

The CDC's official count of approximately 30,000 Lyme disease cases per year in the U.S. has been a constant source of exasperation to the Lyme community. Even after the agency acknowledged some years back that it estimates the true figure to be 10 times higher—300,000+ cases per year—the annual “reported” number has remained in the 30,000 range. (*Reported*” actually means cases that meet the CDC’s rigid surveillance criteria, leaving out tens of thousands of diagnosed cases of Lyme disease because they don’t meet that high bar.)

For years, the agency has insisted that 95% of Lyme cases are found in just 14 states. For a long time, the Lyme disease page of the CDC website contained the following sentence: “This disease does not occur nationwide.” That wording was finally deleted last November, but the sentiment lives on.

Where you live — A huge barrier to access to care

The CDC continues to divide the country into what it terms high-incidence and low-incidence states for Lyme. If you live in a low-incidence state, you may find it practically impossible to get appropriate diagnosis and treatment for Lyme disease. Merely where you live becomes a huge barrier to access to care.



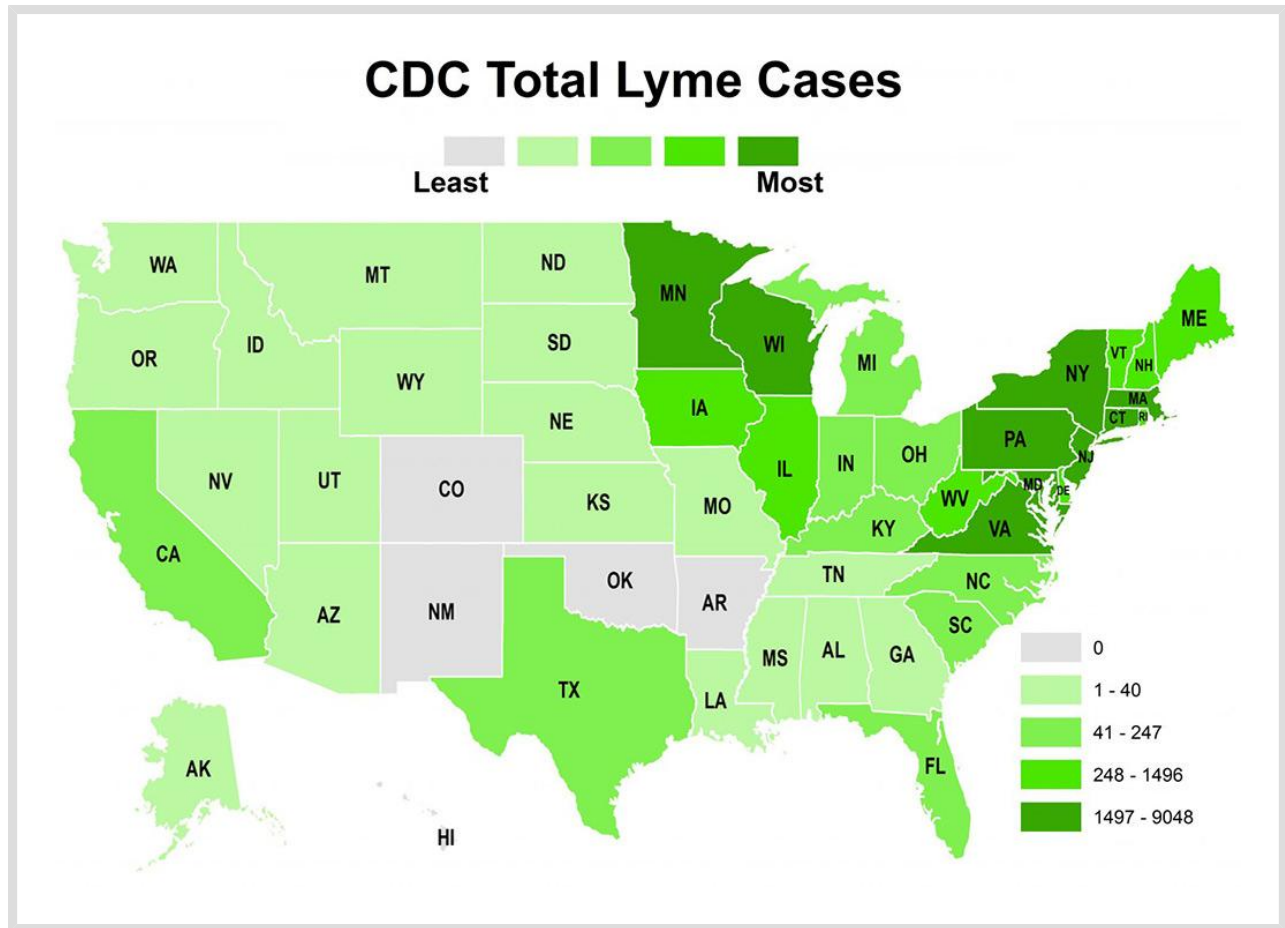
Here's why: the CDC has different case definitions for Lyme disease depending on your state. For instance, an Erythema migrans (EM) rash after a known tick exposure qualifies you for a Lyme diagnosis *only* if you're in a high-incidence state. If you're in a low-incidence

state, you could have a known tick bite, a raging EM rash, as well as multiple symptoms of Lyme disease—and none of it would count. You’d only officially qualify as having Lyme if you also tested positive via the CDC’s highly problematic two-tier lab testing. (There are many reasons why a person who actually has Lyme can “flunk” that test.)

The *Wall Street Journal* recently published an eye-popping article¹ about the deficiencies of the CDC’s method of counting Lyme cases. The following quote cites information from FAIR Health, a nonprofit organization that manages the nation’s largest database of privately billed health insurance claims:

North Carolina reported 32 Lyme cases to the CDC in 2016 but in the same year made 88,539 health-care claims for a Lyme diagnosis. California reported 90 cases to the CDC but had 46,820 claims. Texas reported 31 cases to the CDC but had 31,129 claims. All three are considered low-incidence states.

This data represents the number of “claim lines,” which reflect the number of services rendered to those with a Lyme diagnosis, not the number of unique individuals with Lyme. It captures every time a person with Lyme receives an insurance-covered service in connection with a Lyme diagnosis. So, if North Carolina’s case number of 32 were at all accurate, that would mean each patient saw their doctor or had another Lyme-related interaction 2,766 times that year. Highly doubtful.

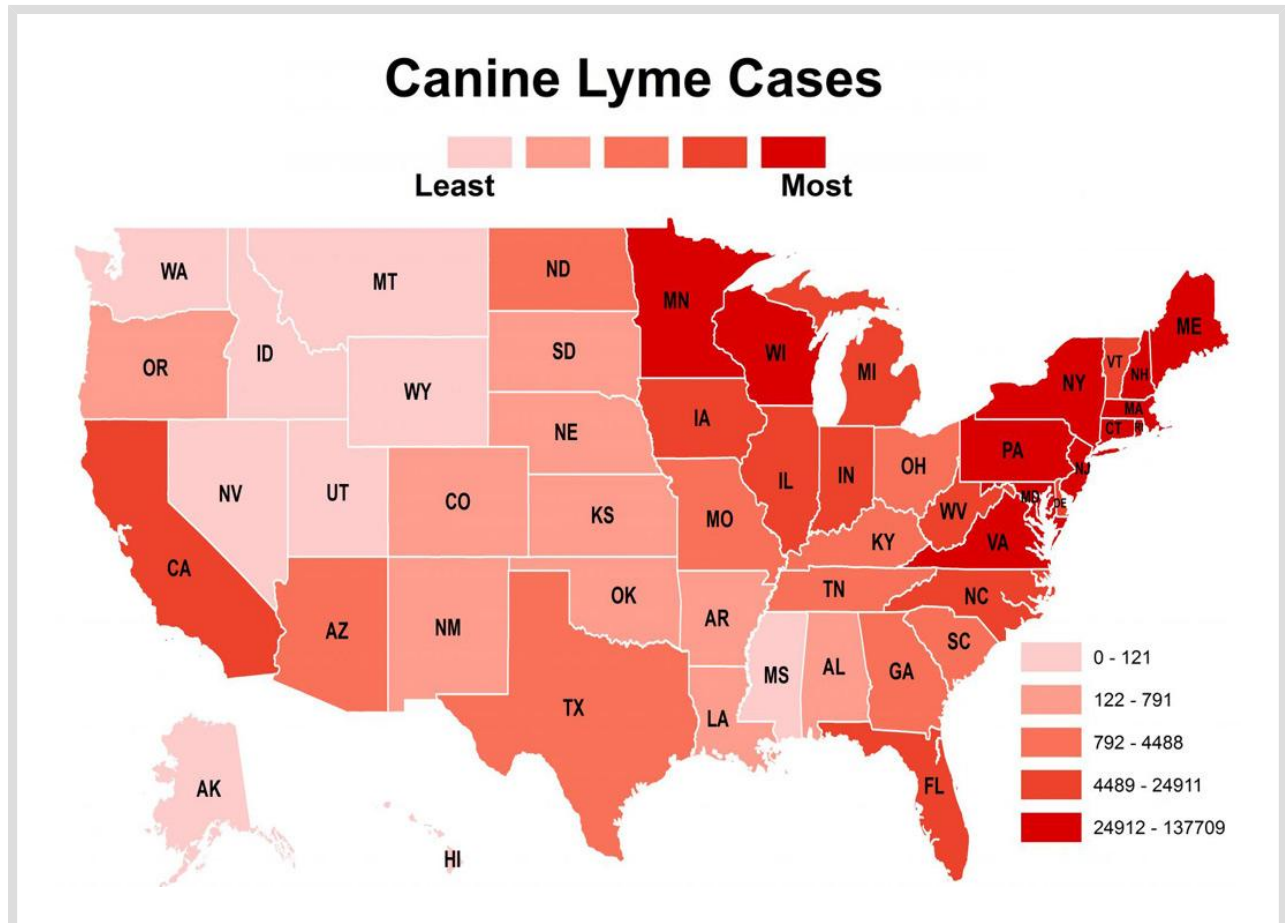


Yet, FAIR Health insurance claim lines don't account for everybody with Lyme. Many patients are diagnosed and treated by Lyme-literate doctors—most of whom aren't in the insurance system at all. In addition, many people with Lyme are never properly diagnosed, either going without healthcare entirely or being misdiagnosed and treated for something else. They, of course, are not reflected in these statistics whatsoever.

Dramatic difference between canine and human Lyme cases

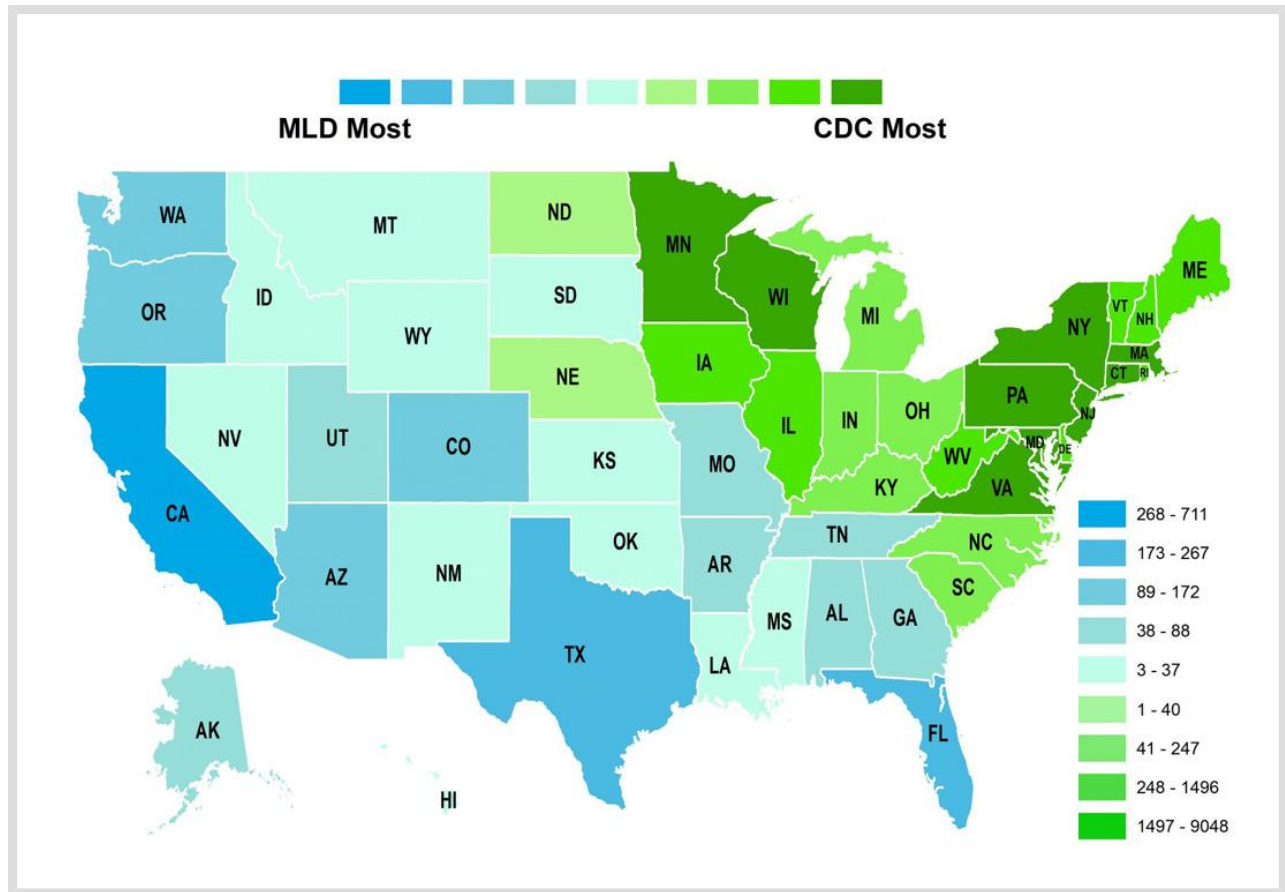
Additional sources of information about Lyme cases throughout the U.S. also paint a different picture from the CDC's. The most dramatically different one relates to canine cases. Between 2011 and 2015, Idexx Laboratories, Inc.—a provider of testing kits for dogs—collected nearly 12 million Lyme disease test results from U.S. veterinarians, on a county-by-county basis. IDEXX reports indicate that there are close to one million cases of canine Lyme disease every year in the U.S., vs. the CDC's paltry 30,000 human cases.

Even compared to the CDC's estimate of 300,000, that's still an extraordinary discrepancy. Furthermore, IDEXX statistics indicate that Lyme is present in abundance in every state in the U.S. This clearly suggests that there are a lot of borrelia spirochetes in the national ecosystem, yes? Even people in supposed low-incidence states are at risk.



MyLymeData reports more cases of Lyme disease than the CDC does

LymeDisease.org's patient registry, MyLymeData, is also instructive on this point. Although our sample size is much smaller than the CDC's, in many states throughout the southern and western U.S., MyLymeData reports more cases of Lyme disease than the CDC does.



CDC's inadequate counting creates a false sense of security

The CDC's inadequate counting of Lyme cases downplays the risk of catching the illness in most of the country. This creates a false sense of security and, in turn, encourages inattention on the part of public health officials, medical personnel, and the public at large. Too often, patients presenting with symptoms highly suggestive of Lyme disease are told, "It can't be Lyme. There's no Lyme in our state."

The plain fact is, no one knows enough about the true geographic distribution of Lyme disease to write off any state as being Lyme-free. Moreover, not allowing an EM rash to be considered diagnostic in certain states deprives many patients of their best chance at getting well. The current system in effect creates cases of chronic Lyme disease, because people can't get diagnosed and

It can't be Lyme.
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treated while still in the acute phase.

I urge the Working Group to recommend the dismantling of this wrong-headed and counterproductive policy of the CDC. In your report to Congress, I hope you'll also underscore the importance of obtaining accurate data about ticks, the infections they carry, and the number of tick-borne disease cases in all parts of the country. This information is essential if the U.S. is ever to get a handle on this burgeoning epidemic.

Further Reading:

- L. Johnson, "Lyme Policy Wonk: Why Doesn't the CDC Count Lyme Disease Cases in the South and the West? Everybody Else Does LymeDisease.org, August 3, 2017; www.lymedisease.org/lymepolicywonk-cdc-count-lyme-cases-south/.
- D. Leland, "Touched by Lyme: No Lyme in Arkansas? Baloney!" LymeDisease.org, September 26, 2016; www.lymedisease.org/touchedbylyme-arkansas-baloney/.

References:

1. J. McGinty, "Lyme Disease: An Even Bigger Threat than You Think," Wall Street Journal, June 22, 2018; www.wsj.com/articles/lyme-disease-an-even-bigger-threat-than-you-think-1529672401

Editor's note: Any medical information included is based on a personal experience. For questions or concerns regarding health, please consult a doctor or medical professional.