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February 4, 2009

"Public Health Committee: H.B. 6200" – Christine Raymond

Greetings Members of the Public Health Committee,

Thank you so much for taking the time to understand the impact that Lyme disease can and does have on numerous Connecticut families. My thanks to you as well for supporting this bill so as to offer those who are so ill the opportunity to find treatment close to home with the medical professionals in whom they trust.

I have been a Connecticut resident for 37 years. I am the mother of eight children, five of whom have contracted Lyme disease at some time. The three who developed a classic erythema migrans rash were treated with a one month course of antibiotics and made recoveries consistent with the expected timeline. My currently 18 year old daughter, however, was not so lucky. She first started showing symptoms of the disease on March 1, 2003 after she returned home from a level 7 competitive gymnastics meet. That was her life . . . that was over. She went from being in the gym 12 hours a week and being a straight A student to sleeping 14 hours a night plus daytime naps, and spending her waking hours in a dark room away from the noise of the family's daily activities with a headache so excruciating that she could do nothing else. Our pediatrician insightfully suspected Lyme disease and sent bloodwork. Yes, even by Connecticut lab standards she was positive. She was prescribed the standard three week course of doxycycline which had her feeling better for the last few days of the treatment and 10 days after, then the fatigue, headache, and asymmetrical migrating joint pain were back and another round of doxycycline had no effect. Our pediatrician referred her to a specialist. We had to wait weeks for an appointment. This doctor performed a spinal tap which left her with a spinal headache requiring a bloodpatch. This doctor felt she needed IV antibiotics, thus she had a PICC line (long-term central IV catheter) placed and one month of antibiotic therapy. By the thirteenth day she was feeling better, by three weeks later she wasn't. We were then referred to a rheumatologist for the differential diagnosis of fibromyalgia. He recommended biofeedback (convincing yourself that you're not sick). We waited weeks for this appointment and from there we waited weeks more to see an infectious disease specialist for another PICC line and another one month course of IV antibiotics. We finally, after frantic internet searching found a doctor who was both Lyme literate and well published on the topic, and incidentally across the state line. At his office my daughter finally received the long-term antibiotic treatment that she needed to become well. I often wonder if she had received this therapy after her initial short course of antibiotics failed, would she have been saved from the senseless agony she had to endure and the yearly relapses that still haunt her, but thanks to competent medical personnel who are skilled in the use of antibiotics to treat all phases of the burgdorferi spirochete these are short lived and more tolerable. Just imagine what it felt like to see my once vibrant active child suffer day after day with no relief. Now, just imagine my horror when last year I realized that my then 11 year old was exhibiting the same symptoms. We went to our pediatrician to discuss her status and then straight over the state line. She too needed a PICC line, but one long-term course of antibiotics had her well in a fraction of the time that it took her sister. If this bill becomes law, then my pediatrician will have the autonomy to prescribe the necessary treatment at the optimal time. Just imagine the impact this will have for Connecticut families. . . Here's one other consideration: all of this treatment across state lines is out of pocket - - financially devastating in this economy.

Thank you for your support of this bill and our Connecticut children.

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