



In The News

Many of you are probably aware of the LDN patient funded (\$25,000) study at University of California San Francisco by Dr. Bruce Cree. In this placebo-controlled clinical trial, 80 people with MS received LDN for eight weeks and then swapped to the other study drug. Researchers found vivid dreaming was the only symptom reported as a result of taking LDN but due to a high dropout rate among trial participants, concluded that larger scale trials are needed to determine the effect of LDN on overall quality of life.

Dr Susan Kohlhaas, Research Communications Officer at the National Multiple Sclerosis Society said, "We are really pleased to see results of this study published. The next step will be to complete larger, more detailed clinical trials to determine the potential of LDN as a symptom relief therapy for people with MS."

For those of us who take LDN, or are familiar how the drug works, will probably find this study a tad frustrating in that it was too short to determine whether LDN had a meaningful impact on disease progression. To do this LDN requires a two-year clinical study, ideally against an established interferon treatment, with MRI tests to measure MS lesions. But a study like this

is very expensive and private pharmaceutical companies are unwilling to invest millions in a new use of a generic drug.

Advancing LDN research is therefore the responsibility of government health agencies and non-profit institutions. Here in the US where I live, that would be the National Institutes of Health (NIH) and The National Multiple Sclerosis Society (NMSS). These two organizations have a close relationship with NIH researchers often advising NMSS along with pharmaceutical companies on studies and trials.

Last year I invited several senior executives from NMSS, headquartered in New York City, to make the short train trip to Washington, DC to attend the 5th Annual LDN Conference at the NIH. They responded that it was a bad year financially and attending the conference was not in the budget plan. I next offered to make a donation to NMSS to pay for their travel and hotel accommodations. They refused my offer.

When I saw the Dr. Susan Kohlhaas' quote I decided to send her and Dr. Patricia O'Looney (Vice President, Biomedical Research) an email inquiring if NMSS had any plans to fund LDN-related research considering Dr. Cree's positive

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study results. Dr. O'Looney responded that while NMSS was receptive to receiving proposals, they had no plans to raise funds or take any initiative on LDN research.

NMSS to date has only made one grant (\$40,000 in 2008) relating to LDN research, to Dr. Ian Zagon at Penn State. You can read about the recently released study results here: <http://tinyurl.com/ydrlvvy>

Dr. Zagon, as well as other researchers, have made follow-up proposals to NMSS for additional funding. All have been rejected without comment by Dr. O'Looney.

By contrast, the NMSS and NIH are working together on a \$19 million dollar study announced in July 2009 that combines the two established MS treatments Avonex (Biogen, Inc.) and Copaxone (Teva Pharmaceuticals, Inc.). Both Avonex and Copaxone cost about \$2500 a month for a prescription and have been rising in cost at 20% a year. The four pharmaceutical companies that make MS drugs, Biogen, Teva, Bayer, Serono, and now Acorda Therapeutics, are big benefactors of the NMSS and you only have to open an edition of MS Today and see their full-page ads, to receive their direct mail, to attend their sponsored doctor seminars, to realize the true extent of big pharma's influence.

And here are a couple of interesting fun facts: The "lifetime value" of a MS patient using these drugs is estimated at \$2 million, or around \$40,000 a year. The annual marketplace for MS drugs is about \$9 billion a year and the total marketplace for immune/inflammatory drugs is \$68 billion a year and includes 350 drugs at 250 companies. Joyce Nelson, the CEO of NMSS makes approximately \$500,000 a year in base salary with many other executives making over \$250,000 annually.

\$40,000 for LDN seems like a pittance, a drug that tens of thousands of people say is the most effective treatment they have ever taken for their MS. However, MS is an industry that supports the lucrative careers of many and makes millions for stockholders. Acorda Therapeutics, who recently released AMPYRA, a sustained release formulation of 4-aminopyradine ("4AP") charges over \$1,000 a month for the drug which helps some people with MS walk better. 4AP has been available for years through a compounding pharmacy and costs about .25 cents a dose. AMPYRA now costs \$17 a dose, same drug. The shares of Acorda have soared, all of Acorda's management team have become multi-millionaires, and Acorda now has advertisements on the NMSS website and in MS Today.

Will the same thing ever happen to LDN? Maybe, but I doubt it, and that is why LDNaware.org is so important. Because there is no money to be made from LDN, people like Dr. Patricia O'Looney, Dr. Susan Kohlhass and CEO Joyce Nelson have no real interest in LDN and likely never will. It's up us, the people who actually have, or love, someone with an autoimmune disease where LDN may help. Dr. Patricia O'Looney, Dr. Susan Kohlhass and CEO Joyce Nelson don't have MS, but if they were diagnosed tomorrow, I'm pretty certain they would visit www.LDNaware.org



LDN Trials

Two New Websites

Please make sure to visit these two new websites now added to LDNAware.org:

www.LDNscience.org

www.TakingControlofMultipleSclerosis.org

We are always looking to add new websites to LDNAware.org. If you need help in creating your own website, we have partnered with LWR OnLine to provide a variety of web services at very reasonable prices. Please visit their website at: www.LWRonline.co.uk



LDN Aware
Conference
In the UK

LDNAware 2010 Conference

This conference is now in the planning stages to be held on Saturday 23rd October at the Britannia Hotel in Birmingham. Attendance is limited to 150 people. The conference online registration website will be available within a month and offer more specifics on the agenda and travel. We are designing the online registration website so that it can be easily used in the future for other ldnaware.org events. If you would like to plan your own LDN conference in your country please contact us and we will help modify the online registration website for your needs and language.

LDNAware.org Sponsorship

LDNAware.org is now receiving over 5,000 visitors monthly and growing. Further, each person who visits our website for more information on LDN has a social networking circle. We are now considering advertising and sponsorship partners for our websites with proceeds going towards the funding of LDNAware conferences and information technology needs. If you, or anyone you know, are interested in marketing to this rapidly growing, worldwide community, please contact us.

The more people who know about LDN the more people benefit from LDN. Spread the word.

Contact Us

We would like to hear from you, telling us what is happening regarding LDN in your Country.

To submit an article for the next newsletter please use the contact form on the website.

Website: www.ldnaware.org

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