

Public Health Committee: H.B. 6200

AN ACT CONCERNING THE USE OF LONG-TERM ANTIBIOTICS FOR THE TREATMENT OF LYME DISEASE

I am writing to urge your strong support of H.B. 6200. Like many late-stage Lyme patients, I developed a severe case of Lyme disease because I was misdiagnosed for many years, despite having had the classic rash followed by severe arthritic and neurological symptoms. I had to drop out of a PhD program and was completely unable to work for nearly a decade. Over the years I was treated for arthritis by a rheumatologist and later pursued holistic treatments. But none of these things resulted in improvement, and I remained mostly bedbound throughout my 20s, at times unable to even hold up my head or sit up in a chair. Ten years went by, and not even a placebo response.

When an infectious disease doctor suggested Lyme was the cause, I was skeptical. Frankly I thought it was just another internet fad. But with nothing to lose, I fortunately took this doctor's advice and treatment, and have continued to improve ever since.

Without a doubt, the only thing that has helped me get my life back is long-term antibiotic therapy. It did not happen overnight, and certainly not in the 2-4 weeks that is the "standard" course of treatment in early infection. But I am no longer bedridden, no longer numb from head to toe, no longer wracked with pain. I am working part-time and continuing to improve as long as I continue treating the disease.

There is still much to be learned about the bacteria that cause Lyme disease. Studies generally don't involve many patients like me, infected for a decade or more before the beginning of treatment. Given the present state of knowledge, it seems only reasonable that clinical judgment should dictate care for complex cases like mine.

Yet right now, aside from struggling with the disease, I am forced to go out-of-network, and worry that my access to care in the future may be in jeopardy because of the politics of this disease.

H.B. 6200 does not mandate long-term antibiotic therapy, or tell doctors how to practice medicine. It simply ensures that Lyme patients have reasonable health care choices, and offers much-needed protection for responsible doctors who are doing their best to care for patients like me – those of us who have been essentially discarded by the rest of the medical community and left with no other options.

Please help ensure my access to the one treatment that is giving me my life back. Please pass this bill.

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