

CT – US Senate HELP Committee Field Hearing

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Senator Blumenthal & HELP Committee Members:

My experiences with Lyme disease began about 27 years ago when, as a board of education member in my NJ township, I witnessed students and staff, in particular from one area of the community, develop a disease called Lyme disease, one which we in the public sector knew nothing about. I got the district to agree to put out information through the schools, after I spent weeks trying to find out what Lyme was and where I could find that information. I finally found what I needed on a local military installation, where some of the first cases of Lyme in NJ had been diagnosed and treated. It was the first time I heard about Juvenile Rheumatoid Arthritis, which had often been the initial diagnosis of the children who were later correctly diagnosed with Lyme.

A few years later, first one then another of my children developed Lyme disease. Fortunately, I was aware of the symptoms of Lyme and when my oldest daughter had symptoms which could be described at best as weird, I sent her to a hospital near her college, where they readily, without fanfare, diagnosed and treated her for Lyme disease. My youngest daughter was not so lucky. Her symptoms were vague and in the intervening years between the onsets of my daughters' health problems, suddenly those who had Lyme became pariahs, and the journey to get my youngest daughter diagnosed and treated was a nightmare which I liken to a trek through Dante's Inferno, with each downward spiral worse than the previous one.

I had intended to raise my 3 children and reenter the work

force when the last had finished elementary school. That was not to be, as my youngest became sick around 10 years old, and remained in the grips of a disease that took her through arthritis, petit mal and grand mal type seizures, temporal lobe type seizures, gastrointestinal problems, back and neck problems, memory loss, mental confusion, tachycardia, brachycardia, panic anxiety attacks, hallucinations, balance problems, eye problems, muscle pain, nerve pain, later morphea sclerodoma and a condition similar to POTS, and blackouts. If you are not familiar with some of those terms, welcome to our Lyme world of the 80s, 90,s and later. I was a mother, not a doctor, but soon had to not only argue legally, scientifically and morally for treatments that worked but had to mix and dispense meds through pumps and hang IV drips. I remember worrying at 3 am whether I would kill my daughter, as I carefully tapped air bubbles out of syringes on a "sterile" kitchen table.

The worst of times were the 3-4 years of seizures, where she was out of school, technically on home instruction, although many sessions had to be cancelled. The "episodes" she had were something no mother should have to deal with, and when a doctor finally gave me a name to put with it, I was ecstatic. A name meant the ability to deal with it. Temporal Lobe Seizures, he said. I searched for an expert on temporal lobe seizures in the US and called him up. He was kind enough to listen to what I told him about my daughter, what her Lyme had triggered, what I had done, and when I finished my tale, he said, congratulations, you now know more about temporal lobe seizures than most doctors in the world. I was stunned and did as much research (no internet then) as I could into what was happening to her, the different manifestations—the times when she spoke with no "affect," the times she spoke like a little girl, the times she just sat and stared for hours on end, the times she screamed for us and did not know we were there, the times she woke up screaming that she had "6" fingers (on one hand), counting them and showing her were useless in those

times, there was no rationality during those episodes. I remember the nights I slept on a mattress on the floor beside her bed, so if she woke up in a seizure state, I would be there to calm her from the awful nightmares and assure myself instantly that the bloodcurdling screams were not someone killing her. These seizures states seemed to be controlled by a switch. They turned on, lasted 16 hours or so a day, and turned off. She, fortunately, was left with no memory of what occurred during them, we were not as fortunate. We were all exhausted, and my entire life was spent tied to my daughter and her terrible illness, trying to find people to help save her life. I wore a beeper (no cell phones yet) so my husband could beep me if I ran to the store and something happened. I rarely left home. Once I came back and found she had retreated into the fetal position. That is when I decided that if my daughter survived, I would never let a family go through this alone again. I have tried to keep that promise.

Fast forward to today, where after many years of antibiotic treatment and alternative treatments, my daughter has a life after graduating with honors from a prestigious college (ironically, the doctors associated with that college refuse to treat chronic Lyme patients) and has held corporate jobs in a medically-related field. Does she still have Lyme disease? Yes, I say that not as an "expert," but from the perspective of 121 mother years of experience and 24 grandmother years of experience of dealing with children with and without Lyme.

There is discourse out there from some who call themselves experts who know nothing about Lyme disease, or worse, do know, but are led by vested interest. They claim Lyme patients and their families think everyone has it. Not true. Two of my daughters have Lyme, one doesn't; all four of my granddaughters do not. I want to keep it that way.

Instead of entering the paid workforce, I devoted my life and energies to volunteer to help those afflicted with Lyme and help others avoid Lyme. To that end, I have spoken and/or

testified in numerous state capitals across this country and in Washington, DC. I have met with leaders connected to all levels of government and all branches of the federal government and met with the military. My 12 years as a board of education member and board president taught me how government should operate, how it does operate, and how to get problems solved. The first issue requires educating people to the problem. I have done that, the next requires lobbying, I have done that—when that fails, it is time to rally those who have the same types of problems—I have done that, and I continue to do all of the above.

It is time now that government recognizes that Lyme has gone from an unknown infectious disease to one which has spread from a few states in the 70s & 80s to all states and to 65 countries throughout the world. It is time to recognize that in 2009, the Centers for Disease Control & Prevention, CDC, said that Lyme surpassed HIV in incidence in the US. It is time to recognize that the testing used for Lyme disease is ancient—while scientists are mapping genomes and using DNA testing, Lyme doctors are forced by government agencies to diagnose by looking for antibodies that may take weeks to develop, if at all, or may not be testable when they do develop.

Patients are caught in the middle of vested interest “experts” who saturate the media with their take on the science of Lyme, shutting down discussion of all the aspects of the science, refusing to partake in any meaningful dialogue with those who hold different opinions based upon science the experts have decided is unworthy. These experts use their influence as medical journal reviewers and also walk the halls in State Capitols and in Washington, DC, and use their significant financial clout to make sure their message is heard and accepted. That leaves us, the patients, the families of patients, who are also advocates, to stand up for the patients who are physically, mentally, emotionally, and financially

drained from Lyme disease, to try to get them the help they desperately need. The “experts” have decided that we too, the advocates, are crazy, unknowledgeable, unstable, and they use their bully pulpit to spread those lies with relish, trying to discredit the people in the trenches who are working to help humanity.

You have the ability to help patients and to prevent others from becoming patients. To borrow from a once popular TV series, “the truth is out there.” You need to uncover that truth, wresting it from those who would prevent it from reaching daylight, those whose gravy train will be derailed if that truth comes to light. On behalf of patients everywhere, I ask that you make that effort. Read the testimony from this hearing and for further details on the science, the reporting, the testing, the numbers, I ask that you go to the US House Foreign Affairs Committee, Africa, Global Health & Human Rights Subcommittee Hearing Record on Lyme disease on July 17, 2012. There, you can find some measure of that truth and have a springboard for actions, which you as government officials, can take to end Lyme disease. Thank you.