

June 22, 2010

Testimony Provided by Gretchen (mother) and Meghan (daughter) Harrison  
Lower Gwynedd, PA  
PA Senate Banking and Insurance Committee Hearing on Senate Bill #1199  
Chaired by Senator Donald White

**Testimony Provided by Meghan:**

Dealing with Lyme disease this past year and a half has been tough. I was constantly nauseous for over a year, taking all pleasure out of eating. I spent 5 months in early 2009 without any short-term memory. I couldn't take tests at school because nothing stayed in my brain. It was so bad that when I got home from school, I couldn't remember anything about the day and relied solely on my notes to do my homework each night. Even with my friends, two hours after lunch, I couldn't remember who I'd eaten with or what we had talked about. I was fatigued, had daily migraines, and trouble sleeping too. I went seven months with only 1-3 hours of sleep per night due to Lyme disease; I was a walking zombie. Contrasting my life before and after Lyme may be helpful to you.

I was an avid rower three seasons a year, and was planning on rowing division one in college. I worked with one of the top coaches in the US in his elite technical development camp and was used to working out at least two hours a day. Now with this disease I can barely walk a mile. Forget even getting into a boat! Exhaustion overwhelms me just from accompanying my Mom to the grocery store.

Once an avid reader, now reading more than five minutes gives me a migraine. Math and science, my two favorite subjects came easily to me. With Lyme, I have trouble thinking and remembering. It feels like there is fog surrounding my brain. I've missed my entire junior year, and don't know when I'll be able to go back to school.

Before this disease I was happy, had great friends, and knew where I was headed. Now I take a day at a time, can't make any plans, and can't see my friends because it takes too much energy.

Last fall, while I was on a waiting list for a doctor knowledgeable about Lyme, I became so sick that all I could do was lie in bed. I was dizzy and struggling with postural tachycardia syndrome (PoTS), migraines, and insomnia. My body was barely functioning. After treatment by the Lyme specialist, my health is now improving. My nausea is totally gone and the faintness/dizziness is less. My sleep has gone from 1-3 hours a night to 5-6 hours. I still have a ways to go, but I feel so different. Just in this past month, I have had moments where my brain fog dissipates and I can think clearly again.

Though I am still extremely sick, it is nothing compared to last year, when I didn't know what was wrong with me. The doctors had no clue, making me into a guinea pig with all their tests, and when they couldn't diagnose me, one told me to see a psychiatrist. I have stayed positive and hopeful throughout this ordeal, taking one day at a time. My family and my faith are a big part of what keeps my spirits up, but also I feel that no matter how much I've suffered, it will all be worth it if I can prevent this from happening to someone else. That is the reason I am here today. No one deserves to go through what I have, and I just hope you'll help prevent others from going through this pain by voting yes.

### **Testimony Provided by Gretchen Harrison**

Good morning Mr. Chairman and Committee members. I am Gretchen Harrison, Meghan's mother, and my husband Dave Harrison, a member of the American Academy of Actuaries, is also here with us today. It has been heartbreaking as parents to see our daughter Meghan go from a full and rewarding life to being bedridden most of the time and not even able to complete school online.

**My family has seen firsthand how differently Lyme disease is handled from other diseases in respect to the exercise of clinical judgment.** In 2003, Meghan had her swollen knee drained and her Lyme titre came back negative, so Lyme disease was immediately ruled out. Yet, she was diagnosed with Juvenile Rheumatoid Arthritis without even doing a test. When I requested one, it came back negative, yet the specialist insisted that, in his clinical opinion, Meghan should receive treatment for Juvenile Rheumatoid Arthritis. Perhaps they shouldn't have thrown out the Lyme diagnosis so easily; it is common knowledge that the currently available tests aren't perfect.

Interestingly enough, in the 1970s the same problem occurred in Lyme, Connecticut. Polly Murray was a housewife whose family started having strange arthritic symptoms; she also started learning from neighbors and others in her community that their children were presenting with similar issues. She brought 51 cases of mostly pediatric arthritis to the attention of Yale researchers. And that is how they discovered Lyme disease. At the time, these cases were being diagnosed as Juvenile Rheumatoid Arthritis. Unfortunately, it seems like things haven't changed all that much in 35 years.

Our daughter had her first diagnosis with Lyme disease in 2005 when she presented with a bulls-eye rash. She was given the standard treatment which seemed to suffice at that time. However, she later began having other symptoms. She experienced several years of migraines, severe allergies, and mononucleosis. Her immune system that had always been strong seemed to have trouble righting itself.

Yet, it wasn't until November of 2008 that Meghan had her first unexplained symptoms, that later were diagnosed as advanced Lyme disease. It all began with constant nausea and fatigue. By the end of January, she had completely lost her short-term memory. In February, she had what the emergency room declared to be "a flu-like virus" where she couldn't keep any food down for over a week and she had sharp stabbing pains in her abdomen that would double her over. In March she started having problems falling asleep at night that were so severe she had to take sleeping drugs. By the end of April, she had daily migraines.

My family's experience indicates a lack of information about Lyme disease and its symptoms by every doctor Meghan saw for a six-month period before she was diagnosed. Cardiologists, gastroenterologists, neurologists, and emergency room physicians - none of them recognized her symptoms as Lyme disease. When I reached that conclusion in February doing my own research, they refused to test her claiming she didn't have the "classic" symptoms. They were looking for arthritic symptoms and hers were now more digestive and neurological. Even though her symptoms clearly met the CDC criteria, they were missed. Instead, she was subjected to many very expensive tests, including an EKG 24 hour holter monitor, gall bladder emptying tests, ultrasounds, x-rays, upper GI, electrocardiograms, etc. It would have been MUCH cheaper for the health system to have run the simple Lyme blood test and to have treated her earlier.

Finally by the end of April, I was desperate to have a Lyme test run and begged our family doctor to test her. He did. In her case, when it was finally run, she did present with CDC positive tests. If the doctors and specialists had been more knowledgeable, maybe she would not have missed her junior year of high school. Dr. Fallon from Columbia University Lyme Disease Research Center ran a trial that showed an average delay of two years between symptoms and diagnosis, so at least the research shows we are not alone.

Even after her diagnosis, physician lack of knowledge was an issue. When the oral antibiotics were not improving her symptoms, her family doctor referred her to an

infectious disease specialist in Philadelphia since he felt IV treatment was necessary. The infection disease specialist, even noting her seven months of severe symptoms, said all she needed was a 100 mg dose of oral doxycycline twice a day for 2-3 weeks and her nausea and headaches would go away and her memory would come back. But, he said her sleep issues must be from something else since he had never heard of sleep deprivation being connected with Lyme disease. I didn't embarrass him by mentioning that the CDC website at that time listed sleep disorders as a symptom of advanced Lyme disease.

He would not put Meghan on IV antibiotics without a spinal tap, despite three different tests already showing she had Lyme. Instead of subjecting her to that, we found an Infectious Disease doctor, almost 50 miles away, who was willing to treat her without requiring a spinal tap. **I got two differing opinions even in the infectious disease community** on the need for the spinal tap. Ultimately I guess it boils down to clinical judgment.

**We also experienced clinical judgment being driven by rigid time guidelines.** The infectious disease specialist who ended up treating Meghan pulled her off all antibiotics in August 2009 and told her she was cured. Her short-term memory had returned, but all her other symptoms were still there. She became dizzy, constantly grabbing onto walls or furniture to keep from passing out. Without antibiotics, her health went downhill. By September, she had a migraine/severe headache that lasted for several weeks, despite emergency room treatment. Once a girl who read constantly, a mere five minutes of reading sent her into a migraine. Her focus and clarity of thinking disappeared too, which made schoolwork impossible. As the fall progressed, her sleep became almost non-existent. Despite seeing one of the top sleep specialists in the area, for seven months, she existed on 1-3 hours of sleep a night, never able to nap or doze, even with the sleep drugs prescribed to her, and never once getting a full night's sleep.

**Finding a doctor willing to treat Meghan's Lyme disease was very frustrating.** We waited eight months for an excellent physician experienced in the treatment of advanced Lyme Disease. Luckily, I had called to put Meghan on the waiting list in May 2009. Meghan finally got in to see the doctor at the end of January 2010.

Where are we now? **Last month our insurance company sent us a letter informing us that coverage for Meghan's IV antibiotic treatment ceased as of May 10, 2010.** We have, however, continued to receive some reimbursements since receipt of the letter. Interestingly, it's the IV antibiotic treatment after the cutoff date that's brought her sleep up to 5-6 hours. She experiences occasional times of clarity now without brain fog.

Meghan's case should have been caught much earlier – it should never have progressed to this stage. In addition, when she finally had a full Lyme evaluation, she did also test positive for co-infections. Besides medical costs that we have borne, I also had to quit my job as Director of Media Relations last summer so that I could be home with Meghan full-time doing what we can to restore her health.

I have one other issue I want to mention in the interest of time. **Awareness is needed in the schools** since many school activities, including strong environmental programs, put kids at risk when the schools don't have enough information about Lyme disease and the importance of prevention. Both of my daughters had many science classes in the woods along the Wissahickon Creek adjacent to their school where they diverted trails, removed invasive species, and planted new trees. But neither daughter remembers any warnings being given about Lyme disease, and I am sure they had plenty of exposure in those woods.

Please pass this legislation. It is **unfair to Pennsylvania's youth** whose lives are compromised, to deal with a health care system that prolongs the disease and worsens its symptoms because of late diagnoses and a lack of knowledge of best treatment protocols. Families that can afford it, have to deal with financial hardship to get their children well because treatments that work are not always covered by insurance. For those families that can't afford it... this is a travesty. Ours is one story, and there are many others we are aware of even more severe than Meghan's case. I ask you to support Bill #1199 to provide health care justice for all the citizens of our state, and to put health care decisions back into the hands of physicians.

The Harrison Family  
Lower Gwynedd, PA