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Public Health Committee: H.B. 6200
Legislative Office Building
Hartford, CT 06106-1591

Dear Members of the Public Health Committee:

I'm writing to urge passage of proposed bill 6200, **An Act Concerning The Use Of Long-Term Antibiotics For The Treatment Of Lyme Disease.**

Here in Newtown, we are waking up to the simple fact that Lyme disease is not retreating, even though we have known about this disease for more than 30 years. According to CDC statistics, Lyme disease is actually on a steep growth curve in our state, in the Northeast, and in the U.S.

Shockingly, a recent survey in our town found that 48 percent of our households have had at least one person treated for Lyme disease. If you do the simple calculation based on our having at least 8,325 households, it means that upwards of 4,000 people have been treated for Lyme in Newtown alone!

What is hidden from sight is the course of their treatment. It splits into two paths.

Some Lyme victims can be considered "lucky" in an ironic way, because they develop the characteristic bullseye rash, or realize they have been bitten by a deer tick. With that information, most physicians are going to prescribe a few weeks of antibiotics, and most people in this situation will recover.

But the other group of patients do not necessarily recognize what they are suffering from, and in many cases, neither do their physicians. They may not develop a rash, may not have noticed the tick bite, and their symptoms may be non-specific. Initially, they may be told that they have the flu.

Their infections may go completely untreated for a long time, and by the time any physician begins to consider treating it as tick-borne disease, the Lyme infection may have spread to many tissues of the body, including the brain. By this time, in a way that parallels another spirochete disease called syphilis, the symptoms may mimic a whole range of diseases. Also, the lab testing we have is inaccurate and inadequate, so physicians often tell a patient she doesn't have Lyme disease, when it's merely a faulty test and the next physician may be able to confirm the infection.

I have heard many first-hand stories from Lyme victims, and one thing I hear over and over again is, "It took two, three, four doctors before I learned I had Lyme disease."

These patients do not get adequate treatment in Connecticut. Looking beyond the issues of rampant missed and mis-diagnoses, even when physicians in our state suspect long-term Lyme disease, they fear to prescribe anything that departs from the highly suspicious treatment regimen put forth by a committee of the Infectious Diseases Society of America. This was a committee so tainted by evident conflicts of interest that it came under threat of lawsuit by our own Attorney General Richard Blumenthal, who secured an agreement that they will form a new, unbiased committee and reconsider their findings.

But meanwhile, until that committee does its work, we are stuck with the IDSA treatment scheme as the "orthodox" regime, and our physicians fear reprisals if they should have the temerity to do anything different.

And yet, it has been found, many Lyme victims cannot get better without long-term antibiotics. So they go out-of-state to find Lyme-literate doctors, or try to keep it on the "QT" if they find any courageous Lyme-literate doctors in-state.

Sadly, our own Connecticut Department of Public Health is orchestrating the hunt for these doctors, not to praise them for selfless service to patients, but to pull their medical licenses because they don't adhere to dogma.

We all understand that the DPH has a role in preventing "quacks" and "snake oil salesmen" from practicing medicine. If some shaman somewhere is trying to cure an infectious disease with incense and incantations, that person ought to lose any medical license they might have.

But in this bill, specifically, the issue to be protected is the freedom to prescribe long-term antibiotics. This is a therapy that is already recognized and accepted with other diseases, such as tuberculosis. It is not unorthodox, and no physician should be penalized in any way for using his or her best medical judgment and experience in prescribing it.

I urge you to speed this bill into law.

Sincerely,

David A. Shugarts
Member, Newtown Lyme Disease Task Force
Newtown Liaison, Fairfield County Municipal Deer Management Alliance