

# President's Blog



LDA LymeLiteracy

Pat Smith, President, Lyme Disease Association, Inc.

## Dirty Little Secrets of Lyme Disease

*May is Lyme Disease Awareness Month, a time to remind ourselves that Lyme is a disease that has been neglected, minimized, and ridiculed over decades and still continues to be. We all need to redouble our efforts to get an accurate test and to get patients properly treated and treated with dignity. The continued arbitrary ban on ignoring persistent Lyme disease and treating persistent Lyme patients must be lifted! Here is my take on the secrets of Lyme from 35 years of advocacy.*

## “Dirty Little Secrets of Lyme Disease”

### ***Where It All Began***

Circa 1984 and recently elected to my municipal Board of Education, I found the district in a state of unrest. Students, teachers, others, were developing a heretofore unknown disease. Many in district were hospitalized, rumor had it the disease attacked their brains and they were getting heavy IV antibiotics to try to get them better. I went to the superintendent and said we needed to alert parents, questions were being asked, no one had answers. No one came into the district to talk to us, no government or health officials. The super gave me the go-ahead if I could get info, he would distribute. That search for information began a 36-year chapter of my life that has yet to end.



*Pat Smith, President,  
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I began my journey as a mother with three children, knowing nothing about Lyme disease, and fought a never-ending battle when two of them developed Lyme disease, in a society where mainstream doctors shut the door on Lyme— refused to discuss, refused to test, refused to treat. Where one of the first questions asked, in front of the child was, so does the child REALLY have Lyme disease or do you just THINK she does; where you had to threaten to get a lawyer when the doctor refused to tell you the results of the Lyme test when it was positive—the office would just keep hanging up. A society where a medical institution with a floor full of children seizing from the disease would take secret videos when the children stopped seizing for periods of time and acted “like normal kids,” then those in charge would tell their parents the children were faking. This is what parents told me as they cried, and I held their hands to try and comfort them. Where a supposed famous Lyme expert doctor from the Northeast would tell a 12-year-old child very sick from Lyme disease, see these children (showing the child cancer patients in the hospital), they are really sick, you are not. One mother tracked me down and begged me to help as her daughter cried all the way home and for days afterward and wanted to commit suicide.



### ***What They Did to Our Children***

The conduct of those who dealt with our children with Lyme was horrifying. Doctors would tell parents they could not talk about their children's seizures from Lyme disease to anyone, or the children would be put into a psychiatric institution and would not be treated for their Lyme. That was hard for even me to believe early on until I heard of a number of those cases involving both children and adults.

I worked with school districts across the country where children were told they were not sick, they were faking— they just did not want to be in school. Lyme disease was arthritis, it could not affect their brains. Districts tried to prevent long-term sick students from graduating. I went to court to help a couple. In one case, the judge, without prior notice, refused to allow me, a volunteer advocate, to speak on the case, the mother could only pass me notes in court. The decision was made that the very sick honor student, would not be allowed to graduate/walk in graduation, as she had a few more weeks of work to finish. The judge ruled against her. I could not say anything. It was awful. I told the judge whom I saw afterwards in the hall what I thought of her decision. Looking back, I guess I was lucky I was not charged with something. That student went home, and although direly sick, worked for day and night for many days, finished and graduated with her class with honors and went on to college.

A teacher directly called a child with Lyme who had been out of school for several years and told her she had to be cheating on home instruction, nobody could get that grade and be sick. I will not tell you what I, the mother, said to the school and to her. A child on home instruction was denied entrance into the honor society as she did not (read: could not) participate in any school activities. A district tried to prevent a student whose IQ was off the charts from taking AP courses, one of the many excuses was in their opinion, he

was too sick to take AP courses, and then they said they had no teachers certified in AP courses to teach him on home instruction. After I pointed out there was no such certification at that time, he ended up not only taking the courses, but I heard, teaching some of the teachers. Another student was forced to take some of the same exact subjects for 3 years straight, as toward the end of each year he was too sick to attend school the last two months and could not complete the courses. The district did not offer any required accommodations, and he had passed a state-required graduation test. They tried to deny him graduation, but due to their non-compliance with regulations, I was able to not only permit him to graduate but the district paid for his community college.

I also heard from doctors, the few who treated then, about child suicides with notes that said no one believes I am sick, my family, my school, even my doctors. (LDA's Lyme: Kid's & Schools Page)



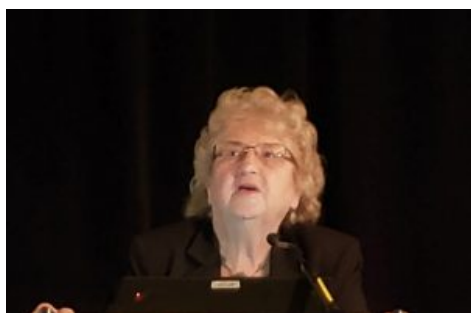
*Pat Smith: Voices of Lyme Rally, Westchester 2006*

### ***Our Doctors Under Attack***

It would take a book and a lawyer or two to talk about what happened to our doctors. We whispered inside doctors' offices about Lyme and its manifestations, after traveling for hours to find someone willing and able to treat, but whose partners would never consider a Lyme diagnosis. Doctors were stripped of licenses, sanctioned, hospital privileges threatened,

doctors relocated, and were told they could not diagnose tick-borne diseases unless they were infectious disease physicians or had one consulting—meaning a diagnosis was not going to happen. As an advocate, I spoke to many attorneys to try and keep doctors from being railroaded. Firms would call me in and question me for hours, trying to find ways to help the doctors and also patients who could not get treatment. Doctors would drop out of treating Lyme, some till this day will not touch a Lyme patient, or cannot, due to legal documents. These stories are too legion to repeat. *(Some doctors too afraid to treat...)*

My journey started in NJ but spread all over the US and even to other countries at times. The above are a very few samples of the abuse, neglect, inhumanity and in my opinion, almost criminal behavior surrounding Lyme. (LDA's Controversy Page)



### ***Current Situation***

Today, I am a grandmother of four, and I stay in this battle to prevent them and their peers from developing this terrible disease, the politics of which have prevented the science from moving forward. Today, conditions are somewhat better; however, there are still no accurate tests that determine whether someone has Lyme disease, or has active infection. Why? The government has prevented the development/approval of such a test, claiming technology from the 1994 Dearborn meeting is still the best.

Certain portions of the country are still “prevented” from having Lyme disease as the government insists a geographic restriction has to remain in the surveillance definition, a definition that is often used to diagnose, yet the government outright refuses to take any stance to ensure that does not happen. Over the past decades, parents have still been threatened with Munchausen by proxy and children have been taken from their families for being treated by licensed physicians for chronic Lyme disease with long-term

antibiotics. Sometimes these cases are a direct result of divorce and custody issues. But it happens, I know, I have had crying mothers on the phone with me.

Doctors continue to be afraid to treat using one of the two Lyme disease guidelines. They continue to be charged. Many in government, mainstream medicine, insurers, and even researchers, who are in positions to stop this abuse, hide behind the "science of Lyme," science which is often long outdated and which has been challenged by new findings from respected scientist and institutions. Yet they refuse to acknowledge this research or refuse to confirm or expand it by approving funding for other studies, which could provide the answers they do not want to acknowledge. Many have positions as peer reviewers and are able to prevent publication of new findings which would move the field forward. Hand in hand, these entities continue to control the entire picture of Lyme disease from testing to treatment to reimbursement to vaccines, hiding their secrets of Lyme.

### ***What Is The Government Really Doing?***

Shockingly, these stories and thousands like them have occurred across the US, and worse, continue to occur. There are some elected officials in Congress and state governments who have bucked the tide and are really helping patients. They are not included here and deserve praise for their efforts by working with the Lyme community to help patients.



But to date, those officials in decision-making public health positions able to "help" Lyme patients have taken actions that are akin to throwing crumbs to those starving for help—placation at its worst. Describing these actions as hypocritical is a gross understatement—the actions, or lack of, exhibit a bias against Lyme patients. It is time that it is recognized for what it is, blatant discrimination against an entire group of Lyme patients with persistent symptoms.

More than ever, patients must do everything in their power to

influence their legislators to take actions to expose the secrets of Lyme, to stop this discrimination, and to hold these decision-makers accountable. Only then, will there be a test, be effective treatments, and be a cure. Only then, will patient suffering be alleviated.

***Bottom Line***

Those individuals who suffer with or care for patients with Lyme disease have had to face not only the disease, economic ruin, and family demise, but also ridicule, scorn, and a journey through Hell, never knowing what the next level will be or when their torment will end. It is a journey burned into the soul.