WISCONSIN LYME NETWORK MAY 2019

AT A GLANCE

Ticks Bite and We Fight!

Our State News

By Sherry Sievewright, Board President

May is Lyme Awareness Month and each year we remember those who have been affected by Lyme Disease and the co-infections that debilitate and consume lives. (2019 Wisconsin Resolution)

The stories that come through our Facebook page are just astounding, and there are so many individuals that need doctors that will treat efficiently and effectively to get patients into a remission state so they can live their lives again.

If you are a patient, or have a family member or friend that has been affected by Lyme disease, please know that we continue to bring awareness to the state of WI. We are actively seeking doctors to attend CME courses and we are working toward becoming a Lyme friendly state for patients where doctors will recognize, treat and stay up-to-date with current research.

If you wonder whether or not research is even being done, the answer is yes. At ILADS last year, I saw that the research is ongoing, no matter what anyone tells you. They have been researching since the 1970's and in our state, they have been keeping an eye on Lyme and tick borne illnesses since 1980. We cannot explain why we are where we are. At this point, however, we remain positive and encouraged that we will soon have help.

-Sherry

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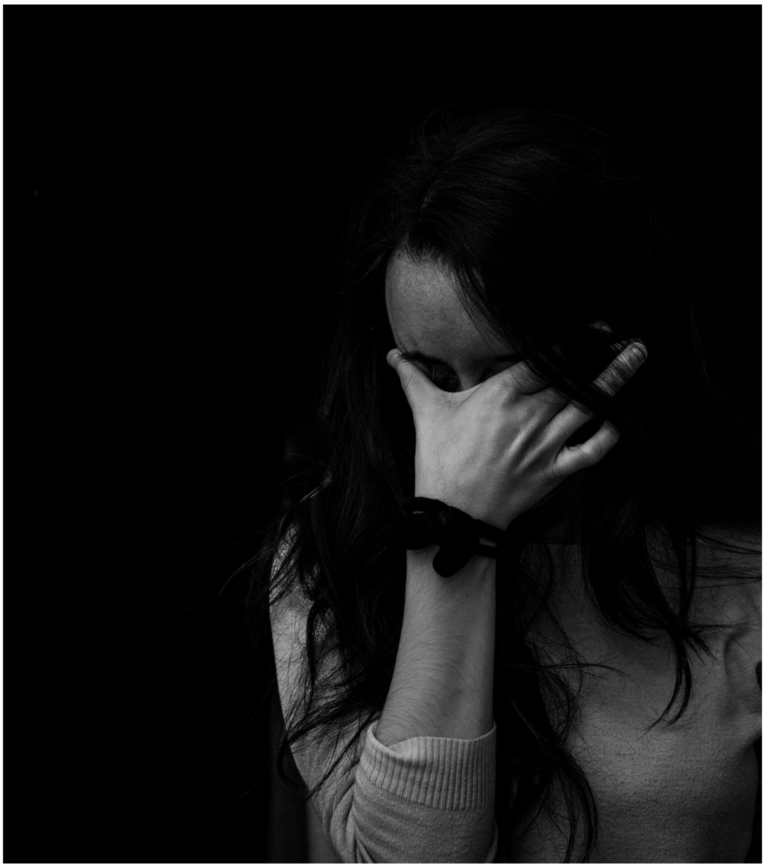

Lyme Research:

Is the Sky Truly Going to Fall for Patients with the ‘Untreatable’ Form of Lyme Disease?

by Alicia Cashman

Recently an article appeared in Newsweek magazine titled,“Untreatable Form of Lyme Disease Could Hit 2 Million Americans By 2020, Scientists Warn” (1). The title of this article is misleading at best and inaccurate at worst and will lead many to falsely believe that Lyme disease cannot be treated properly.

If you are new to the world of Lyme, please understand there is huge polarity in the medical and research communities on nearly every single aspect of it. Disagreements on definitions, testing, diagnosis & treatment, and even on an understanding of the very organism itself abound. Thousands, possibly millions of patients are left alone to suffer in the fray with doctors too afraid to even treat them (2).

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Looking for some great volunteer opportunities? Wisconsin Lyme Network needs you!

The Wisconsin Lyme Network is in need of individuals who are interested in leading the way in the State of Wisconsin to educate, bring awareness and share with others about the debilitating effects of Lyme disease.

Through educating our communities, we seek to heighten awareness so that our medical facilities and health care professionals can no longer look past the symptoms and dismiss the cause. We need people who are willing to step up within the entire state, working with the Wisconsin Lyme Network.

If you feel this to be your calling, please sign up through our website or email us to let us know of your interest and where you are located. Send us some of your ideas of how you can assist us in this important cause. We need more volunteers who are up to the task, who know Lyme disease and who are willing to share their stories. Hope to meet you soon!

-WLN Board of Directors

Lyme Research cont...

Lyme disease, around from the beginning of time, was “discovered” over 40 years ago by William Burgdorferi, but since then research has been scant and controlled by a highly vested group of individuals with patents on everything from test kits and vaccines, to other metabolomics (3). There are currently two lawsuits against the Centers of Disease Control (CDC) (4/5). The CDC completely ignores credible animal and foreign studies, continues to fixate on the acute phase, only supports its own research, and is run by what many call, “The Cabal.”

On the opposite end of the pendulum from the CDC and Infectious Disease Society of America (IDSA) is the International Lyme and Associated Diseases Society (ILADS), a group that despite persecution by state medical boards abiding by the antiquated and unscientific CDC criteria, dares to treat patients appropriately. The CDC states that 21 days of doxycycline will essentially “cure” Lyme disease at every stage, yet denies that people can be chronically/persistently infected. ILADS states this disease is far more complex and requires many nuances to treatment. Recent research supports their stance.

Just last year, Garg et al. stated in their groundbreaking paper, “Our findings recognize that microbial infections in patients suffering from TBDs (tick borne diseases) do not follow the one microbe, one disease Germ Theory as 65% of the TBD patients produce immune responses to various microbes” (6). This polymicrobial aspect is completely ignored by CDC/IDSA, yet research has shown patients that are infected with numerous pathogens have more severe disease symtoms of longer duration, not to mention the need for different medications for a longer period of time due to the stealthy nature of the pathogens but also due to vast immune suppression (7).

Garg et al. also highlighted the fact that borrelia is pleomorphic, which simply means that it has the ability to shape-shift when it feels threatened (6). Pleomorphism is also completely denied by the CDC. There are essentially four forms borrelia can take: spirochete, cell wall, non-cell wall (cyst or dormant form), and biofilm (a protective colony). At least two studies to date demonstrate that the CDC’s mono-therapy of doxycycline may actually push borrelia into the non-cell wall/dormant form to reemerge later when conditions are opportune (8/9). This could very well cause or exacerbate brain diseases such as Alzheimer’s, dementia, ALS, Parkinson’s, and many others (10). Patients have been misdiagnosed with these diseases only to find out much later that they are in fact infected with Lyme and/or the other pathogens that come with it (11). Once they start proper antimicrobial treatment effectively dealing with all the pathogens, these symptoms disappear altogether or improve dramatically.

Continued on page 4...

UPCOMING EVENTS

SCOUT LEADER TRAINING:
JUNE 9
SPEAKER: MIKE NICHOLS
(THROUGH THE ORGANIZATION).

WE WILL KEEP YOU INFORMED AS DETAILS BECOME AVAILABLE FOR UPCOMING EVENTS.

Lyme Research cont...

Drilling this home further, Pathologist Alan MacDonald found Borrelia (Lyme) DNA in 7 out of 10 brain specimens in patients who died from Alzheimer's, and Dr. Klinghardt has gone on record stating that he's never had a single patient with a Alzheimer's, ALS, Parkinson's, or MS diagnosis who didn't test positive for Lyme (12). Most of the quibbling is over patients who remain with symptoms, and despite what the CDC states, there's a lot of them.

Recently, microbiologist Holly Ahern wrote about this issue of persistent symptoms clearly delineating that the CDC and mainstream researchers have been quoting and utilizing an inaccurate statistic about this important but neglected group (13). She states that the CDC's usage of 10-20% of patients who remain with symptoms, whom the CDC labels with Post Treatment Lyme Disease Syndrome (PTLDS) only includes patients who were diagnosed and treated quickly. It does not and should not include a much larger group who are infected for weeks to years before getting a proper diagnosis and treatment. Research shows this second group to be 30-40% of patients. Simply adding the two groups reveals that 60% of Lyme patients end up with chronic symptoms. This higher percentage more accurately reflects what I see as a patient advocate. Simple math also shows that if the CDC estimates that there are over 400,000 new cases of Lyme disease each year (more than double that of breast cancer), that means more than 24,000 will have continuing symptoms. This is per year - mind you.

This crucial issue has been denied by the CDC. Not only is it important from the standpoint that 5.8 million Americans are living with Alzheimer's and dementia deaths have doubled in the last two decades (14), both of which could be caused or exacerbated by Lyme disease and/or the various co-infections that come with it, but because only certain drugs work on the various forms of Borrelia as well as these co-infections. In fact, besides potentially pushing the spirochetal form into the cyst form to reemerge later, the CDC mono-therapy of doxycycline only works on two of the four forms (8). The remaining forms necessitate different drugs and potentially a longer treatment time - far longer than days. Bizarrely, my own dog with asymptomatic Lyme disease was treated for months by our veterinarian.

The other glaring issue is that the falsely skewed low percentages do not accurately reflect the numbers of those suffering with debilitating symptoms, which will automatically place it further down the pipeline of crucial research needing to be done. It's the proverbial "Catch-22" with sick patients left to cope.

For the Newsweek article to state that this is an "untreatable" form of Lyme is a tad bit early since the CDC doesn't even recognize pleomorphism, the polymicrobial nature of the disease, and that Borrelia can even persist.

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Did you miss the interview with Alicia Cashman? Click on the link to read and see the interview she did in Madison. Thank you Alicia for stepping up and taking this on to educate the public and bring more awareness to our Wisconsin community.

https://www.channel3000.com/news/its-way-more-complicated-and-complex-woman-warns-of-lyme-diseases-lingering-effects/1073590289

TICKS BITE
AND
WE FIGHT!

Lyme Research cont...

While researchers, mainly from outside the U.S., have published studies on all these factors, the U.S. sits idly by, only doing yet again more research on the acute phase with faulty study parameters, and the continued CDC stance of using a simplistic mono-therapy that potentially could very well make patients worse off in the long run. My own experience and that of many, many others is that we wouldn't be alive today without treatment given by experienced practitioners utilizing judiciously applied and varied long-term antimicrobials.

I must add here that this is a far more herculean issue than it appears at first blush. Due to the CDC guidelines, doctors for decades have been persecuted by state medical boards for utilizing anything outside these literal mandates. My own doctor had to pay fifty-thousand dollars in legal fees to keep his practice (15). He's far from alone. This is happening all over the U.S. as well as in other countries (2), and it's often insurance companies turning them in.

Recently, I wrote an article about experienced and successful treatment nuances after Dr. Joseph Burrascano created a video for ILADS (16). In it, he not only lays out the sordid and politically motivated details of the history surrounding Lyme disease, but explains his in-house studies performed with other health professionals to determine antibiotic efficacy utilizing microscopy. Let's just say it's a far cry more complex than 21 days of doxycycline which for the knottiness of Lyme disease and it's co-infections is akin to throwing sand into the ocean.

While I'm thankful journalists are writing about this very real 21st century disease that has become a true pandemic, I hope they start doing their homework and report the fact that this disease has been downplayed, denied, and mishandled for decades. The author of the Newsweek article not only used yellow journalism but erroneously used a picture of an American dog tick/wood tick that while capable of transmitting numerous pathogens, to date does not even transmit Lyme disease.

Few journalists are studying the contradictory science and presenting both sides. Most articles read as CDC/IDSA propaganda, and that propaganda is killing people. With all that is coming out on the seriousness of Lyme disease, the increasingly high infection rates, and the continued suffering of so many, the CDC, NIH, IDSA, and the big-name institutions working with them blithely continue on the same short-sighted road without blinking, while patients are still unable to get proper diagnoses and treatment (17), and are still being told, "It's all in your head"(18/19/20). The sky is going to fall for those with Lyme disease; however, if authorities continue to ignore worldwide research and fail to act on discoveries that show this plague is quite outside the box they've created for it. The only possible box this plague fits into is Pandora's.

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WE HAVE PRETREATED SOCKS

Community Outreach

The Wisconsin Lyme Network has been able to partner with a company that manufactures factory bonded repellent socks.

We have women/girls socks that are more colorful and look similar to ski socks. We also have men/boys crew socks.

If you are interested, please go to our website to order them directly from our web store. If you have any questions, email us at info@wisconsinlymenetwork.org.

Remember: Prevention is key to protecting yourself.

Wisconsin Lyme Network
wisconsinlymenetwork.org

This is Brynn. Brynn tested positive at 12 months old. Brynn still camps with her family, and this is how her family protects her. Join them at "RV there yet...Our camping adventures" on WLN's Facebook page. Photo taken and designed by Jillian Burgess