

Tracking Lyme Disease in the United States

[Announcer] This program is presented by the Centers for Disease Control and Prevention.

[Sarah Gregory] Hello, I'm Sarah Gregory, and today I'm talking with Dr. Kiersten Kugeler, a CDC epidemiologist. We'll be discussing the use of commercial data to estimate the trends and frequencies of Lyme disease in the United States.

Welcome, Dr. Kugeler.

[Kiersten Kugeler] Thanks Sarah. Thanks for having me.

[Sarah Gregory] Let's start out with a basic. What is Lyme disease and what causes it?

[Kiersten Kugeler] Lyme disease is a tickborne disease caused by a bacteria. So, people can get...get Lyme disease if they've been bitten by an infected tick. And this Lyme disease bacteria, it cycles between ticks and small mammals in nature in certain parts of the U.S. and in other parts of the world as well. And Lyme disease is associated with a wide variety of symptoms. The most common is a rash (a red, expanding rash) that happens early in the course of illness. It's often accompanied by some flu-like symptoms, such as fever and fatigue. In rare cases, Lyme disease can be more severe, even fatal.

[Sarah Gregory] How is Lyme disease different from other tickborne diseases?

[Kiersten Kugeler] There are a number of tickborne diseases in the United States, aside from Lyme disease. They are transmitted by different ticks in the different parts of the U.S. Some of these tickborne diseases people may have heard of, such as anaplasmosis or babesiosis. Some are more rare, including Rocky Mountain spotted fever and tularemia. Many of these tickborne diseases have similar symptoms, especially early in illness. Lyme disease is, however, by far the most common of all of these tickborne diseases. And actually not even just of tickborne diseases, but of any vectorborne disease. So, any disease that people can get from being bitten by an insect or an arthropod (such as a tick or a mosquito), Lyme is the most common.

[Sarah Gregory] Is that right? I always thought and have heard that mosquitoes were the number one little deadly killer. No? Not anymore?

[Kiersten Kugeler] No, no. Well, this...I'm talking about frequency. So...and specifically in the United States as well. Mosquitoborne diseases obviously do cause a lot of illness and death worldwide. But in terms of what happens in the United States, Lyme disease is the most common of all of these diseases.

[Sarah Gregory] I had no idea. What are the geographic locations for Lyme disease in the U.S.?

[Kiersten Kugeler] Lyme disease doesn't occur everywhere, and it is important to understand why. So, there are a few things that need to occur in a given area for Lyme disease to happen there. So first, the right species of tick has to live there, has to be okay living in that environment. In the eastern U.S., this is the blacklegged tick. And in the western U.S., there's a western blacklegged tick that lives in parts of the Pacific coast. And then next (and very importantly), these ticks have to be infected with the Lyme disease bacteria. And this does not happen everywhere that these ticks live. And then third (and perhaps most obviously), people have to come into contact with these infected ticks for Lyme disease to occur in humans. So, together these three things that I mentioned come together in certain parts of the U.S., namely the

northeastern and mid-Atlantic regions of the country as well as the upper mid-West states and certain areas along the Pacific coast.

[Sarah Gregory] What would those areas be?

[Kiersten Kugeler] There's a...a certain region through, like, central and northern California as well as pockets of Oregon and...and Washington where this can occur.

[Sarah Gregory] Ah, wow. Okay, well, are those locations expanding?

[Kiersten Kugeler] Yes. In fact, over the last few decades we have seen an expansion in the geographic areas that have a high risk of Lyme disease. And additionally, we've also seen an increase in the number of areas that have the blacklegged ticks established in those...in those specific areas. There are a wide variety of possible reasons for this, including some ecologic and climactic factors, but also how people interact with forested environments is really another factor that's driving...driving the spread.

[Sarah Gregory] Could you explain a little further about what you mean about how people interact?

[Kiersten Kugeler] Over the last several decades, you know, our population is expanding. We have new developments going in...into forested areas that may previously have not been areas where humans are, you know, readily...readily interacting with the environment around them. So, what you see in a lot of these places is...is folks that are really...they're getting infected in their yards. Their yards are...you know, abut forested environments that are prime tick habitat. So, you know, there are measures that people can take to make their backyards more tick safe, including removing brush and leaf litter....you know, putting gardens and...you know...kids' play equipment away from the edge of the forest. Those sorts of things can...can help mitigate the chances of coming into contact with an infected tick on your own property.

[Sarah Gregory] Does it matter how long a tick stays attached or does removing it sooner help avoid infection?

[Kiersten Kugeler] For a variety of reasons associated with how the Lyme disease bacteria live inside of a tick, it does take some time for that bacteria to spread to humans during a tick bite—at least 24 hours, if not longer. But, we also don't have great evidence about that timing for other tickborne infections, and often that transmission can happen in less than 24 hours. So, the bottom line is that when you find a tick attached, you need to remove it as soon as possible to minimize the risk of any tickborne infection—not just Lyme disease.

[Sarah Gregory] Supposedly Lyme infection creates a target-like rash (I think you mentioned that earlier) at the site of the bite. Is this a reliable way to tell if you have Lyme disease? Or does it not always manifest?

[Kiersten Kugeler] Yeah, symptoms can vary widely and not everyone will get...will get a rash at the site of the tick bite. But it is in fact the most common. Sometimes this can look like a target or be shaped like a bullseye, but other times the rash can be more solid and take on some different colors, such as like a purplish color or reddish or even blueish. So...but there are other conditions that can cause similar rashes. So, no, it isn't actually a reliable way to tell that you have Lyme disease. But if you do have a rash and you may have been exposed to ticks, you

really should see a healthcare provider to have them assess what may be causing the rash and then treat it appropriately.

[Sarah Gregory] Is there a test for Lyme disease?

[Kiersten Kugeler] Yes. Testing for Lyme disease is serologic testing, which measures the body's immune response to the infection. It does not look for the infection itself. So as a result, it takes a few weeks for the immune response to reach a detectable level. So early on in infection, such as when someone comes in for a...a rash, this really needs to be a clinical decision based on exposure history, timing, geographic location, all of those things for a clinician to decide yes, this person likely has Lyme disease and I'm going to treat it. They should not be relying on a test to do that. Later on in infection with later stages of infection after enough time has passed, the serologic testing for Lyme disease is actually quite...quite accurate. So, we recommend that clinicians use those...those laboratory results in concert with their own clinical judgement to make a diagnosis.

[Sarah Gregory] How many people get Lyme disease in the U.S. annually?

[Kiersten Kugeler] Each year about 30,000 to 40,000 cases of Lyme disease are officially reported to CDC from state health departments. But we know that this is an undercount, that there are more cases of Lyme disease out there. A decade ago we thought the true number was about 300,000 cases each year, and we have reason to believe that that number is higher now. We've been working to understand if using other data sources can give us a more accurate picture of how common Lyme disease actually occurs in the U.S., and to better understand the breadth of the problem with data that...that may not be the type of data that we would get through public health surveillance.

[Sarah Gregory] You touched on treatment a couple of questions ago (getting treatment right away). What kind of treatment is available?

[Kiersten Kugeler] Yeah. The good news is that Lyme disease is readily treatable with antibiotics. People who receive appropriate antibiotics early in disease usually recover rapidly and completely. Most often, this is a few weeks of oral antibiotics. For forms of Lyme disease that have spread to other parts of the body, sometimes intravenous (or IV) antibiotics are...are required. But the healthcare provider would make that...would make that judgement.

[Sarah Gregory] I've heard that doxycycline is the first-line antibiotic of choice for Lyme disease. Is that...is that correct?

[Kiersten Kugeler] Yes, doxycycline is one of the few oral antibiotics that are recommended for treatment of early and uncomplicated Lyme disease.

[Sarah Gregory] I know personally people who have used bee stings as treatment. Is that actually helpful in any way? It seems so strange, and actually dangerous, to me.

[Kiersten Kugeler] Yes. Oh Sarah, we've heard of people using all sorts of things as treatment for Lyme disease. But really only certain antibiotics have been demonstrated to work as treatment for Lyme disease. And as I mentioned, they're generally prescribed for a few weeks to a month. But other alternative or even long-term treatments are not only unlikely to work, but also can be harmful to your health. So, it is important to listen to your healthcare provider and follow

instructions for any prescribed medication. And if something seems a bit off, you know, it perhaps is a bit off. So it's worth double-checking.

[Sarah Gregory] Expanding a little bit here on something you covered a little while ago...if a person does get bitten by a tick, how quickly do they need to seek medical help and exactly kind of what are the steps?

[Kiersten Kugeler] Yeah, great question. As mentioned, removing a tick as soon as possible is key. And the best way to do this aside from...you know, folklore remedies aside, the best way to do this is to use a simple set of fine-tipped tweezers, grasp the tick by its mouthparts, pull upward away from the skin with even pressure, remove the tick entirely and then clean the bite area with soap and water or some rubbing alcohol. And, you know, I'd like to point out that tick bites themselves usually don't require any medical treatment. There are certain circumstances, however, where a single dose of doxycycline (which is an antibiotic) may lower risk...the risk of Lyme disease. But in general and broadly, antibiotics simply for a tick bite without any accompanying signs of illness is not recommended. Also, it's important to watch your...you know, watch your health. Look for symptoms for, you know, about 30 days after a tick bite. If you develop a fever or rash or flu-like symptoms, definitely you should talk to a healthcare provider and make sure that you mention the history of a tick bite because that can really help them understand if a tickborne disease, you know, may be causing your...may be causing your illness.

And there's a lot of questions that come up around tick bite removal and should I get a tick tested for, you know, presence of any...any infections. The answer to that latter...the...that latter question is that CDC does not recommend testing ticks for infection. And really we...we would point people for more information on all of this to CDC's Ticks webpage which has a variety of information, which is www.cdc.gov/ticks. So, pretty easy to remember there.

[Sarah Gregory] Okay. What happens if a person neglects to get this medical treatment?

[Kiersten Kugeler] Yeah. Most people with Lyme disease diagnosed early in infection and who receive adequate treatment do recover rapidly and completely. If left untreated or those early signs are not...are not recognized by someone, the infection can spread to other organ systems in the body. And some of these later symptoms of Lyme disease can manifest in several different ways, one of which is a facial palsy, also arthritis (particularly in large joints such as the knee), more rarely Lyme carditis which affects the heart and really needs to be treated immediately. Those are some of the...the longer term complications of untreated Lyme disease.

[Sarah Gregory] Do people die of Lyme disease?

[Kiersten Kugeler] Yes. Fatal infections have occurred, particularly the cardiac manifestations of Lyme disease. And, you know, as time has passed we've become increasingly aware of these occurrences. CDC put out a few reports several years ago describing some...some cases of...of fatal Lyme disease. But given how common the infection is, you know, these...these are very rare occurrences.

[Sarah Gregory] Is anyone working on vaccines for Lyme or any other tickborne diseases?

[Kiersten Kugeler] We are aware of some clinical trials of new vaccines for Lyme disease that are underway currently. And once one of them is approved by the U.S. Food and Drug

Administration, demonstrating its safety and efficacy, we at CDC have a plan to communicate recommendations (broadly) about its use, increase awareness of the availability of such a vaccine among both the public and the clinical community (the healthcare providers), and also be able to more fully address people's questions regarding safety and efficacy of any new vaccine.

[Sarah Gregory] You personally have two articles in the current February 2021 issue of *Emerging Infectious Diseases* about using commercial data in addition to surveillance to track Lyme disease infections. Why did you decide to investigate using commercial data to track trends in the first place?

[Kiersten Kugeler] For decades, we have relied upon public health surveillance. So, the reports that state and local health departments transmit to CDC. We've relied upon these data to understand current trends associated with Lyme disease throughout the United States. But this system is becoming increasingly challenging for health departments to keep up with, especially in the most highly affected areas in the northeast, mid-Atlantic, and upper mid-West states. So, as a result we have been exploring using additional data sources to supplement our understanding of Lyme disease in the U.S. Commercial insurance claims data are already being collected (they are being collected for billing purposes), and we wanted to see if these data could help us get a more complete picture of the burden of Lyme disease in the U.S.

[Sarah Gregory] How did you decide on the particular data and company that you used?

[Kiersten Kugeler] So for this effort, we used the MarketScan Commercial Claims and Encounters database. This is a very large insurance claims database that includes data on healthcare encounters for tens of millions of Americans each year, and this database has been around for over 15 years. So, we appreciate that stability as we, you know, like to look at those historical trends as well as...as characteristics on an annual basis. So the sheer size of this database was definitely an important factor for what we were trying to do.

[Sarah Gregory] How are commercial data and surveillance data—that CDC has, say—different?

[Kiersten Kugeler] This is a really important distinction. So, thank you for bringing it up Sarah. So, surveillance data are collected according to a very standardized case definition. And as a result, we are pretty confident that those cases that are reported are truly Lyme disease. In contrast, with insurance claims data, you know these are collected for a different reason. They're collected for medical billing, and they don't have the same degree of detail that happens when cases are investigated through public health surveillance. So as a result, we do have to make some assumptions about what we think constitutes a Lyme disease diagnosis in claims data. These data are obviously more readily available and more automated than public health surveillance data, but the tradeoff is that some of these records that are captured may not truly be Lyme disease.

[Sarah Gregory] You used claims data to estimate how many people are diagnosed with Lyme disease in the United States each year. How does your finding compare this year to previous estimates?

[Kiersten Kugeler] Yeah. With this new estimate, with this new effort based on claims data, we estimate that about 476,000 Americans are diagnosed with Lyme disease each year. This estimate is substantially larger than prior estimates from a decade ago that were closer to 300,000. We know that Lyme disease is spreading to new areas and that that is an important

factor that's contributing to the growing burden. This increased number underscores that Lyme disease continues to be a...big big public health problem in this country. And, you know, we want to continue to use a variety of different data sources to understand how Lyme disease is affecting the American public and how it may be changing, and to improve our understanding of how we can best prevent this increasingly common disease.

[Sarah Gregory] Tell us how you structured your investigation (going through all that data must have been overwhelming) and what you found.

[Kiersten Kugeler] Yeah. So, first we explored the ability of the MarketScan database to serve as a reliable and representative source of data on Lyme disease. So, we really wanted to investigate if this is something that we could use as an alternative way to track trends associated with Lyme disease on an annual basis, not just in a research effort. We then described what Lyme disease diagnoses look like in claims data and compared that to what we see among cases reported through surveillance. And then, ultimately we took the data from the insurance claims database and applied a series of different steps in order to be able to extrapolate the trends that we saw within the claims data to the entire U.S. population to ultimately arrive at a figure for how commonly Lyme disease is diagnosed and treated in the United States each year.

[Sarah Gregory] Did you find any notable differences in who gets Lyme disease? Do people need to worry more about their children? Does age matter? Does ethnicity? Gender? I mean, some...some diseases those are huge factors, so does it matter with Lyme disease?

[Kiersten Kugeler] So overall, the characteristics of the diagnoses that we found in the claims data looked pretty similar to what we see through surveillance data and what we've seen over the decades. So in particular, Lyme disease has what we call a bimodal age distribution, which means it affects kids and it affects older adults. Most diagnoses occur in warmer months, and this is something that we know because of the seasonality of the...of the ticks that transmits Lyme disease, and when it's out looking for bloodmeal hosts, this occurs in the warmer months. So, we saw these similarities in the claims data and...and know that that is...that what we know about the epidemiology of Lyme disease based upon decades of surveillance data.

But we also saw some subtle differences in Lyme disease diagnoses in the claims data. Namely, we saw proportionally more diagnoses among adults...so...so fewer children in the...in the insurance claims data compared to what we see in surveillance. We saw more diagnoses among women than what we see in surveillance. And we also saw more diagnoses occurring outside of the summer months. So, while yes, the vast majority were in the summer months, we did see just more...more occurring outside of that timeframe. And additionally, in terms of geography we saw more diagnoses occurring outside of the traditional high-incidence areas. So, we do plan to dig into these differences a bit more and we are very well-aware that some of these differences could represent misdiagnoses. And to your question about race and ethnicity, we were not able to look at that in this investigation, but we do hope to dig into that more in the future.

[Sarah Gregory] What are the biggest challenges to using commercial data for these trends?

[Kiersten Kugeler] The biggest challenge by far is that these data were not collected for the purpose that we are using them. And as a result, we cannot verify that these...that these diagnoses are in fact truly Lyme disease. But yes, it provides a different piece of information than what we

get through public health surveillance. As with any data, however, there are limitations and those are important to consider when we're making conclusions.

[Sarah Gregory] How will you personally use these findings going forward in your work?

[Kiersten Kugeler] Well, we are hoping to continue to explore these data as a routine source of information on trends associated with Lyme disease. And, this investigation in and of itself really highlighted for us some areas where we have limited information about coding practices, treatment patterns, and the like associated with Lyme disease. So, we are investigating other ways to help answer some of those knowledge gaps. And we are hoping to use insurance claims as well as some...perhaps some other data sources to better understand how we can really hone in on ensuring that what we are calling Lyme disease in these data sources is more...most likely to be Lyme disease.

[Sarah Gregory] So, you obviously have a lot of experience using these...this commercial data. Do you or your coauthors have any recommendations for using commercial data to track future trends for other people?

[Kiersten Kugeler] Yeah. I think, you know, as we...as we sought out to do with this investigation, I do think it's important when considering new data sources to really take into account the volume of the...the records that you are looking at, the stability of these data sources over time, and how representative they are of the population at large and to take those into context as you're interpreting your findings. But it's important for investigators to not just understand the limitations of the data source, but also the analytic choices that come...that come with that in order to be able to provide additional context for interpreting your findings accurately.

[Sarah Gregory] So, not to be redundant here, but more particularly are there any further studies that you would like to see done on using commercial data and surveillance together?

[Kiersten Kugeler] Yeah. Well, we...we definitely plan on doing some similar work moving forward, perhaps using other data sources to see if we see similar patterns. But, you know, in terms of the knowledge gaps that have been identified and using these alternative data sources to understand Lyme disease, we do hope that additional investigations into coding and treatment patterns associated with Lyme disease will occur. And with those data, it will help refine our understanding of what we...what we deem as Lyme disease in these types of large data sources and hopefully what other investigators also deem as Lyme disease in these data sources.

[Sarah Gregory] So, you mentioned vaccinations in trials right now. What else is public health doing to protect people from Lyme disease? Can more be done?

[Kiersten Kugeler] CDC is actively working to better understand who gets Lyme disease, where, why, and how best to prevent it. And we're doing this in many different ways. We support our public health partners in terms of surveillance and prevention efforts by providing direct assistance to them. We're also actively engaged in broad, collaborative research in which we evaluate prevention methods to see if they reduce human disease risk. There are actually still a lot of scientific questions out there, and we are working with others to try to answer those questions. Ultimately, we want to be able to find prevention methods that not only work, but are broadly acceptable by the American public.

We're also expanding our efforts to create educational materials and get them into the hands of the people who need them most. And as we've been talking about here, you know, information is key. So, we're looking at new ways to understand this growing problem in the U.S. by using different types of data.

[Sarah Gregory] And how can people protect themselves from getting it?

[Kiersten Kugeler] Reducing exposure to ticks is the best possible way to prevent Lyme disease and any other tickborne diseases. So, you can do this a few different ways: using EPA-registered insect repellants, wearing clothing that is treated with permethrin (and if you have outdoor gear, also treating that outdoor gear with permethrin), showering soon after coming indoors has actually been demonstrated to reduce the risk of Lyme disease. You know, and this happens by not only removing your clothing (so you are getting ticks off of you that you may have acquired outside but they haven't quite attached yet) as well as removing them off of your body by the simple nature of getting in the shower.

And also...and related to that, checking for ticks daily and removing them quickly. This is really the...the key to preventing Lyme disease and other tickborne diseases.

[Sarah Gregory] Tell us about your work at CDC and what you enjoy most about it.

[Kiersten Kugeler] Well, I am an epidemiologist in CDC's Division of Vector-Borne Diseases. And with that, I get the opportunity to work on a variety of diseases that range from common (such as Lyme disease) to...to very rare. I get to use statistics to understand more about these diseases on a national level, but I also get to work internationally and I get to see the impact of disease prevention activities on a far more personal level. I love the opportunities for both personal and professional growth that have been afforded me by the sheer chance of being able to work for CDC.

[Sarah Gregory] We are now a year into the COVID-19 pandemic. How has your life changed because of it?

[Kiersten Kugeler] Well, I am a working mother with two school-aged children. So, my day-to-day life...

[Sarah Gregory] Oh dear.

[Kiersten Kugeler] Yeah...looks very different than it did before the COVID pandemic. And, you know, I know I'm not alone. This is obviously the case for so many people across the nation and world. Additionally, I've spent quite a bit of time supporting CDC's COVID-19 response. And I am happy to do that to be able to support the public health response for this unprecedented public health threat that we've all been dealing with over the last year.

[Sarah Gregory] You're deployed to the COVID response right now, right?

[Kiersten Kugeler] Yes, I am.

[Sarah Gregory] Well, thank you very much for that. And thank you for taking the time to talk with me today, Dr. Kugeler.

[Kiersten Kugeler] Thanks, Sarah. It was a pleasure.

[Sarah Gregory] And thanks for joining me out there. You can read the two February 2021 articles, *Estimating the Frequency of Lyme Disease Diagnoses, United States, 2010–2018*, and *Use of Commercial Claims Data for Evaluating Trends in Lyme Disease Diagnoses, United States, 2010–2018*, online at cdc.gov/eid.

I'm Sarah Gregory for *Emerging Infectious Diseases*.

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