

March 22, 2023

LD 906

Sarah Cotnoir Testimony

Good afternoon, Senator Baldacci, Representative Meyer and Members of the Health and Human Services Committee. My name is Sarah Cotnoir and I would like to share my personal experience with tick-borne testing. Thank you for taking the time to hear my testimony. I have chronic Lyme, Bartonella, Babesia and Anaplasmosis. My youngest daughter has chronic Lyme, Babesia, Brucella, Bartonella and Anaplasmosis. My oldest daughter has chronic Lyme, Babesia, Bartonella and Anaplasmosis which was passed to her in utero, though we did not know it until she was just recently diagnosed this year, at age 18.

My youngest daughter was bitten by a tick and presented with a fever and bullseye rash at the age of 2. I had heard of Lyme briefly but knew virtually nothing about it at the time. She was given a blood test by her pediatrician and it came back positive for Lyme. She was put on a 3-5 day antibiotic and sent home. Little did we know what would be in store years down the road. At 8 years old her body started failing her. Her pancreas couldn't regulate her blood sugars, she was spiking fevers, always complaining of being tired, having joint and muscle pain, her liver started to shut down, she would intermittently lose her eye sight for hours at a time, neurologically she was so impaired that on bad days she couldn't add simple numbers such as 2+3, many days she couldn't walk and would need to be carried, she had horrific seizures...amongst many other things. We had brought her into the doctors for another Lyme test but it came back negative. We did not receive the test results. Only the lab saying "negative". And so, they sent us different directions trying to diagnose her. They thought she might have diabetes, then they thought Lupus, one after another we saw specialist after specialist and she just kept getting more and more sick. We knew something wasn't right and we fought with her pediatrician over the fact that she was severely ill, likely fatally if nothing was done. Finally, we went to get a second opinion at a different doctor. Her bloodwork was re-done and we were given a positive result for both Lyme and Bartonella. The doctor used a more comprehensive test with a lab out of state. Because of this new information, paired with my daughters symptoms, she was able to make a diagnosis. This was the beginning of her journey towards healing.

My story is quite similar. I began getting severely ill with symptom onset coming out of seemingly nowhere that only continued to get increasingly worse. I went to see my doctor and was tested for Lyme multiple different times. Every time it came back "negative" but we did not receive any lab results. So, my doctor looked for answers elsewhere. Over the next year I saw many specialists. I received proposed "diagnoses" of lymphoma, multiple sclerosis, autoimmune disorders, fibromyalgia, etc. The list goes on. By this point I had suffered from daily fevers of 102-104 for over a year. I was barely able to walk and often needed a cane and on other days was bedridden. I was having problems with my heart, liver, kidneys, stomach and digestive system. When my digestive system began to shut down, I was no longer able to eat solid food. I got down to 85 pounds and was losing 1-2 pounds per week. My doctor wanted to send me to the Barbara Bush hospital as he had exhausted everything he could think of here in Maine. I went to a different doctor, for a second opinion and was diagnosed with the above tick borne illnesses. 1 year later, after receiving correct treatment, I am completely well, healthy and thriving. Had the test results been made available to my doctor, at the very beginning, when

we tested for Lyme, he may have come to a different conclusion and I may have been able to get the help I needed faster, which would have prevented all the bodily damage to my organs that I incurred. No one should have to suffer that horrifically simply because of lack of medical information.

This bill is imperative to the health of patients suffering from chronic Lyme and/or other tick-borne co-infections. Because chronic Lyme has a higher percentage of coming back as a negative, it is crucial for doctors to have the ability to compare the comprehensive lab results against the patients' symptoms to get a truly accurate picture of their overall state of health in order to arrive at an accurate diagnosis and treatment plan. Had the full results of the lab work been available to me and my daughters, our lives could have been spared a lot of pain and suffering, time spent chasing down diagnoses that were dead ends, financial burden from unnecessary medical bills, and also taking up precious time and energy from specialists who didn't need to see us could have been avoided. I think it's important to note that not having raw data from lab tests results is a strain on the medical system at large. It is not fair to the patient nor the providers, as it takes specialist's time and attention away from patients who really do need them. My doctor told me that if I hadn't received the care I did, when I did, I would have "suffered loss of life". My organs were shutting down and Lyme would have claimed my life in less than a year. I am very thankful to be here today, I am also very concerned for other individuals who are where I was 2 years ago- searching for a diagnosis – and I am deeply grieved at the stories I see where people have lost their lives because of something that could be so easily rectified. This bill has the potential to save lives, at the very least to significantly improve them. Every patient has the right to the raw data that was tested on their body. Every doctor has the right to that data so they can discuss and come to an accurate treatment plan together with and for their patient. Refusal to release this data to doctors and patients leads to the question, why? Why wouldn't you share this??

Thank you for taking the time to hear a small piece of my story and that of my children.

Sincerely,

Sarah Cotnoir