

Dear Congressman Lyddy and Members of the Public Health Committee:

I have had Lyme disease since 1989. I had a soft-ball sized rash and positive test. I was undertreated at the time (in Ridgefield, CT), and later on had extreme difficulty walking or standing very long.

By 1992 I was bitten again, with another documented rash, but this time the symptoms were all neurologic instead of rheumatologic. When I wound up luckily at a well-educated doctor's office, my bloodwork came up for CVA (cerebrovascular accident) or stroke. I did not have a stroke, per se, but I was pretty close to it. I could not feel one side of my face. I was stuttering and slurring my speech. My memory was gone. The doctor was extremely well-versed in Lyme literature and patients presenting with this complex illness.

Nevertheless, despite much treatment, by 1993 I was disabled from Lyme disease. I still have Lyme-induced hyperacusis (extremely severe/acute sound sensitivity, eg the sound of a refrigerator hum often sounds like a motorcycle engine). I am home-bound due to the extremes of sound and how they affect me. I am treated for this problem with seizure medicines.

From 1989 to 2009 I have been on and off antibiotics over the years. When I was acutely ill in 1992, I was on IV Rocephin for several months. It saved my life and saved what's left of my brain.

I have a Masters degree in English from Columbia University but can only read non-fiction now because I cannot remember what I am reading (on previous pages in fiction, with characters, plot twists, etc). I volunteer in a quiet museum in Danbury.

I would like to have a life again, and know that when I see my doctor, I won't have to worry about him having been put out of business by IDSA's new strict Lyme Disease Treatment Guidelines (which bear no resemblance to reality or the current science).

Having witnessed what undertreated and misdiagnosed Lyme disease can do to neighbors and friends over the years, I feel that any Guidelines for the Treatment of LD should reflect all points of view and the most current and up-to-date medical literature on the topic.

Patients should not be punished and sentenced to lives of disability and despair just because IDSA sets rules which are clearly at the behest of insurance companies and other conflicted parties.

Please forward this as my testimony to your hearing today, and please strive to put patients before profits (something that IDSA has never been known to do).

Sincerely,
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