

We are writing to support proposed bill #HB6200, the purpose of which is to allow physicians to prescribe long term antibiotics to patients clinically diagnosed with Lyme disease. Lyme disease is a bacterial infection and requires antibiotics. There is no one standard of care at this point that can be applied to all. The length of time for various antibiotics to be effective will be influenced by how long the individual has had the infection before appropriate treatment; the number of coinfections that were also transmitted by the tick (such as babesia, bartonella, ehrlichia, mycoplasma); the individual's unique body chemistry including already existing bacteria, viruses, or other toxins; and the state of the individual's immune system and its ability to fight the infection(s). The presence of multiple infections will contribute to the severity of the disease and the complexity of eradicating the infection(s).

The following is our story. Our son, Christopher, during his junior year at Cornell University (2003), developed flu-like symptoms that never totally resolved. First, he was put on a short term course of antibiotics, for a supposed sinus infection, and the severe and new daily headaches he was experiencing went away. Thereafter, the daily headaches reappeared and worsened, and after several trips to doctors, he needed to take a leave of absence from college because the reading and physical effort of getting around the campus were more than he could handle. We went to a neurologist in Hartford who did not understand the tremors and headache that our son was having, and referred him to a headache specialist. The headache specialist tried many medications for migraines, but nothing worked. We discovered, through much testing, that our son also had many other deficits that fit into a diagnosis of Lyme.

In treating our son's illness as sinus and migraine, we lost 22 months before he was clinically diagnosed with Lyme borreliosis after specific antibodies for Lyme showed up on a blood test, although not a sufficient number to meet the CDC definition. He received minimal treatment with no improvement. In 2007, he did test positive to Lyme according to the definition, and last year, when we switched to a doctor outside of our insurance network and out of state, who used a different lab for testing, we found that Chris was also positive for babesia, bartonella, and mycoplasma. Thus, five and one half years went by before we had a complete diagnosis and Chris started to be treated for the specific infections. While some of our son's symptoms are improving, he is still in pain every day. We are grateful that we finally know what we are dealing with, and hopeful that longer term treatment can eradicate all symptoms.

We have been disturbed by the Department of Public Health's prosecution of Charles Ray Jones, who has treated so many children successfully and is a state treasure. This, and other cases in the country brought against physicians who have treated Lyme with long term antibiotics, have created a chilling effect on many doctors statewide and nationally. They are reluctant to diagnose and treat Lyme outside of the guidelines promulgated by the IDSA (Infectious Diseases Society of America), which are so narrow that many new cases are being missed and it is difficult for those with longer term disease to get appropriate treatment. The Attorney General has found several conflicts of interest among members of the IDSA who formulated the guidelines. It is critical to allow physicians to clinically diagnose Lyme and come up with a treatment plan on the basis of

symptoms and history since the tests for Lyme and its coinfections are presently inadequate. If Lyme is caught quickly, the chances for a full recovery are good, and the cost of treatment is low. When the disease is not treated in the beginning, the expenses are very high even if you have health insurance. The health insurance policy for our son does not cover the doctor's visits, supplements, and many of the alternative services. We have also had to appeal the insurance company for several necessary related tests. There are many people throughout the state who were not treated early enough and have had their lives turned upside down by this disease. The proposed bill will make it easier for them to receive longer term treatment, and for many, will lead to much healthier, fulfilling, and productive lives. Thanks for your support.

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