

January 24, 2015

Chairs and Members of the Committee on Children

I am writing to you to express my support of Raised **Bill No. 207**, an act concerning funding for a **Lyme Disease Prevention and Education Program**. I strongly believe that the Connecticut Department of Health should be awarded \$450,000 to execute a statewide Lyme disease prevention effort based on the Ridgefield task force BLAST model.

I am a chronic Lyme patient, currently undergoing treatment. In addition, I am a caregiver to my two children, both with active infections. We had no prior knowledge of prevention, no basic education on how to diagnose or treat this disease and unfortunately neither did our community physicians.

If a Lyme program, such as the one outlined in Bill No. 207, had been implemented several years ago, I would not be in my current situation.

I can tell you firsthand what the **lack of prevention** has done to my family. Three and one-half years ago I was an active mom who worked part time as a pharmacist until I became ill for no apparent reason. I suffered through many symptoms that included daily chronic headaches, neck pain, joint pain, neuropathic pain, neurological and cognitive deficits, cardiac abnormalities and many other bizarre and unrelated complaints. Barely functioning, and unable to take care of my children or work, I spent the next 18 months desperately seeking answers from dozens of physicians and specialists extending from the Danbury area to Yale New Haven hospital. Countless hours and several thousands of dollars later, I was still left suffering in desperation and frustration with no diagnosis whatsoever.

Finally in December 2012, a self-diagnosis was made after much independent research. Needless to say, I was thrilled to finally have a diagnosis but now I was faced with a new chapter... **treating Lyme**. I found a Lyme literate physician in Connecticut and was excited to begin my recovery.

After being in treatment for over 2 years now, I can say that treating Lyme has been an intense battle. The effects of the antibiotics on my body are at times worse and more debilitating than the disease itself. At the age of 44, I now take to take heart medication to control an irregular and rapid heartbeat and I continue to suffer from nerve pain, tremors, anxiety and sleeplessness on a regular basis. With symptoms continuing to wax and wane, I still struggle through each and every day. A constant reminder of how devastating this disease is.

If a Lyme prevention and diagnosis program had been available to me at the onset of this disease I am confident I would not be in the condition I am in today.

In September 2014, my 10 year old son, was diagnosed with Lyme disease. One month later, my 13 year old daughter was diagnosed as well. Can you imagine the devastation and fear I experienced?! Both being misdiagnosed by their pediatrician and other local physicians, I was

forced to seek a Lyme literate MD that was willing to treat children. They are currently undergoing treatment as well and are hopefully on their way to a full recovery.

Why does the state of Connecticut need this funding? **Lyme disease is preventable!** If there was a statewide BLAST program in effect 3+ years ago, I would not be in this desperate situation. I would be healthy and fully functional and my children would be healthy and happy as they deserve to be. The cost of treating Lyme once it has been misdiagnosed and allowed to become chronic is astronomical! My family currently spends an average of \$1000 per month in our efforts to eradicate this disease from our lives. This has put our family into tremendous debt and has created an extremely stressful situation for us. If only we had had prior education on prevention. We would have taken the precautions when we were outdoors playing, gardening and hiking. My kids' counselors would have reminded them to apply repellents during their days at camp. Our yard would have been sprayed and we would have done daily tick checks. This is what a statewide prevention program would have done for my family.

Since my diagnosis, the Ridgefield task force has been a tremendous support system. They have provided me with a support group and the ability to network with other individuals and families suffering through Lyme disease. I have witnessed firsthand how they fight the battle on this horrible disease using education on prevention as their main strategy.

I am requesting that this funding go to a statewide expansion of the BLAST Lyme Disease Prevention Program. We live in an area that is hyper-endemic. This is NOT going away! Prevention and proper education will prevent others from becoming infected and will yield an early diagnosis for those that do.

I am available and would be honored to discuss my Lyme disease story with the committee. Feel free to contact me at ukahndoit@yahoo.com or at 203-790-8603.

Thank you for your time in this very important and urgent matter.

Sincerely,

Becky Kahn