

President's Blog

Shame on the New York Times!



Pat Smith, LDA
President

What a tremendous disservice the New York Times has done printing an article in 2019 that carries a message that doctors, supposedly experts in the field, tell parents of children who they diagnose with Lyme “Great news, it’s Lyme disease, that’s the best thing it could be...It’s baloney that you can’t cure Lyme disease, it’s eminently curable.”

Let’s cut through the baloney...Lyme disease has been around 44 years in the US that we know about. In 2017, based on CDC’s reporting underestimate by a factor of 10, 427,000 cases occurred. Numerous peer-reviewed journal articles cite 15-20% of patients continuing to remain symptomatic or relapsing after treatment with treatment percentage rates of those not diagnosed early believed to be even higher. “Chronic Lyme,” which the “experts” call Post-Treatment Lyme Disease Syndrome (PTLDS)– a term that implies no additional treatment should be given–a term couched of course, as a research construct, which any researcher courageous and principled enough to beg the federal government for grant funds to try to get answers for chronic Lyme is probably required to use in his/her studies. Many researchers cannot get a grant if they try to study “chronic Lyme.” Word has been whispered through the halls of DC... *all the research that needs to be done on chronic Lyme has been done.* Now, that is baloney.

A lot of research that has been done on chronic Lyme/PTLDS has been initially or completely funded through non-profits across the country. Those researchers who dare to defy ridicule from some of their "expert" colleagues for dabbling in a "patient invented" condition, have found that there are a number of reasons why Lyme may be chronic, two examples follow. "Persisters," are cells which remain after a course of treatment and are able to survive in a different state in the body, so traditional antibiotic treatments cannot kill them, and they may reemerge under certain conditions to again cause a patient to be symptomatic (K. Lewis, Northeastern; Y. Zhang, Johns Hopkins). Biofilms are aggregates of the bacteria that develop survival mechanisms en masse (E. Sapi, University of New Haven). Some of these same researchers are further examining what other types of antibiotics are able to kill the Lyme bacteria in those states.

Different researchers from various institutions have shown in studies that indeed, the spirochete can be found in animals after antibiotic treatment for Lyme disease, for example, mice, dog and monkey studies (S.Barthold, University of California, Davis; R.K.Straubinger, Cornell; M.Embers, Tulane). Even the NIH did a xenodiagnoses study where clean ticks bit infected individuals who had been treated and yet some picked up the spirochetes that were still in those individuals (A.Marquez,NIH).

I am not a scientist, but respect the science and know that much more needs to be done. I have spent time not whispering conspiratorially in the ears of Congress but educating Congress about the science and the patient problems, so it can make informed decisions about directing more monies and attention to Lyme disease. I am a mother who "vicariously" experienced Lyme disease through two of my children, one who was out of school for 4 full and two partial years, 3 years with seizures. I am a Lyme and tick-borne disease advocate and have been for ~35 years, since I first encountered Lyme in my

school district. I was a board of education member there and dozens of students and staff were sick with a disease which no one talked about, no one provided information about; none from the health department; none from the federal government. I finally went to the military to get information to provide to parents in the district. Fortunately, by the time my kids developed it, I was able to eventually recognize it and get my children diagnosed and treated until they were restored to health to a large degree.

The same Lyme "experts," decided in a testing meeting in 1994 in Dearborn, MI, that only certain Lyme tests would be used, after they carefully stripped away from the tests two highly specific Lyme bacteria proteins that many Lyme patients with late disease responded to, meaning many of the sickest patients no longer met any diagnostic standard. 25 years later, we use this antiquated technology and testing criteria, developed for surveillance, for Lyme disease testing, which picks up ~50% of the cases. To hear the "experts" tell it, if you test positive for Lyme, it's a false positive, and you don't have the disease; if you test negative, you don't have the disease; and if it's equivocal, maybe get retested. Imagine using 25-year old computer technology today! Yet their vested interests and powerful lobbying in the halls of Congress has put the general public at great risk of delayed diagnosis and delayed or inadequate treatment, which can lead to chronic Lyme.

The Times article indicates a month long course of antibiotics is effective regardless of stage. There are two sets of guidelines out there that don't agree on Lyme treatment. The IDSA guidelines, which embodies a few weeks of antibiotics and you are cured, or perhaps you get sent to a psychiatrist or told to go home and live with it. The ILADS guidelines, followed by the community physicians out in the trenches risking their licenses to treat patients—treatment which allows for clinical judgement. Treating these often difficult

cases no one else wants is a thankless job which requires anyone tackling it to climb a steep learning curve with peer education involved. Diagnosis and treatment often requires hours of intensive patient history-taking and record keeping, and follow-ups, 15 minute visits are not an option. These doctors never know when the "experts" who dismiss their own patients with "baloney" will find a way to have medical boards go after them or find some way to tarnish their reputations and prevent them from publishing studies showing the progression of disease. Please do not think all in the medical field have the patients' best interest at heart—not with Lyme disease anyway.

Meanwhile, the epidemic spreads with 50% of the US counties with ticks that transmit Lyme, and that CDC data is already 5+ years old. Not only do deer and small mammals carry those ticks, but also birds, on whose migrating pathways researchers often see the spread of certain ticks and diseases they carry—about ~20 tick-borne diseases and conditions in the US now.

Yes, there are individuals who have been caught early and treated and recovered. Since there is no test for cure that I am aware of, the jury is out on the term "cure" in my opinion. I am happy that the child in the article has recovered.

I am sad, angry and repulsed that the Times would use this type of sensationalism to denigrate those with chronic Lyme and spread a dangerous message that Lyme is not serious and that it being chronic "could be nothing further from the truth." It is that unproven dogma spread by the "experts" that has allowed millions world-wide to become sick and disabled, and some to die an agonizing death. The Times passed up an opportunity to provide a balanced scientific article on the chronic versus non-chronic debate by interviewing some of the researchers cited above for their perspective but chose the baloney instead.

[Click here for NY Times article, *My Son Got Lyme Disease. He's Totally Fine*](#)

Pamela Weintraub is a science journalist and winner of the American Medical Writers Association book award for *Cure Unknown: Inside the Lyme Epidemic*. Psychology and health editor at Aeon and former senior editor of Discover Magazine.

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