

Public Health Committee

House Bill #6200

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

Dear Public Health Committee:

My family moved to CT on 1997. Four months after moving to Greenwich, my 7-year-old son received a tick-bite, developed a rash and received 21 days of antibiotics for Lyme disease, 3 days after the initial bite. His Elisa test came back positive at the end of the 21 days. I asked what this positive test meant. How do we know the disease is gone? All that the pediatricians could say was, if he feels fine he is fine. This test is not an indication that the disease is gone. There was not a test then nor is there one today that will tell us that.

There was improvement with my son's symptoms during the course of the 21-day treatment and we stopped treatment based on the doctor's suggestion. Our local physician gave no further appointment or information. I wanted a second opinion. I phoned a major University in the state of CT and asked for advice as to whether or not I had done the right thing – searching desperately for a second opinion. At the time I felt fortunate to get a pediatric infectious disease specialist on the phone with me. I will never forget the words he spoke after I asked him if the treatment for my son was correct. His words to me were, "Your son is fine. Don't read anything, don't go on the Internet. Your son is fine." Yes, I was pleased to hear that he felt the treatment was appropriate, however his words advising me not to learn more about a disease which made my young child feel terrible did not sit well with me. Also the fact that he said my son was fine over the telephone without seeing him caused doubt. I continued to learn more and was deeply concerned with what I had been learning. I did nightly, thorough tick checks on my young children after this episode.

Within 3 months of the initial bite, and initial 21-day treatment, my son began to lose his vision. During my research about the disease, which I was advised not to do, I learned that vision issues could be a symptom of Lyme disease. I took my son to an optometrist who could not find anything wrong. I then took the advice of a Lyme-literate physician who had spent 2 hours during an office visit with my son and who felt he still had active infection due to the under-treatment of the original bite. That advice and help saved my son's vision and health. It took 1-½ years of oral antibiotics for my son to make a full recovery. Today my son is in college, has excelled in school and sports. I placed my son's health in the hands of a physician who was allowed to treat as he saw fit and it saved my son's health/life. PLEASE allow physicians to treat tick-borne illnesses clinically.

I have since devoted a large part of my life to finding more answers about Tick-borne diseases for families as well as doctors. I am a founder and Co-Chair of Time For Lyme. We have raised over \$4 million dollars, opened the first endowed Lyme disease research center at Columbia University and fund top researchers at Johns Hopkins, Suny Stony Brook, Cornell, Columbia and more. Until an accurate diagnostic test is found to determine you have the disease and/or that you have taken the correct treatment and it is gone, physicians MUST be allowed to make clinical decisions based on their sound judgment without fear of being chastised for it. The HEALTH of our children demands it.

Thank you.

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