

Le Suer – SB 5104

The Senators and Representatives that have proposed this bill should be commended for bringing attention to a disease that is impacting so many people in our State and in the Country.

Bringing together individuals involved in the political arena and those in the medical profession to discuss Lyme Disease testing, diagnosis and treatment is a major step in the right direction. However the composition of the proposed Committee is severely lacking. The Bill proposes two persons from the Infectious Disease arena, two physicians experienced in treating Lyme disease, two persons experienced in the clinical laboratory evaluation of Lyme Disease, the Commissioner of Public Health, and a representative of an organization in the state focused treatment of Lyme Disease.

As a mother and caregiver of a twenty-two year old woman who was misdiagnosed for seven months and is now being treated for long-term Lyme Disease, my experiences with the type of physicians you state in this bill were, to say the least, less than satisfactory. My daughter's symptoms started with nasal congestion and progressed into blurry/cloudy vision, pain behind the eyes, pain in the top of her head, migraines, ringing in her ears, loss of hearing, pain in her joints, extreme fatigue, nausea, vomiting, severe pain in her abdomen, weakness in her legs, inability to hold a pencil, loss of cognitive skills, chest pain, low blood pressure, and tachycardia.

My daughter saw a total of **fifteen** doctors between August 2011 when the symptoms started, and March 2012 when she was finally diagnosed with Lyme Disease. She had numerous tests including MRIs, CAT scans, X-rays, blood work, urine tests, and nuclear kidney tests. And, she was admitted to the hospital for two nights of observation. In early January of 2012, she had a blood test for Lyme Disease which provided a negative result. She continued to try to find answers from physicians in addition to scanning the internet for any information that would help to figure out what was wrong with her. At the end of February 2012, she pleaded with her Internist to order the Western Blot test. Finally, she received results that showed that two of the five bands show positive for Lyme antibodies. She tested positive for Lyme Disease AB (IGM) WB, reactive for the 23KD (IGM) BAND, and reactive for the 41KD (IGM) BAND. The notation on the test results indicated that The IGM Western Blot which have two (or more) of the three significant bands are considered positive for specific antibody to *B. burdorferi* (*Proceedings of the 2nd Conference on Lyme Disease, Dearborn, MI, 1994.*). We were thrilled that we finally had a diagnosis and now would get treatment. Much to our surprise receiving treatment for Lyme Disease was quite a process unto itself. The Internist referred us to an Infectious Disease doctor who met with us for about fifteen minutes, told us that he did not believe there was such a disease as "long-term" Lyme Disease, that he would only prescribe Dioxycyclene (an antibiotic) for three weeks even though he didn't believe she had the illness, and she should see a Rheumatologist even though he didn't believe they would find anything wrong with her. But, his most disturbing comment to us was that my daughter should see a Psychiatrist because he believed all of these symptoms were in her head and maybe her boyfriend was making her feel bad about herself so she was making up these symptoms to get attention. This was surreal. For the better part of seven months, I watched my daughter continually deteriorate. She went from a vivacious, intelligent, active young woman to someone who could not even get out of bed to tend to personal hygiene, and the Infectious Disease doctor

believed it was a psychosomatic issue! Needless to say, we sought a second opinion only to find that the second doctor also did not believe that long-term Lyme Disease existed. He, too, was willing to give a prescription for three weeks of antibiotics that my daughter had already tried with no success.

We finally took matters into our own hands, and through talking with other individuals who were diagnosed with Lyme Disease and were treated, we were able to work through the “underground railroad” to get more intensive treatment. This meant traveling an hour each way to see doctors. A small price to pay to receive appropriate treatment, which started with the insertion of a PICC line and thirty days of intravenous drug therapy administered at home. Throughout this process we have gone to Lyme Disease Support groups, meetings at State Universities, and private fundraisers and have seen the individuals affected, heard the atrocious stories of lack of diagnosis, lack of treatment, and lack of funding. It is still so inconceivable to me that doctors associated with the Hospital of Central Connecticut and Hartford Hospital don’t believe that long-term Lyme Disease exists. It’s incomprehensible! And, these are the doctors that the Committee on Public Health is looking to put on the Task Force.

Please continue your efforts to get this Task Force in place, but please equalize the playing field. This Task Force needs to have representatives that **currently and consistently** treat long-term Lyme Disease patients, not just those that treat Lyme Disease. To me those that treat Lyme Disease are the doctors that treat it by prescribing 3 weeks of dioxycyclene and telling their patients to go bother someone else and see a Psychiatrist because they are crazy. The Task Force also needs to include Naturopathic doctors who specialize in building the immune system and have had success in treating long-term Lyme Disease patients. The Task Force should also have a liaison who can work with the organized Lyme Disease organization and support groups to open the communication between the “underground railroad of Lyme Disease” and those that have an opportunity to change things and do what is right for the citizens/patients of the State of Connecticut. Lyme disease was so named because it was in Lyme, Connecticut that the disease was first discovered in the United States. Let Connecticut be the State that leads in making changes to the “guidelines” (that somehow have become the absolute determination) that are currently in place so that people can be tested, diagnosed and treated in a much quicker fashion.

Thank you for your attention to this matter and this email. Should you wish to contact me regarding anything in this email, you may email me at slesuer5@comcast.net or call me at 860-351-5094.

Sharon J. Le Suer