

There are 300,000 new cases of Lyme disease reported each year in the United States. While the majority of cases can be cured with a 28-day regimen of doxycycline, if treated early, a prominence of misdiagnosis and unreliable testing can oftentimes lead to a far more devastating and difficult disease to treat. The current test employed for Lyme Disease relies on the detection of antibodies developed against *Borrelia burgdorferi*, the causative agent of Lyme Disease. If tested too early, or if the person is infected with one of the 99 other strains of *Borrelia*, a false negative may occur. This is such a common occurrence that the State of Maryland has introduced Senate Bill 926 that now requires any lab drawing blood for a Lyme test must provide a written statement to the patient stating: "... THE CURRENT LABORATORY TESTING FOR LYME DISEASE CAN BE PROBLEMATIC AND STANDARD LABORATORY TESTS OFTEN RESULT IN FALSE NEGATIVE." It states: "IF YOU ARE TESTED FOR LYME DISEASE AND THE RESULTS ARE NEGATIVE, THIS DOES NOT NECESSARILY MEAN YOU DO NOT HAVE LYME DISEASE. IF YOU CONTINUE TO EXPERIENCE UNEXPLAINED SYMPTOMS, YOU SHOULD CONTACT YOUR HEALTH CARE PROVIDER AND INQUIRE ABOUT THE APPROPRIATENESS OF RETESTING OR INITIAL OR ADDITIONAL TREATMENT."

Unfortunately, I was one of the patients that initially tested negative for the disease that ultimately left me bedridden for the better part of two years. A decade after my initial complaint of severe neck and shoulder pain, I was finally diagnosed with Lyme disease. My symptoms had progressed to partial vision and hearing loss, constant nausea, dizziness, high fevers that would last months on end, the inability to walk, temporary paralysis in both hands, cognitive issues, and ungodly pain and fatigue. The list can go on and on.

Because PA Senate Bill 100 has not yet passed, doctors are not protected in this state to effectively treat Lyme patients. I had a difficult time trying to find a medical doctor that specializes in Lyme Disease. I chose a doctor in New York. Partly because of his reputation and years of experience in treating Lyme patients, and partly because I could not find any specialists in Pennsylvania. Passing PA Senate Bill 100 will protect our doctors so they can treat this disease accordingly. Our current model conveys to doctors that it is not safe to take on or treat Lyme patients. Medical doctors are literally losing their practice for treating patients beyond 14-28 days of antibiotics. This is not some untested or controversial treatment plan. This is not a

new or experimental regimen. Antibiotics have been used to treat and cure bacterial infections since their discovery. There are a number of doctors who are treating patients with Lyme Disease against the standard (and expired) protocol proposed by the IDSA, and with great success. However, these Lyme Literate Medical Doctors are oftentimes difficult to find and typically do not accept insurance for fear of being reported by insurance companies to the medical board and having their license suspended or revoked. My first consultation with a Lyme specialist cost \$850. Each monthly appointment thereafter cost \$340 with a travel time of 6 hours each visit. The cost of lab work was an additional \$50 every three months. My total expenditure on just doctor visits alone was over \$6,000 out of pocket. This does not include cost of prescriptions, trips to the ER, gas, tolls, and food. You can see how this can be quite cost prohibitive. Again, all for antibiotics. Passing this Bill would eliminate the need to seek out such a specialist and allow patients to remain under the care of their primary care physician if they so choose.

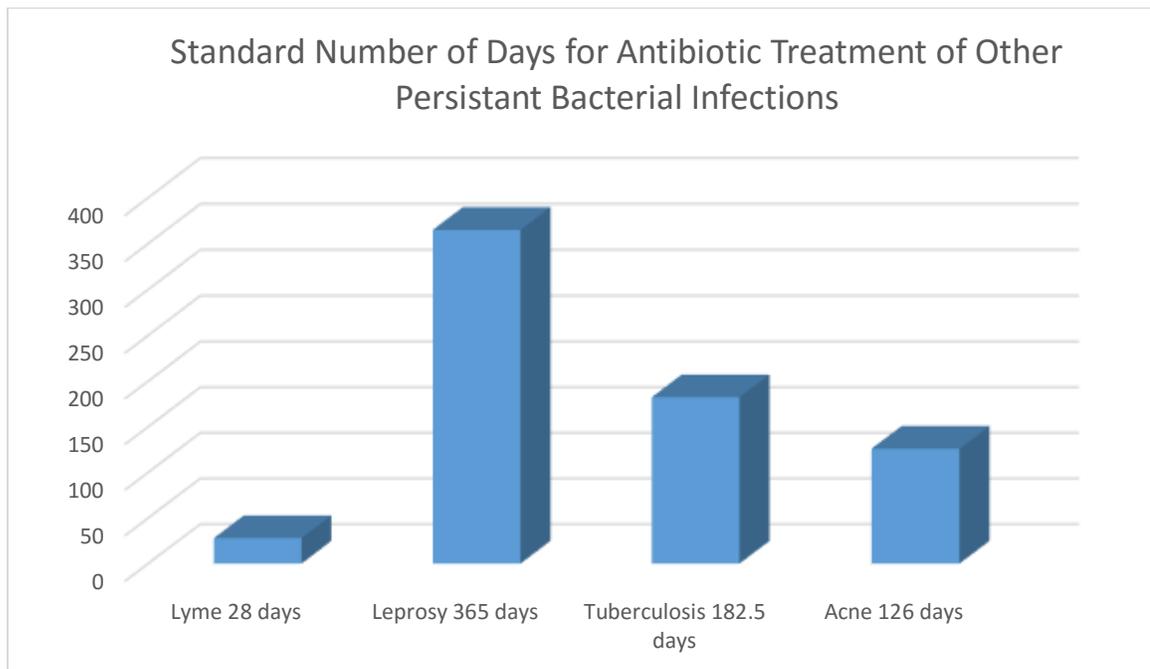
Pennsylvania leads the country in reported cases of Lyme Disease with 7,351 new cases reported in 2015. To put this into perspective, the next highest reporting state, New Jersey, reported 3,932 new cases in 2015. That is 53% more new cases of Lyme Disease in Pennsylvania than New Jersey (<https://www.cdc.gov/lyme/stats/tables.html>).

Pennsylvania should be at the forefront of Lyme legislation, but instead we are lagging. Other states passing legislation to advocate the right to treatment for Lyme disease patients include:

- Connecticut Lyme Disease Law 2009 Substitute House bill No. 6200
 - Doctors are able to treat patients with long term antibiotics without fear of repercussion for as long as they deem medically necessary
- Maryland SB 926, “The Lyme Disease-Laboratory Testing-Required Notice” bill
 - Requires anyone tested for Lyme is notified that the tests are often “problematic” and often result in “False Negatives”. Recommends any patient with continuing symptoms return to doctor.
- Massachusetts Lyme Disease Law 2016
 - Doctors allowed to prescribe long term antibiotics, commercial insurers must cover the extended antibiotics.

- New Hampshire Lyme Disease Law 2011
 - Doctors are protected from disciplinary action for prescribing long term antibiotics for patients with Lyme Disease

Lyme Disease is not the only infectious disease that sometimes requires longer than 28-days of antibiotics. Other infectious diseases that require longer treatment according to the World Health Organization include:



Some will argue that long-term antibiotic use can be risky. This may be true in some cases. However, it carries far less risk than chemotherapy to a cancer patient, or immunosuppressive therapy to an organ recipient. It is nowhere near as dangerous as cutting into someone's chest for open heart surgery. There is always a risk associated with treatment. No one would choose to receive chemotherapy if they did not have cancer. No one would choose to live on immunosuppressive therapy for the rest of their lives unless medically necessary. However, we all know and love people that would not be here today had they not opted for such treatment. A few studies followed a small and selected number of patients that extended their treatment for a month or so longer than the 14-28-day protocol. These studies did not follow patients like myself who needed treatment for a year or longer. It took me four months of antibiotic treatment before

I felt any improvement. None of the studies went beyond the three-month mark. I did not begin to see real progress until month four or five. By six months, I felt better than I did in ten years. I stopped taking antibiotics prematurely. I was hoping the pain and fatigue I had left was residual and would clear up on its own. About three months off antibiotics, my symptoms came back and I was unable to open or close my hands. My family doctor referred me back to my Lyme specialist. I started antibiotics again and continued for another six months. It took a little over twelve months total of antibiotic treatment to get to the point to where I am today. Again, not testing the effectiveness of long term antibiotic treatment beyond three months is akin to ending a cancer patients' chemotherapy prematurely, only to claim the treatment itself is ineffective, with no regard to duration. No treatment can be 100%. Not everyone who receives chemotherapy will survive. Not everyone who receives an organ transplant or open heart surgery will survive. However, they are given the option. Lyme patients also deserve the option to extend our antibiotic treatment if we are making progress on the antibiotics and want to continue. We deserve to be treated by an informed medical doctor that will accept our insurance and we should not have to leave the state to find them.

I would like to close with a question to anyone who is considering to vote down Senate Bill 100 or who has voted down similar Bills in the past. That question is "why?". Why deny Lyme patients the same treatment for a bacterial infection as is currently used to treat acne, but for longer periods of time than what is approved for Lyme Disease? The Lyme community is not looking for dangerous, obscure, experimental treatments. We are not looking for controlled substances or narcotics. We are looking for the same antibiotics you look for when you need to be treated for a bacterial infection. Like everyone else, we need to be treated until the infection is gone. So many people are suffering beyond imagination and the vast majority of them can be cured. CURED. Please, please use your better judgement and bring back the rights, dignity and quality of life to the thousands of sick people that elected you. Long term antibiotic treatment works in curing Lyme Disease. I am not anecdotal evidence. I am standing here because of it.

