

Carolyn Cramoy, MS, CNS  
(Resident of Connecticut from 1974-2000  
- both children diagnosed and treated in Connecticut)  
Nutritionist  
81 Intervale Way  
Lake Placid, NY 12946  
(518) 523-7502  
[Cramoy@aol.com](mailto:Cramoy@aol.com)

February 26<sup>th</sup>, 2007

*Testimony for Public Health Committee Bill #5747*

Lyme disease is one of most complex and currently confusing diseases in medicine. There are no easy answers and no single answer that works for all cases. Only through clear-minded gathering of more and more information about the disease will we be able to arrive at correct answers.

Lyme testing is less than perfect at this point in time, but requiring the reporting of positive and equivocal Lyme disease test results is one of the few methods available for maintaining reliable (if partial) statistics on the prevalence of the disease and the effectiveness of preventive measures within the state.

As the Connecticut mother of two long-term, relapsing Lyme disease victims who were successfully cured with long-term antibiotics when nothing else worked, I am appalled that the IDSA is willing to risk the well-being of a particular portion of Lyme disease patients by using their organizational power to push through a distorted and simplistic view of Lyme disease which can potentially deny proper care to a number of people. Under the guidance of the IDSA, both of my children would continue to be invalids in extreme pain and perhaps with permanent neurological damage from their test confirmed Lyme disease. Luckily, my kids were ill some years ago and each is now a healthy young adult with no lingering Lyme symptoms.

My daughter was ill with Lyme disease for more than 5 years - was treated with all the standard treatments recommended by the IDSA, but continued to be ill. The only times that she showed any positive responses were the times when she was treated with IV antibiotics. We had an infectious disease doctor cut off her first IV treatment after 2 months because his large multi-physician practice felt it was too legally risky for him to continue a successful treatment (she was about 70% better), given that the "Lyme experts" were saying the treatment wasn't necessary. She relapsed within 7 days.

Luckily, our pediatrician let rationality rule. She was willing to risk the wrath of the medical community and willing to do the investigating necessary to try to find appropriate answers.

Bottom line for my daughter was that the "standard" treatments, including the "standard" cephalosporin IV antibiotic used most of the time in treating Lyme and never shown to be more than 95% effective in eliminating Lyme disease, were somewhat effective but did not eliminate her illness. But when consultation with two of the top Lyme disease specialists in the Northeast led our doctor to prescribe another IV antibiotic, the response was amazing after a 4 year struggle with arthritic, neurological and cognitive problems despite ongoing treatment with large doses of oral antibiotics and an occasional IV treatment with one of the IDSA approved antibiotics. Initial response to treatment with this alternate antibiotic made us hopeful (better in 3 weeks than she had been in 3 years) but it took 3 months of treatment with this alternate IV antibiotic to get to the point of being totally symptom-free. Our doctor continued the treatment for an additional few weeks to assure that the regularly cycling Lyme symptoms were truly gone and then, for the first time in 4 years, this young woman was able to enjoy being a healthy, antibiotic-free young adult concentrating on her college studies and being alive. That state of wellness lasted for almost a

year. Then symptoms relapsed. Retreatment on relapse with 4 more months of IV seems to have resulted in a true cure.

This patient has now been well for 9 years, completed college and medical school with high honors and is now a physician with no signs of having had Lyme disease other than a total unwillingness to revisit the emotional pain caused by spending 5 years as an invalid accused by some of the top physicians in the country of having nothing wrong with her and of being a malingerer simply trying to avoid going to school.

An external review through the Connecticut Department of Insurance resulted in a ruling that every step our physician took in treating this patient was reasonable, well-thought out, medically appropriate and medically necessary (to use the jargon of the insurance company that tried to deny coverage of the treatment).

My son's story is similar, but less dramatic because our doctor had learned from our daughter's case and treatment was quicker. Still, he developed ELISA positive Lyme disease even though he was treated with the "standard" oral antibiotics for 3 weeks immediately following a known tick-bite. He had an equivocal Western Blot test and we were told by the head of the Lyme disease laboratory at Stonybrook that combined with his clinical symptoms and history our doctor had more than sufficient reason to treat him for Lyme disease even though he did not meet the full CDC criteria needed to be included in a research cohort. He suffered 3 relapses (with no possibility of reinfection), did not respond to large doses of oral antibiotics, and was cured by the same "non-standard" antibiotic that cured his sister. He has now been well for 5 years.

There are cases of Lyme disease which require more than the "standard" treatment. There are apparently many patients who do not respond to IDSA recommended IV antibiotics, ( - though I suspect many of these patients would respond to alternate antibiotics or combinations of antibiotics, if there were anyone willing to do an appropriate study. There are already case studies which back up this concept.) To deny treatment that has worked for many patients in the past, on the basis that "the treatment doesn't work" is not only the height of ridiculousness, but extremely unethical to boot!! Long-term IV does work against certain cases of long-term Lyme disease. In cases where all possible alternate diagnoses have been eliminated, clinical signs and exposure history make Lyme disease the most likely diagnostic possibility, short-term courses of antibiotic bring indications of clinical improvement and no alternative treatment of equal or better effectiveness can be offered, decisions on treatment with long-term and alternative antibiotics should be left to board certified physicians personally familiar with the case in question.