were made available for International LDN Awareness Week:

(1) Book '100 Reasons Why... you should know about LDN' contains 100 patient testimonies from LDN Research Trust

<http://www.ldnresearchtrustfiles.co.uk/docs/International%20LDN%20Awareness%20Week%20eBook.pdf>

(2) International LDN Awareness Week 19-25 Oct 2009 press release was the collaborative effort of Linda Elsegood, Samantha Wilkinson, Julia Schopick, and Malcolm West

<http://www.ldners.org/Awareness/>

(3) Book 'Those Who Suffer Much, Know Much' 2009 edition features 47 detailed case studies attributing low dose naltrexone (LDN) with improved health, as well as an explanatory article and interviews with 9 health professionals familiar with LDN.

<http://www.ldnresearchtrustfiles.co.uk/docs/2009.pdf>

(4) 'The Faces of Low Dose Naltrexone', is a compilation of LDN Information by Julia Schopick of Honest Medicine

<http://honestmedicine.typepad.com/ebook-sept%2023-2009--The%20Faces%20of%20Low%20Dose%20Naltrexone.pdf>

MEDIA LIST & CHANGING LANDSCAPES

CHANGING LANDSCAPES

(1) MS Society UK - Dr Alasdair Coles

http://www.mssociety.org.uk/applications/discussion/view.rm?post_id=840296&id=14320

(2) Congress Presentation: 'Low Dose Naltrexone and its Regulatory Effects on Cancer Cell Growth and Autoimmune Disease' by Paul Battle, PA-C, to the World Congress on Antiaging Medicine and Regenerative and Biomedical Technologies held at the Mandalay resort in Las Vegas, Nevada, USA on 12th Dec 2009 www.worldhealth.net

(3) Oct 2009 - LDN Research Trust invited to submit an article to the British Journal of Neuroscience Nursing – article accepted.

<http://forum.ldnresearchtrust.org/index.php?/topic/1502-1st-ldn-article-in-a-british-medical-journal/>

(4) 'What is the evidence for low dose naltrexone for treatment of multiple sclerosis?' Medicine Q & As, Ref No 69.3, October 2009, NHS - Prepared by UK Medicines Information (UKMi) pharmacists for NHS healthcare professionals
Expiry: 31st Oct 2011 <http://www.nelm.nhs.uk/en/NeLM-Area/Evidence/Medicines-Q--A/What-is-the-evidence-for-low-dose-naltrexone-for-treatment-of-multiple-sclerosis/?query=naltrexone&rank=100>

(5) 'Introduction to Low Dose Naltrexone' by Dr Ian S. Zagon, October 2009
<http://forum.ldnresearchtrust.org/index.php?topic/1389-dr-ian-s-zagon-an-introduction-to-low-dose-naltrexone-ldn/>

What all this means is that the week has been successful, but that it is too early to assess all outcomes as word is still spreading, promised articles are still to be published, and activities are continuing.

NEWS ARTICLES - ONLINE NEWS MEDIA

(1) 'Another Drug MS and Other Immune Problems' (contains incorrect URL - ldnresearchtrust.orgg)
<http://www.veteranstoday.com/modules.php?name=News&file=article&sid=8393>

(2) 'The Drug that Changed my life should be available to all', Tuesday, October 13, 2009 By Cheryl Stonehouse
<http://www.express.co.uk/posts/view/133731/The-drug-that-changed-my-life-should-be-available-to-all>

(3) 'MS drug could save NHS millions', Monday 19th October 2009
<http://www.nursinginpractice.com/default.asp?title=MSdrugcouldsaveNHSmillions&page=article.display&article.id=18962>

(4) 'Life-Changing MS Drug Could Save NHS £300 Million A Year', UK
Source: LDN Research Trust
<http://bionews.zampbioworld.org/2009/10/22/31354>

(5) Oxfordshire MS sufferer calls for drugs trial after finding LDN, Thursday 12th November 2009, by Amanda Williams, featuring Silvia Lane
http://www.oxfordmail.co.uk/news/headlines/4736055.Oxfordshire_MS_sufferer_calls_for_drugs_trial_after_finding_LDN/

(6) Addicts' drug has changed my life, says MS sufferer - featuring Steven Blaikie, 13 November 2009, by Sandra Dick
<http://edinburghnews.scotsman.com/features/Addicts-drug-has-changed-my.5822183.jp>

(7) Leicestershire woman in fight for drug to be available on NHS, Thursday, November 26, 2009
<http://www.thisisleicestershire.co.uk/news/Leicestershire-woman-fight-drug-available-NHS/article-1552176-detail/article.html>

(8) Sufferer's fight for 'miracle' MS drug - Doncaster Today
<http://www.doncasterfreepress.co.uk/free/Sufferer39s-fight-for-39miracle39-MS.5900752.jp>

NEWS ARTICLES - TABLOID MEDIA & MAGAZINES

(1) 'Until There's a Cure there's LDN...' by Cheryl Campbell, The Orcadian, 15th October 2009

<http://www.ldnresearchtrustfiles.co.uk/docs/C&C.pdf>

(2) Let's Talk Magazine - in the news... 'Local Charity goes International' featuring Linda Elsgood - copy of article available online

<http://www.ldnresearchtrustfiles.co.uk/docs/1.pdf>

(3) 'Hoping for MS cure with Steely Resolve', The Herald, Newcastle, Australia, by Ian Kirkwood 20th October 2009

<http://www.ldnresearchtrustfiles.co.uk/docs/Article-Hoping%20for%20MS%20cure%20with%20Steely%20Resolve%20The%20Herald%2020%20Oct09.pdf>

(4) 'Miraculous drug for MS', letter to the editor of Henley Standard UK by Silvia Lane

<http://www.ldnresearchtrustfiles.co.uk/docs/Henley%20Standard%20letter1.pdf>

(5) Hounslow Branch of the MS Society - LDN Article

http://www.mssociety.org.uk/docs/bloy_December.pdf

(6) "For me, LDN is life-changing" Woking News and Mail 17th December 2009 by Nicola Rider

<http://www.ldnresearchtrustfiles.co.uk/docs/Woking%20News%20and%20Mail.pdf>

WEBSITE NEWS

(1) Free Ebook Now Available for International LDN Awareness Week: 'The Faces of Low Dose Naltrexone', Stanford Wellsphere, Patient Empowerment article, posted Sep 20 2009 10:10pm

<http://stanford.wellsphere.com/patient-empowerment-article/free-ebook-now-available-for-international-ldn-awareness-week-the-faces-of-low-dose-naltrexone/806877>

(2) 'The Faces of Low Dose Naltrexone': New Book Explores Cutting-Edge Autoimmune Disease Treatment, Thyroid-About, Tuesday September 22, 2009

<http://thyroid.about.com/b/2009/09/22/low-dose-naltrexone-book-ldn-schopick.htm>

(3) 'LDN, the drug that changed my life, should be available to all'

Source: The Daily Express ©2006 Northern and Shell Media Publications (13/10/09) Community Channel

http://www.communitychannel.org/component?option=com_rnyourvoice/task.view/id,3181/sectionid,10/Itemid,104/

(4) 'LDN, the drug that changed my life, should be available to all'

Source: The Daily Express ©2006 Northern and Shell Media Publications (13/10/09) News, Patient Co UK

<http://news.patient.co.uk/newspaper.asp?ss=10&pc=11941>

(5) LDN, the drug that changed my life, should be available to all

Source: The Daily Express ©2006 Northern and Shell Media Publications (13/10/09) Med Worm

<http://www.medworm.com/rss/search.php?qu=Daily+Express+-+Health&t=Daily+Express+-+Health&s=Search&f=source>

RADIO

(1) Mary Boyle Bradley Interviews Linda Elsegood on Blog Talk Radio
21 October 2009

<http://www.blogtalkradio.com/mary-boyle-bradley>

(2) Radio Interview - BBC Radio Norfolk, Oct 2009 with Linda Elsegood - not available online

(3) Radio Interview - Heart Radio, Oct 2009, with Linda Elsegood - not available online

LOCAL NEWSLETTERS

(1) LDN Awareness Week article in local 'Best Oxfordshire Village Newsletter', by Silvia Lane, October 2009

<http://www.ldnresearchtrustfiles.co.uk/docs/Woodcote%20Correspondent2.pdf>

BLOGS, FORUMS, POSTS MESSAGING

(1) Blog.Oregonlive

http://blog.oregonlive.com/myoregon/2009/10/international_ldn_low_dose_nal.html

(2) MDJunction

<http://www.mdjunction.com/forums/fibromyalgia-discussions/general-support/875525-international-ldn-awareness-week>

(3) Facebook

<http://www.facebook.com/topic.php?uid=12801301255&topic=10183>

(4) MSPeople

<http://ms-people.com/forum/index.php?showtopic=8674>

(5) Healthcare.Tweetmeme

<http://healthcare.tweetmeme.com/story/197885279/international-ldn-awareness-week-october-19-25th-2009>

(6) 'Life-changing' MS drug, LDN, could save NHS £300 million a year

<http://www.tiny.cc/CM7wV>

(7) Daily Express, UK: The drug that changed my life should be available...

News Source: Uinta County News

<http://www.allvoices.com/contributed-news/4379345>

PRESSWIRE

ILDNAW Press Release:

<http://www.prweb.com/releases/2009/10/prweb2968694.htm>

<http://www.einpresswire.com/article/46767-international-ldn-awareness-week-october-19-25th-2009>

Press Release featured here:

Silobreaker

http://www.silobreaker.com/international-ldn-awareness-week-october-19--25th-2009-5_2262641129331621922

News Yahoo

http://news.yahoo.com/s/prweb/20091001/bs_prweb/prweb2968694:_ylt=AvoEJMrdiMUAjBZKKDGSmVw51sIF:_ylu=X3oDMTJtODhmNTduBGFzc2V0A3Byd2VlLzlwMDkxMDAxL3Byd2VlMjk2ODY5NARwb3MDMTUEc2VjA3luX3BhZ2luYXRlX3N1bW1hcnlfGldARzbGsDaW50ZXJuYXRpb25h

Individual

<http://www.individual.com/storyrss.php?story=107755123&hash=3842ee822bf311f8060368963e996802>

PharmacyChoice

http://www.pharmacychoice.com/News/article.cfm?Article_ID=464471

NewsTin

<http://www.newstin.com/tag/us/148325125>

Pennant

<http://www.pennant.com/prweb/3268-international-ldn-awareness-week-october-19-25th-2009.html>

Newsguide

<http://www.newsguide.us/health-medical/neurology/International-LDN-Awareness-Week-October-19-25th-2009>

Bio-Medicine

<http://www.bio-medicine.org/medicine-news-1/International-LDN-Awareness-Week--October-19---25th--2009-58681-1/>

NSpace

<http://nspace.nigeria.com/main/news/international-ldn-awareness-week-october-19-25th-2009-pr-web-press-release>

BehaviouralHealthCentral

<http://behavioralhealthcentral.com/index.php/2009100196265/Alcohol-Related-Disorders/international-ldn-awareness-week-october-19-25th-2009.html>

Care2

<http://www.care2.com/news/category/health/International%20LDN%20Awareness%20Week>

HonestMedicine

<http://www.honestmedicine.com/2009/09/free-ebook-now-available-for-international-ldn-awareness-week-the-faces-of-low-dose-naltrexone.html>

Wellsphere

<http://www.wellsphere.com/patient-empowerment-article/international-low-dose-naltrexone-awareness-week-october-19-25th-2009/779144>

Bio-Medicine Org

<http://www.bio-medicine.org/medicine-news-1/International-LDN-Awareness-Week--October-19---25th--2009-58681-3/>

LDN TALK TRANSCRIPTS

Mary Boyle - 19th October 5th LDN Conference DC US

<http://forum.ldnresearchtrust.org/index.php?topic/1400-transcript-mary-bradleys-talk-in-dc/>

Linda Elsegood - 25th October Norwich UK

<http://forum.ldnresearchtrust.org/index.php?topic/1394-transcript-ldn-talk-in-norwich-25th-oct-2009>