

My Testimony for Kansas Senate

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By Kathy White

Case Reports

Lyme disease has been reported in all 50 states. Kansas has reported cases every year since 1988. A total of 412 confirmed cases have been reported from Kansas. Most cases are in the eastern half of the state, but some people have contracted Lyme disease in the western half. Support groups in Kansas have helped hundreds of patients, most whose cases did not get reported. IDEXX Laboratories, the makers of the SNAP test for dogs, have reports of 233 cases in dogs in Kansas during the past 5 years. They estimate that most cases in dogs have not been reported to them. They have no reports during the past 5 years of Lyme disease in dogs in western Kansas. (see www.dogsandticks.com.)

My Story

I contracted Lyme disease on April 16, 1998 from a tick that bit me while I was supervising recess in a grassy area of a schoolyard in Kansas City, KS. I got a bull's-eye rash and became very ill. I didn't get in to see my doctor until 4 ½ weeks after the tick bite, which was too late. He prescribed 3 weeks of doxycycline, but it was not enough. I managed to finish the school year but was never well enough to resume my teaching career. I was a special education teacher for preschool-aged children who had a variety of disabilities.

Difficulty Getting My Case Reported

I don't know whether my case ever got reported. I called the Wyandotte County health department to report it. They said they were aware that Lyme disease is in the county, but that I needed to report it in the county where I live. So, I called the Johnson County health department. I was told that I needed to talk to the county epidemiologist, but that he was spending 3 months in China and was unavailable.

The following year, I called again and talked with the epidemiologist. He took my doctor's phone number and said he would call him. Doctors have to do the reporting.

The reporting criteria are very strict, and my case may not have qualified. I had a huge bull's-eye rash, 11 ½ " long, but it was gone by the time I got in to see the doctor. The rash is not reportable unless the doctor sees it. I also had a baseball-sized rash that was gone by then. My doctor did see three smaller spots of the rash, but they did not develop the bull's-eye appearance until several days after my doctor visit. They were just the size of a quarter, so they were not reportable. The doctor has to see a rash that is least as large as a half-dollar to report it.

If a doctor doesn't see a large rash, two positive tests are required for a case to be reportable. I had a positive ELISA test and a positive IgM Western blot test. However, 2 positive tests are not sufficient for a case to be reported. The patient must also have one of a few other symptoms.

Heart symptoms: I had chest pains and irregular heartbeat, but the only reportable heart symptoms were 2nd and 3rd degree heart block, and I was not diagnosed with that.

Neurological symptoms: I had numbness and weakness in my face, but I could still smile faintly, so my doctor said I didn't have Bell's palsy. Bell's palsy is reportable. I had numbness all over, but unless the doctor diagnosed radiculoneuropathy, my case was not reportable. I don't know whether I was diagnosed with that.

I will never know whether my case was reported. I have called the Johnson County and the state health departments, but they both told me that records are destroyed for confidentiality purposes, so they don't know.

Reporting Criteria Changed

The reporting criteria have changed several times, each time making it more difficult for cases to be reportable. The reporting criteria are at <https://wwwn.cdc.gov/nndss/conditions/lyme-disease/>. The original criteria were created in 1995. The criteria changed in 1996, 2008, 2011, and 2017. In 1996, a person had to get 2 positive bands on the IgM Western blot or 3 positive bands on the IgG Western blot. Now a person needs 3 positive bands on the IgM or 5 positive bands on the IgG. Most people don't get that many positive bands. I got 2 on the IgM, which does not meet the criteria now. Overall, I have had 8 positive Lyme tests of various kinds, a huge bull's-eye rash, and just about every symptom of Lyme disease, but today I would not meet the surveillance definition for Lyme disease.

The IgM Western blot doesn't even count for reporting anymore, unless the testing is done within 4 weeks of the tick bite. Doctors aren't even supposed to order the test until 4-6 weeks after the bite, because it can take 6 weeks to develop antibodies. Therefore, the IgM test is now useless for reporting purposes.

Reporting Differences in Different States

States in the Northeast can report the bull's-eye rash as a case of Lyme. About 70-80% of the cases reported in the Northeast are based on the rash rather than on positive tests. The CDC says the rash is not reportable in the central, southern, or western states without two positive tests, which gives the Northeast the chance to report 70% more cases that can get reported here. The CDC keeps emphasizing that the disease is in the Northeast, which makes many doctors fail to diagnose it in most states. When people do test positive in the central states, they are often told that it is a false positive, because "We don't have the disease here."

States are not required to report cases of Lyme. Hawaii quit reporting it in about the year 2000, so no cases have been reported there since then. People who get the disease in Hawaii have been going to California for treatment. There is now a doctor in Honolulu who treats Lyme.

Lyme Doctors are Being Persecuted

Some prominent doctors have received payments for services to insurance companies, and these doctors are discouraging other doctors from treating chronic Lyme disease with long-term antibiotics. Many Lyme patients benefit from lengthy IV antibiotics, but this treatment can cost about \$2,000 a week, and it can take a year or more of treatment to get people out of their wheelchairs and back to school or work. It benefits insurance companies when doctors discourage lengthy treatment, and when the CDC recommends poor antibody tests which miss many cases, and when the reporting criteria are so strict that most cases don't qualify. Many patients have seen more than 40 doctors before they can get diagnosed with Lyme disease. Even at this late date, most improve with antibiotic treatment, but it is difficult to find a doctor who will treat them. Doctors are reluctant to treat Lyme disease, because doctors in several states have had their licenses threatened for "overdiagnosing and overtreating" Lyme disease. Some states have passed doctor protection bills to protect doctors who treat chronic Lyme disease with antibiotics. There are several doctors in Kansas who know how to treat Lyme disease but are reluctant to do so because of fear that their licenses will be threatened. This forces people in Kansas to travel to other states for treatment or to do without treatment.

We need a doctor protection bill in Kansas. Lyme advocates have proposed such a bill. We are calling it "Patient Access to Care" rather than "Doctor Protection," because the shortage of doctors treating Lyme is causing patients to be denied Lyme disease diagnosis and care in Kansas.