

Testimony submitted by:  
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Thank you for allowing me the opportunity to discuss Connecticut's proposed legislation to make Lyme disease reportable by labs. I would like to share our families' experience with Lyme disease to explain how easy it is to catch and how hard it can be to get rid of. Lyme is not always straightforward. I ask that you please keep in mind how very important it is for the public – including physicians to understand the truer rate of infection in our state so that they are not so dismissive of it.

In 1997, my husband and 3 small children moved to Greenwich, CT from London. Five months after moving to CT, I found a tick on my 7-year-old son.

The local pediatrician prescribed 21-days of Amoxicillin after visiting him twice with concerns, and told us to have an Elisa blood test done at the end of the 21-days. My son took the treatment, the rash and symptoms I could see disappeared, and the test came back positive.

I wanted a second opinion. I blindly phoned the switchboard at a major teaching university in CT explaining I would like reassurance on the treatment of Lyme disease. I felt lucky at the time to be patched through to a pediatric infectious disease specialist. I explained my child's symptoms and treatment. The response I received was, "Your son is fine. Don't read anything. Don't go on the Internet. Your child is fine." At first I was delighted to hear that I had done the right thing. However, the fact that he said I should not read or learn anything about a disease that affects children while playing in their backyard did not sit well with me. I began reading and calling anyone I could think of that had dealt with Lyme. I became aware of how often the disease is misdiagnosed and under-treated and the dire consequences that occur because of this. One Lyme-literate pediatrician's name kept coming up throughout my conversations. This wonderful physician spent 2 hours with us on our first visit and went through the disease soup to nuts. What he said made sense to me after the reading I had been doing. He felt that the 21 days of treatment my son received was not enough and that it was only a matter of time before more serious symptoms would occur. I walked away without treatment because I had two other physicians telling me my son was fine.

Ironically, within one week of seeing the Lyme-literate physician, my son began to lose his vision. Knowing this could be Lyme and ruling out other eye issues, he began treatment which lasted about 1-½ years, and cleared up other symptoms of arthritis in my son's neck, back and fingers, headaches, vision problems, night sweats, nightmares and fatigue.

Today, my son is happy, doing well in school and at home. Once I had my son on the right track, with a Lyme-literate physician, I asked my school principal and nurse to help me get the word out about how devastating this illness can be. They put me in touch with the Greenwich Dept. of Health, and in 1998, we held a town-wide educational forum that over 300 people attended. From that forum, a group of very concerned mother's formed what is now an organization called, Time For Lyme, Inc. Our volunteer organization is dedicated to eliminating the devastating effects of Lyme disease and other tick-borne illness. Our mission is to prevent the spread of disease, develop definitive diagnostic tools and effective treatments, and to ultimately find a cure for tick-borne illness by supporting research, education and acquisition and dissemination of information. In addition, we will continue to act as advocates for Lyme disease sufferers and their families through support of legislative reform on the federal, state and local levels.

We need to have lab reporting of Lyme disease reinstated to get truer numbers of infection. These truer numbers will lead to:

- 1) Greater awareness of high incidence of the disease by residents, thereby making residents more aware that they need to take prevention very seriously.
- 2) Greater awareness of high incidence of the disease by physicians, thereby making them more aware of necessity to put Lyme disease at the top of their differential diagnostic list.
- 3) Getting the attention and the help of our state and federal legislators to combat this disease more effectively.

Note: When lab reporting was first discontinued by the DPH because of the \$150,000 cost, our organization offered to pay for it to be continued. DPH wouldn't even consider it.