

Esteemed Members of the Public Health Committee

Re: SB 368

My name is Trent Molter, and I am a husband, a father, an outdoor enthusiast, an engineer/scientist and an entrepreneur. I've resided in Connecticut virtually all of my life and have lived in Glastonbury for over 13 years. I have a Ph.D. in Materials Science and Engineering from the University of Connecticut, am currently part-time faculty there. I also run a highly successful energy company in Glastonbury.

As a lover of the outdoors, I spend much of my leisure time hiking, fishing, involved in outdoor athletic activities, gardening, and photographing wildlife. As a consequence, I have managed to receive a tick bite nearly every other year over the past 10 years. Standard practice for me was to simply remove the tick, destroy it and move on with whatever it was that I happened to be doing at the time. In late Summer/early Fall of 2010, I received a bite from a very small tick that left an oval red rash on my abdomen. The rash didn't appear like the kind of rash that I had been told was characteristic of a Lyme infection. It wasn't a perfect circle, and it didn't really look like a bull's-eye, so I ignored it. Several weeks later, I felt feverish and wrote it off as a cold or flu. As time passed, my muscles and joints began to ache. I saw several physicians who carefully evaluated my symptoms, including running blood tests for Lyme, and could find nothing out of the ordinary. Months later, after cycling in and out of periods of achiness, my ears began to ring, my thinking became clouded, I became extraordinarily fatigued, I developed tremors, paralysis, vision problems, migraines, and bone-crunching pain in my spine and neck, among other symptoms. After seeing over 30 physicians - including many top specialists, enduring hundreds of laboratory tests, taking 6 trips to the hospital emergency room - 4 by ambulance, and a brief hospital stay there was no definitive unifying diagnosis reached for my bizarre constellation of symptoms.

During this two year process, I found it necessary to become my own diagnostician; pouring over information available on the internet, talking with people, comparing symptoms and reading medical journals. I pushed back at the medical community; suggesting that I may have Lyme disease, but had no proof in the form of a positive blood test per CDC guidelines. At the end of an appointment, physicians would typically provide me with an official read on my condition and perhaps suggest other pathways to pursue. Sometimes, while walking out the door with me, they would unofficially suggest that I continue with the line of investigation that I was on – even providing me with clues of symptoms to look for. I could tell that they found themselves in a difficult position; wanting to adhere to the established norms for diagnosis and treatment, while, at the same time, wanting to be proactive in helping me address my illness through whatever means necessary. As I became weaker I found it more and more difficult to advocate for myself. Perhaps for the first time in my life I began to lean heavily on family and friends for support. My ability to work was significantly impacted as I was able to work less than 3 hours per day. I consider myself fortunate that my company still experienced robust revenue growth even in these difficult times.

I ultimately found an out-of-state physician that specialized in Lyme disease. He initiated a long-term treatment protocol with oral antibiotics in October of 2012. The few Lyme specialists in that I found in

Connecticut were way over-subscribed as each seemed to have patient waiting lists of well over 100 people. With the help of others I was also able to employ a vast array of supportive therapies in hopes of either accelerating the process of healing, or at least to feel better and regain function temporarily. Month-by-month since initiating treatment I have tracked my symptoms. While they are not at all gone, the severity of the symptoms has been reduced by over 70% on average, and some have completely disappeared. I've returned to work full time and have resumed some of my leisure activities.

My story is not very different than a great many others that I've heard. To this day, I have not tested positive for Lyme disease on any blood test. There are many physicians that will say that I have never had Lyme disease. I am not a physician, but the empirical evidence suggests to me that the treatment protocol appears to be working.

Connecticut happens to be geographically positioned at ground-zero in the debate over the diagnosis and treatment of Lyme disease. As elected officials, I'm certain that you take your charge very seriously, and I applaud your efforts to consider action to better understand the issues surrounding this devastating disease. As you consider legislation, please realize that the lives of many thousands of Connecticut patients and their families have been, and continue to be, impacted by this disease in far-reaching ways. The disease has stripped many of their financial resources as well as their will to move forward. Perhaps this is, in part, due to the polarization of the medical community over diagnosis and treatment.

I ask you to take several bold steps to better understand the societal impact of this disease and to help mitigate the negative effects on patients and their families. Some of these are already considered in proposed S.B. 368, and some are not.

Testing Protocols - Testing protocols appear to be woefully inadequate based on both literature review, and anecdotal information. As a man of science, I understand the importance of standardized protocols in evaluating anything on a quantitative basis. I believe that with recent advances in medical research and improved analytical instrumentation more accurate testing protocols may already exist, or may be able to be implemented in the near future. As a first step, I ask you to consider assessing the availability and promise of advanced diagnostic methods.

Economic Impact – I question what the economic impact is to the State of Connecticut as a direct and indirect consequence of Lyme disease. Surely, the loss of personal resources due to costs for diagnosis and treatment must be staggering for patients, families and caretakers. The losses to Connecticut businesses must also be significant both in terms of lost productivity due to workers' illness and the impact to insurance carriers; several of which are headquartered in the State. I ask you to consider conducting a comprehensive economic assessment performed by an unbiased third party to evaluate the economic impact of Lyme disease on Connecticut. Given our State's current focus on job retention and growth, the importance of this study cannot be overlooked.

Education – Most will admit that public education on the topic of Lyme disease is poor. Some will agree that physicians and healthcare providers are not always armed with the most current information. I ask you to consider supporting funding for programs that provide educational information to physicians,

healthcare providers and the general public with regard to prevention, diagnosis, and treatment of Lyme disease.

Health Advocacy – Neurological forms of Lyme disease can compromise a patient’s memory and executive function to the point where they are not as capable as they once were of advocating for themselves. Please consider developing and implementing patient advocacy assistance programs for those that are compromised in that manner.

Review Panels and Committees – Perhaps most importantly, review panels and committees must be made up of individuals having a wide range of expertise and experience to handle the task before them. They must be unbiased relative to their charge and must also be objective in terms of the process used. Because of the well-known polarization of the community over this matter, I ask you to use great care in selecting these individuals to support any studies concerning Lyme disease.

Thank you for considering my comments.

Respectfully Submitted,

Trent M. Molter, Ph.D.