

Lyme in Arkansas?

Patients say they have the disease. The Department of Health says they didn't get it in Arkansas.

CHEREE FRANCO

ARKANSAS DEMOCRAT-GAZETTE

“Am I awake?” Joanie Hopson thinks. “Is this some sort of half-dream?”

She can hear her husband in the shower.

“I’m awake,” she decides. “My eyes are open. But why is everything black? Did I suddenly get cataracts? At 29?”

She hears the water stop and, a few moments later, her husband moving around the bedroom.

“Wayne, I can’t see,” she says carefully, trying not to panic.

“Put your glasses on,” he teases.

“No,” Hopson says, more emphatically. “I really can’t see. Everything is black!”

* * *

That morning Hopson began a journey that led from her internist and an ophthalmologist to two neurologists, as she sought relief for symptoms such as sinus problems, limb numbness, fatigue, rashes, intermittent crying, unexplained pain and eventually, brain lesions.

She was diagnosed with Lyme disease in 2013, two years after her sudden blindness. In her right eye, the vision loss was temporary, but she only recovered partial vision in her left eye. Because of this, the Little Rock resident, now 33, avoids driving.

Her current doctor, who she calls her “Lyme doctor,” believes her vision problem is a symptom of Lyme.

In 2009, Hopson moved from Stuttgart to Bryant. Her new yard was infested with ticks. Once she found six ticks on her body in a single day.

She has been diagnosed (misdiagnosed, she thinks) with shingles, depression and chronic sinus infections. She has undergone a spinal tap and multiple MRIs, taken allergy and fibromyalgia drugs, steroids and anti-depressants. She had even been tested for Lyme, unbeknownst to her, by a neurologist who remains convinced that Hopson has a rare form of multiple sclerosis that simply hasn't shown up in her spinal fluid yet.

When her Lyme doctor — based 600 miles away, in Georgia — flipped through Hopson's medical records, she said, “I have a positive Lyme test from 2012 for you. Why haven't you started treatment?”

That was when Hopson learned of her initial Lyme test, which — with its single positive indicator — was not considered positive under standards set by the federal Centers for Disease Control and Prevention. Lyme is a contentious area of medicine, in part because a CDC diagnosis

relies on multiple positive indicators that may differ from patient to patient.

If Hopson has or had Lyme, it's unlikely she contracted the disease in another state. She has visited Texas once, Oklahoma (which, according to the CDC, doesn't have Lyme) and, as a child, Mississippi.

NO LYME IN ARKANSAS?

“If you have a very low incidence of a disease and the symptoms are not classic, then it's much more likely that the patient has some other type of disease. If you take a broad approach and test everybody for Lyme, you're going to have a high rate of false positives, and you're going to go down the wrong road trying to take care of people,” says Dr. Gary Wheeler, chief of infectious disease at the Arkansas Department of Health — which does not acknowledge any cases of Lyme disease in the state.

Borrelia burgdorferi, the bacterial spirochete that causes Lyme, is present in ticks collected in Arkansas, but another bacteria of the same genus, *B. lonestari*, is much more common. “Maybe they exist in high enough numbers to push the other forms out?” Wheeler says.

He says there is no obvious reason why Lyme couldn't be present in Arkansas — the state has the right type of tick, and some of those ticks carry the right bacteria. But perhaps, he suggests, the state doesn't have the infected tick at the right point in its life cycle.

According to the CDC, Lyme is transmitted by young blacklegged ticks (also known as deer ticks) at the nymph phase, when the ticks are the size of poppy seeds. “Adult [sesame seed-size] ticks can also transmit Lyme disease bacteria, but they are much larger and likely to be

discovered and removed before they have had time to transmit,” reads the CDC’s Lyme disease Web page.

“They’re finding a lot of the Lyme spirochete in the larval forms [in Arkansas] but not necessarily in the nymphal forms, which seems to be the form where they most infect humans,” Wheeler says.

One theory is that larval ticks in Arkansas primarily feed on lizards, and certain species of lizards have immune systems which clear *B. burgdorferi*, rendering the tick unable to pass the bacteria to later hosts. But Wheeler doesn’t think researchers have “a specific answer” yet.

The CDC reports that 300,000 people are diagnosed with Lyme each year, and it considers Lyme to be endemic to the Northeast and Mid-Atlantic regions of the nation, with the bulk of cases occurring in Pennsylvania, Massachusetts, New York and New Jersey. A 2014 Lyme map released by the CDC shows no cases of the disease in Arkansas, Oklahoma, Louisiana, New Mexico and Colorado.

But according to IDEXX Laboratories Inc., which processes the majority of canine Lyme tests, in the past five years, 281 Arkansas dogs have tested positive for Lyme.

In his former private practice, Wheeler saw a few patients with the classic Lyme symptom, a bull’s-eye rash. He called it Lyme and prescribed antibiotics. But those cases are rare and not supported by lab work, he says: “If you see the rash, often you don’t test, you just treat.”

What constitutes Lyme to individual physicians may not constitute Lyme to the Arkansas Department of Health.

“As far as the Health Department goes, we use these rigorous national diagnostic categories, and we’ve not seen Lyme disease reports that qualify,” Wheeler says.

Sick Arkansans are not waiting for validation from CDC-specific test results or, in some cases, the support of their primary care physicians. The Arkansas Lyme Disease Facebook page has 444 “likes,” and the Facebook Arkansas Lyme Support Group has 25 members. Many of these people are treated out-of-state.

“It’s frustrating to be told that Lyme doesn’t exist in Arkansas,” says Karen Cox, 52, of Bruno. She believes she contracted Lyme in Yellville in 2006, after a tick bite on her head led to a flulike illness and lingering arthritis symptoms.

Ultimately she was diagnosed and treated by a doctor in California, where she traveled annually from 2006 to 2013. She paid \$20,000 out of pocket in her first year of treatment, and by 2008, her symptoms — pain, fibromyalgia, food allergies and chronic fatigue — had become so challenging that she quit her job as a Mary Kay sales director and began to receive disability assistance.

According to the CDC, Lyme symptoms can include multiple rashes, Bell’s palsy (facial drooping), limb and nerve pain, heart problems, dizziness and memory problems. The International Lyme and Associated Diseases Society (ILADS) lists additional symptoms — among them debilitating fatigue and neurological, vision and hearing problems. The society, a nonprofit medical organization based in Maryland, advocates for the use of antibiotics to treat “chronic Lyme disease,” in which symptoms persist beyond six months. Most U.S. medical authorities (including the National Institutes of Health) recognize the persistence of

symptoms in a few patients but consider long-term use of antibiotics as unsafe.

Anne Gaddy, 33, of Greers Ferry, is among the one percent of Lyme patients who experiences potentially lethal heart inflammation. Gaddy developed an arrhythmia following a Lyme diagnosis and writes that she currently “rock[s] a pacemaker and [an implanted] defibrillator.”

IMPERFECT TESTS

The Lyme bacteria was discovered by scientist Willy Burgdorfer in 1982, but researchers were first mystified by a tick-related rheumatoid arthritis accompanied by a bull’s-eye rash in the ’70s, when children in Lyme, Conn., developed the condition.

The details of infection — symptoms, prevalence and treatment — have sparked debate reaching all the way to Congress. Even the “signature” rash is contested, since it could occur in other tick-related conditions, and the CDC states that up to 30 percent of patients never develop a rash.

Lyme testing is imprecise. Wheeler says cross-contamination, or the presence of antibodies from similar bacteria, may trigger false positives, while testing too early — prior to the development of antibodies — may lead to false negatives. The society claims that CDC’s diagnostic protocol misses up to 30 percent of Lyme cases.

Until 2012, the CDC guidelines included a disclaimer that “this surveillance case definition was developed for national reporting of Lyme disease” and “is not intended to be used in clinical diagnosis.”

These guidelines include a two-tiered testing system. If a patient tests positive or indeterminate on a first test that looks for certain enzymes, the CDC recommends a Western Blot test. The guidelines accept one type of Western Blot test for up to 30 days post-infection (for the antibody immunoglobulin M, aka “the IgM”) and another (for immunoglobulin G, or “the IgG”) once those 30 days have passed. These are the criteria used by the Arkansas Health Department.

Hopson has been tested for Lyme twice since her first, unwitting, Western Blot. Each time, she was tested with both IgM and IgG Western Blots. All three IgM tests have come back negative. Her three IgG tests have consistently indicated the same solitary marker of Lyme reactivity (the CDC criteria require five markers).

Her counts of a particular type of white blood cell are routinely low, which is common in Lyme patients.

The website for Lyme and Tick-Borne Diseases Research Center at Columbia University Medical Center in New York considers the CDC guidelines “not very helpful ... to detect late-stage neurological Lyme disease” and notes that such “narrow surveillance case criteria” may contribute to “delay in treatment” that “may result in an acute treatable illness becoming a chronic, less responsive one.”

UPHILL CLIMB

Hopson has been on antibiotics for Lyme and two other tick-borne infections, babesiosis and bartonella (termed “co-infections,” by her doctor, since they often show up alongside Lyme), for more than two years. Her insurance covered the first year of treatment, and she has been paying \$1,100 a month out of pocket for the past year and a half.

Recently she and her husband declared bankruptcy over \$50,000 in unpaid medical bills.

Currently Hopson takes three antibiotics, two antifungals, vitamin D, magnesium and probiotic supplements, as well as medicines for her thyroid, muscle spasms and drowsiness, progesterone for hormone depletion, and oxycodone for pain. She no longer eats dairy, red meat, gluten or sugar, and she makes her own cleaning supplies from orange peels and vinegar to avoid chemical sensitivities.

But she says she is “60 percent better” than she was at this time last year. Last spring, she was able to make it halfway up Pinnacle Mountain.

“I’m having to stop and take breaks, but I look perfectly normal and physically able ... a few people are kind of rude, like, why are you stopping?” Hopson says. “But a little girl with Down syndrome came up and she was so cute, she said, ‘You can do it. I’m gonna do it. You can do it, too.’”

Hopson grows emotional, dabbing at her eyes with tissue. The woman who used to work 50 hours a week, waiting tables by morning, cutting hair in a beauty shop by afternoon, and cutting hair at Wal-Mart by night, has simpler goals now.

“I’m going to hike Pinnacle, the whole thing, this spring,” she says. “I’m going to go whole days without taking naps.”

Read part 2, Missing the Bull's-eye, [here](#).