

Public Health Committee

House Bill #6200

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

To the Public Health Committee:

I have lived in Auburn, Maine for the past 4 years. I am formerly from Ridgefield, Connecticut for over a decade (69 Peaceable Ridge), where my son and I both contracted Lyme disease, as did our landlord and the former tenant on the property. I am encouraged that you are trying to enact legislation that will allow for long-term treatment when it is warranted.

Please understand that there are currently two sets of guidelines for the diagnosis and treatment of Lyme disease, both based on medical evidence and both recorded in the National Guidelines Clearinghouse of the US Department of Health and Human Services. One set of guidelines, put forth by fourteen members of the Infectious Diseases Society of America, is currently under review after an investigation by the Connecticut Attorney General for antitrust violations, for excluding valid scientific research, and for serious conflicts of interest on the parts of the writers. (The National Institutes of Health recently cancelled a guidelines panel for neonatal herpes over these exact issues [Goozner et al, 2007].)

I would like to point out a few things in the IDSA guidelines that I found puzzling. They discuss that one of the symptoms of late-stage Lyme disease is peripheral neuropathy -- tingling and nerve pain in the arms and legs. I have that -- at times it has made it hard to walk. Yet these "Lyme experts" have only noted 9 cases between them in the last 5 years (Wormser et al, 2006, p. 1111). They noted encephalopathy -- brain impairment in thinking, such as in speed processing and short-term memory. My son has had that, proved it in neuropsychological testing. I have had it, too, when sick. Yet the IDSA "experts" have diagnosed only 7 patients with it in the last 5 years (p. 1111).

Did you ever wonder what happened to those first patients near Lyme, Connecticut, who were treated at Yale? I did. The researcher who first coined the phrase "Lyme disease," Dr. Alan Steere, followed up on the group every year or so, to see how they were doing (Steere, 2002). Many of them were getting sick. When two of his associates followed up to chart their symptoms, they noted, among other things, hearing loss in many of the subjects (Logigian, Kaplan, and Steere, 1990). I have that. It does not appear anywhere in the IDSA guidelines.

However, here's a statement that *does* appear in the IDSA guidelines. "In many patients, post-treatment symptoms appear to be more related to the aches and pains of daily living rather than to either Lyme disease or a tick-borne co-infection" (Wormser et al, p. 1115). I resent that statement. I was a professional dancer for over 25 years. I began studying at the age of 4. I know what "aches and pains" are. I've lived with them, and worked through them, my whole life. But when I was sick, I could barely walk a block, couldn't

work more than half a day, and couldn't remember what I was supposed to be doing from one moment to the next. Now that I am in fairly good health, I just completed working 3 jobs while putting myself through graduate school, earning an A average. I know the difference between sick and well. I am not a complainer, and Lyme is more than "aches and pains."

There is another set of guidelines, put forth by members of the International Lyme and Associated Diseases Society, that recognizes that Lyme disease and its co-infections might take more than a couple of months to cure. They have worked with hundreds of patients with peripheral neuropathies and encephalopathies caused by Lyme. They have listened to their patients, and have helped many to get better. They helped me get my life back. They are helping my son.

In other diseases (such as breast cancer, for example), when there is more than one treatment protocol, it is up to patients, fully informed of their options, to choose what works best for them. Please promote that approach in the diagnosis and treatment of Lyme disease. Make certain that the insurance industry will support the treatment of Lyme disease in accordance with any and all authoritative guidelines. Perhaps in the future, the research will be complete, and a new treatment protocol will replace the others. But until that time, please support all approaches that help make people well.

Thank you.

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