

My son had Lyme disease.

Frank C. Demarest, Higganum, CT.

March 2013 for **Connecticut SB-368**

My son had the classic Lyme rash in the summer of 1989, but we didn't recognize it as anything needing medical attention.

Shortly after that, he started having severe headaches, and over the next 3 years he had a number of other medical problems. He was tested for Lyme in 1990, '91, and '92, all tests were negative.

By October 1992, he was too sick to attend school. At this time his symptoms included: fatigue, occasional headaches, neck pain, migratory joint pain, muscle pain, numbness, dry eyes, conjunctivitis, sore throat, nausea, stomach discomfort, and swollen lymph nodes.

Our pediatrician suspected Lyme disease, prescribed antibiotics, and ordered blood work with a Lyme test. Over the next few days, the symptoms got worse, this is known as the Jarisch-Herxheimer reaction. When the Lyme test came back negative the pediatrician told us to stop the antibiotics and send our son back to school, – and he refused to do any other testing.

As we searched for answers, he also developed additional symptoms: loss of short-term memory and perceptual difficulties. The Lyme Disease Foundation (now defunct) helped us find a doctor who knew how to diagnose and treat neurologic Lyme disease. After another month of oral antibiotics, the doctor placed him on IV antibiotics.

After the first week of IV antibiotics, he seemed much better -- he looked good, was sleeping normally, had more energy, no neck pain for the first time in 2 years, more facial expression, and started back with his tutor (doing well).

Three days later he became allergic to the antibiotics, and had to stop. Within a few days all the old symptoms started returning, first the neck pain, then the other joints, tiredness, etc...

During that year, we battled the disease with various antibiotics and supportive treatment. We were fortunate that we had no insurance problems, although costs exceeded \$100,000. During the summer, he was tutored, and by the fall of 1993 he was well enough to return to school with his class, while still on oral antibiotics.

In 1996 he was doing well both academically and in sports. He stopped the antibiotics, and his teachers noticed he was not doing as well, for example missing things that he knew on a test. After resuming antibiotics, he again did well. He also did well in college and graduated in 2002.

Now it's 2013. My son continues to do well. There have been some great advances in medicine. But Lyme disease has the same problems it had twenty years ago. A group of entrenched doctors continues to insist that Lyme is easily diagnosed and easily treated, while patients suffer or are permanently harmed. The truth is:

- (1) The lab tests are not a reliable means of excluding a Lyme diagnosis.
- (2) Antibiotics do not easily cure late stage Lyme disease.
- (3) Prophylactic treatment of tick bites in a hyper-endemic area is a cost-effective and relatively safe means of preventing Lyme disease.

I previously presented this history at the CT Attorney General's hearing on Lyme disease in 1999.

Frank C. Demarest
53 Earl Roberts Rd.
Higganum, CT 06441
860-301-1829
fdemarest@comcast.net