

Testimony for HB 6200, Public Hearing
February 6, 2009

Dear Mr. Lyddy and Members of the Public Health Committee:

I moved to Redding, CT from Norwalk in 1992 and in the summer of 1994 I discovered the telltale Lyme Disease rash on my neck and sought what I believed to be adequate treatment (later I learned that it wasn't). It is 2009 and I still have Lyme Disease. After fourteen years of ever-increasing health problems that have curtailed both my athletic and professional life, I was finally diagnosed with Chronic Lyme Disease (backed up by extensive lab tests) in Sept. 2008 by an out-of-state, out-of-network doctor in Massachusetts and I am currently on combination oral antibiotic therapy, as well as exercise therapy, vitamin and nutritional therapy. The doctor has said that he expects I will be taking antibiotics for a total of 12 to 18 months.

Even though I have health insurance from Anthem Blue Cross Blue Shield (for which my husband and I pay dearly - \$1200/month; we are both self-employed), my insurance does not cover certain critical lab tests (they will only pay for those done at Quest Labs) nor do they cover the more expensive of the two antibiotics I take because they do not recognize CDL as a disease that warrants treatment with this drug (cefuroxime axetil whose retail price at CVS is \$4/pill - I take four of these pills a day).

At every turn, both in diagnosis and treatment of CLD, I have had trouble. The better doctors (and there have been many) have been mystified by my symptoms and done their best to alleviate them; a few have ridiculed me. I am currently 49-years-old but when I was in my early 40's, after suggesting to my primary care physician that something must be wrong with my immune system, he simply told me that I "was getting old." More recently, when going for a second opinion concerning the treatment of my CLD to an in-network doctor whose office said they treated CLD, the doctor's parting words to me were, "I recommend that you stop taking the antibiotics and go have a drink." (I haven't been able to drink alcohol for 14 years without getting acute chronic sinus infections.)

As I look back on my history, I realize that there were many chances for the correct diagnosis to be made, and I believe that this didn't happen largely due to the ignorance of the medical community. The reality of Chronic Lyme Disease needs to be acknowledged and doctors need to be trained to recognize it (and learn about the few critical tests that can often aid in confirming the diagnosis, i.e. tests at Igenex Lab and the HNK1 (CD57) Panel at LabCorp). Then once diagnosed, the treatment of CLD as outlined in ILADS Guidelines needs to be covered by insurance companies.

To end on a positive note, when I went back to my primary care physician this fall and showed him my folder of test results, he gladly took them and said, "Maybe I can learn something." And most recently my insurance company has authorized a single out-of-network appointment with Dr. Steven Phillips, a renowned expert in the treatment of CLD; I will see him next week for a second opinion on my ongoing treatment.

After four months of combination antibiotic therapy, my CD57 has gone from 10 to 30/uL (normal range 60-360) so I am starting to get better, but after 14 years with this disease, I still have a long way to go.

Good luck with your efforts to get the all-too-frequently chronic nature of this disease acknowledged by the medical community and its treatment costs covered by insurance companies. Perhaps once the real cost of this disease is acknowledged, the contributing problem of deer overpopulation will also be addressed.

Sincerely,
Mary Bailey
Redding, CT