

DC – US Senate Lyme Hearing, before Senator Edward Kennedy

August 6, 1993

Written Statement of Pat Smith, Wall Township, NJ

I have two daughters, Michelle and Colleen, who suffer from Lyme disease. Colleen is a fifteen year old honor student who has been out of school for 3 years. She receives home instruction and is currently working feverishly over the summer to try and complete her freshman year. She has been experiencing seizure activity for a year and has abnormal EEG's consistent with Lyme. During the temporal lobe seizures, which can last for 2-3 days, she initially experiences speech impairment and a paralysis of her legs, and throughout the seizure, she is withdrawn from reality and experiences mental confusion, paranoia, and emotional turmoil. In addition to the seizures, she has had arthritic, ophthalmologic, dermatologic, and other neurologic and musculo-skeletal symptoms of Lyme.

Colleen has had to give up most of her childhood because of Lyme Disease. She was a very athletic and musical child who has had to forego all her activities and has experienced weight gain and dramatic changes to her life due to Lyme. In the past 3 years, she has had eye problems which have not allowed her to read for any extended period of time without violent headaches and/or distorted vision. Throughout these ordeals, she has maintained a positive attitude.

Over the past 4 years, Colleen has had approximately 5 months of IV antibiotic treatment with several different drugs. For the past 2 years, she has been on oral antibiotics. The antibiotics have helped; when she was removed from them for an extended time period, she relapsed. Her doctors include an internist, rheumatologist, ophthalmologist, neurologist, MD

nutritionist, and chiropractor.

Michelle is twenty-four and has had Lyme disease since college. After oral antibiotic treatment, she suffered no symptoms for almost 3 years, then relapsed. She is chronically tired, has headaches and recurrent eye infections. Her current treatment regimen includes oral and ophthalmic antibiotics. She continues to work, since her symptoms are not as severe as Colleen's.

Last year while serving on my local board of education, I prepared a preliminary report on how Lyme has affected nine New Jersey school districts. I presented this to the Centers for Disease Control and the National Institute of Health in Washington by invitation of my Congressman. As a result of the report, CDC sent Dr. David Dennis to New Jersey to complete a more in-depth report on the effects of the disease on school children. I worked with him and the New Jersey Department of Health to expedite the data gathering. Although I do not agree with some of the conclusions drawn by the CDC in its follow-up report, I believe the data collected speaks to the seriousness of the disease.

There are a number of problems with the State and Federal public health response to Lyme that deserve Congressional scrutiny. The doctors currently underreport the number of Lyme disease cases, primarily because the CDC definition of the disease is an epidemiological one which has been inappropriately applied to diagnosis in clinical situations. Additionally, when these agencies had obtained useful data and case studies on Lyme, they applied the information toward focusing on one treatment complication of a particular antibiotic rather than focusing on the *

The National Institute of Health (NIH) also possesses data, including tissue sam- *

Jiles exhibiting spirochete survival after long-term

antibiotic therapy, which it has *
ailed to release to extramural researchers.

In conclusion, I urge serious consideration be given to the testimony of physicians such as Dr. Burrascano who treat hundreds of chronic Lyme patients and are knowledgeable about the variability of symptoms and the survival of the spirochete even after extensive antibiotic therapy.

Lyme has deprived children such as my daughter of their activities, friends, school and of their childhood; for others, it has taken their lives. You have the ability to stop this mmscriminate killer. Dont let our children down. Thank you.

http://www.archive.org/stream/lymediseasediagn00unit/lymediseasediagn00unit_djvu.txt

* This testimony may contain some missing segments which is beyone our control since it came from the Senate Hearing record with those omissions.