

## PATIENT RIGHTS RALLY

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[www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org)

We are here in Connecticut to take a stand. We are here over 30 years after LD was recognized, to tell the public, doctors, and government officials that we expect to receive treatment, we expect doctors to be able to treat, and we expect to be accorded the respect and the compassion we deserve as Lyme disease patients and families of patients.

It is a travesty that in this great country of ours where we can send machines to others planets and we can access every part of the globe with a click of a button, we continue to allow a microscopic bacterium to run amuck in our bodies and the bodies of our children.

Wreaking havoc on the person physically, mentally and emotionally, the tiny spiral-shaped Lyme bacterium invades the body tissue and the central nervous system including the brain, stealing ambition, ability, and sometimes even life itself from the hapless victim.

Suddenly John loses his job, Mary her high school years, Jane her husband through divorce, and the family its house, because Lyme disease has struck. While society rightfully assists and is sympathetic to those with HIV, cancer, tuberculosis, and diabetes, it turns a blind eye and a deaf ear toward victims of Lyme and their families despite the fact reported by John Messmer from Penn State Milton S. Hershey Medical Center on Penn State Live Wednesday that Lyme disease is reported more often than HIV or tuberculosis.

The government expends little to fund research for Lyme disease, the most prevalent vector-borne disease in the US—~\$32 million annually for a quarter of a million new cases each year, compared to \$77 million for a few thousand reported WNV cases.

Over 30 years into the disease, there is still no gold standard test for Lyme disease. Two of the most prominent indicators of Lyme disease in the lab,

the 31 & 34 bands, have been removed from testing, leaving thousands of patients without a definitive diagnosis. There have been few funded treatment studies. The CDC Lyme surveillance definition is rigid and antiquated— reported cases reflect 10% of case numbers that meet the CDC surveillance criteria, chronic patients are not even tracked and most often not in the reported count at all since physician-diagnosed cases not meeting surveillance are thrown out by health departments and the CDC.

Treating physicians are scarce. Expending precious monies needed for treatment on transportation and lodging, patients often travel by car, bus, train for hours or days and fly across the continent or across the world to find a doctor knowledgeable, willing, and brave enough to treat this chronic disease. They sometimes sit for hours in the doctor's office for their opportunity to describe to a Lyme literate physician how the disease has stolen their lives. This doctor may be the first person to lend a sympathetic yet professional ear to this patient and may be the first to diagnose and treat long standing disease, although the patients may have already seen dozens of physicians, some unknowledgeable at best, others who were arrogant, dismissive, paternalistic, or even rude.

Disturbing stories from patients abound. I heard from a parent who took her 11 year old daughter to a "Lyme expert" because the child was in severe distress from Lyme disease. The doctor took the Mom and child on a tour of the medical facility and after dismissing the child's complaints said "Here are children who are really sick," showing them children with cancer and other diseases. The child cried all the way home.

Opening question from an ophthalmologist about to perform an eye exam: "Does your daughter really have Lyme disease or do you just think she does?" A parent took a child to a doctor after Lyme symptom relapse. He insisted on ordering a slew of tests but refused to order a Lyme test. If all the others come back negative, I will order the Lyme test, he told the mother who had vehemently argued with him on this issue. All the tests did come back negative, the mother reminded him of his promised Lyme test. He never called back. She had to threaten legal action with the office to get the results: positive for Lyme. "I am not intellectually convinced your daughter has Lyme disease," the physician told the mom, who intellectually wasn't convinced this was the doctor for her child and found another.

(Personal family Lyme story here)

Lyme patients are treated like dogs, you say? Not so. Our furry friends fare much better. Most veterinarians are sympathetic to animals with Lyme, and they educate pet owners to the serious, pervasive and debilitating nature of this disease, especially relating to dogs. They test and treat them, sometimes prophylactically (meaning without symptoms) and even acknowledge the deaths caused by Lyme disease in dogs. I have not heard of any vets who are harassed for treating the disease either.

Long-term treatment with antibiotics is described as harmful to patients with Lyme disease. Patients with acne, for which long-term antibiotic use is standard and appropriate therapy and tuberculosis which may require 6 months or more of treatment, are not denied treatment. The results of a 48 week NIH trial using the antibiotic minocycline are touted in an NIH headline on their website “Clinical Trial Shows Minocycline is Safe and Effective for Rheumatoid Arthritis.” Remember, we are talking 48 weeks of treatment.

Some say long-term antibiotic treatment is causing antibiotic resistance. Look at the facts. The Union of Concerned Scientists reports “there are 25 million pounds of antibiotics used in cattle, swine and poultry for nontherapeutic purposes,...including growth promotion and disease prevention. ... By contrast, the report finds only 3 million pounds of antibiotics are used in human medicine. That means we are using 8 times the amount of antibiotics in healthy animals [emphasis added] as we are using to treat diseases in our children and ourselves. The bottom line is that our data suggest that agricultural use of antibiotics is likely to be a larger part of the antibiotic-resistance problem than is currently thought. In sum, our report indicates that antibiotic use in agriculture far exceeds use in human medicine.”

Despite mounting science, case numbers, and clinical successes, doctors who treat Lyme long-term continue to be ridiculed and harassed by their peers, government, insurance companies, even businesses, who all at some time may have intersecting agendas. Witness the May 29, 2006 COVER STORY “Medicine's Industrial Revolution” in *Business Week*. University of Pittsburgh Medical Center's Presbyterian Hospital chief medical officer Loren Roth is featured in the following quote within a quote from the article.

“UPMC's Roth says that improving the quality of care may also mean challenging a bedrock belief: that each patient is unique and that doctors must bring individualized judgment to each case. This view ‘has a kind of appeal to it for both the professional and patients,’ says Roth, ‘but it is not so.’ Most illnesses and injuries can best be treated by standardizing care, he argues. The goal is to ‘industrialize every process we can.’ This idea horrifies some doctors, but businesses and insurance companies, who pay many of the bills, are cheering Roth on.”

The dangerous political climate has sometimes translated into medical board actions against physicians nationwide for long-term Lyme disease treatment. These actions have had a chilling effect on the number of treating physicians who often stop to weigh the risks to themselves of treating patients against the benefits to patients of treatment. Many opt not to treat.

Actions by patients and families of patients are making changes in the way this disease is viewed, diagnosed and treated, just as the actions of one mom, Polly Murray, led to the discovery of Lyme disease itself right here in CT. The patient community has closed ranks to help protect the rights of physicians to diagnose and treat, the rights of laboratories to test, and the rights of patients to be treated and reimbursed for that treatment.

State by state, we have taken our educational campaign to officials and to mainstream medicine. Laws and policies have been introduced and even passed to protect physicians and to strengthen patients’ rights. Fully accredited CME medical presentations have been made to mainstream physicians, alerting them to the dangers of late diagnosis and improper treatment.

Unfortunately, this educational campaign is not enough. The IDSA, Infectious Diseases Society of America, an organization with tremendous power to shape medical public policy, has published guidelines which ignore the plight of chronic patients and only address short-term treatment. Most infectious disease doctors continue to use the phrase “post Lyme syndrome” to describe the symptomatic patient after short-term therapy for Lyme disease and provide those patients no options, banishing the chronic patient to a purgatory from which there is no plan of escape. Out of sight, out of mind. If we do not recognize it, we do not have to treat it, seems the mantra.

Fortunately, many of our treating physicians have formed ILADS, International Lyme & Associated Diseases Society, a society of medical professionals who are dedicated to helping Lyme patients get better. ILADS has published its guidelines for long-term management of Lyme disease in peer review. Lyme literate physicians are practicing under those guidelines. Now there are two standards of care under which doctors may treat. We have to let doctors, hospitals and insurance companies know there are two standards of care for Lyme disease, one addressing long-term treatment.

We need to demand support from our congressmen for the federal bills, S-1479/HR-3427, which will provide monies for research, physician education and prevention and set up a task force to coordinate the Lyme effort. We need to demand hearings on Lyme disease and demand government investigations of all agencies that place our doctors' right to treat Lyme and our rights to receive treatment in jeopardy.

We must tell government officials our stories of chronic Lyme, of lack of care, of lack of reimbursement, of lack of physicians. We must tell them we no longer will tolerate this situation where animals get better treatment than people, where healthy food animals consume most antibiotics produced in this country, yet sick humans are denied. Write them, phone them, email them. Follow-up if you don't like what they say. Follow-up if they do not respond. Have family members do the same.

Write to the IDSA, tell them you think it is unconscionable for them to take a position of no chronic Lyme disease. LDA wrote to the IDSA asking for an opportunity to be part of the guidelines process. LDA was told they do not want patient input into the guidelines.

We must demand the same rights as other disease victims have: the right to be treated by our doctors as they deem medically necessary, the right to be treated with long-term antibiotics, if necessary, and the right to be treated with dignity. This national disgrace perpetrated upon us by vested interests must end.

We deserve better. Our children deserve better. Over 30 years of dogma, half truths, unethical behaviors, neglect, inadequate treatment, or lack thereof, is enough! Stand up for Lyme patients' rights today and be counted.