

Episode Title: Lessons on Lyme

Topic: First Hand Experiences with Lyme Disease

Summary: Lyme disease is the number one vector-borne illness, and as our guest says in the episode, it is often underreported. In our last episode of this season, we spoke with Scott Heiberger, Communications Manager of the National Farm Medicine Center. He wrote about his and his wife's experience with Lyme disease in his 2019 Spotlight for the Upper Midwest Agricultural Safety and Health Center (UMASH): "Tick-borne diseases on the rise, but often misdiagnosed, underreported."

Expert: Scott Heiberger, National Farm Medicine Center

Episode Quote:

"It was the classic bullseye, like it was drawn on you."

– Scott Heiberger, National Farm Medicine Center

Transcript

00:10 E Presnall

Welcome to the *FarmSafe* Podcast brought to you by the Great Plains Center for Agricultural Health. In the blink of an eye, an injury can change your life and your farm forever. During each episode, we share first-hand stories and real-life tips for making safer and healthier decisions while on the farm.

00:32 E Presnall

In 2022, there were over 63,000 cases of Lyme disease reported through routine national surveillance to CDC by state health departments and the District of Columbia. Recent estimates using methods other than routine national surveillance suggest that approximately 476,000 people may be diagnosed and treated for Lyme disease each year in the US.

As discussed in our previous episode on tick-borne disease, farmers are at increased risk of contact with ticks due to the nature of their outdoor occupation, so it is important to be aware of the symptoms of Lyme disease and measures you can take to prevent tick bites.

01:16 E Presnall

In this episode on Lyme Disease, I talked with Scott Heiberger, communication manager at the National Farm Medicine Center in Marshfield, Wisconsin. Scott is also the managing editor for the peer reviewed journal of *AgraMedicine* and supports research efforts through media relations, working on press releases, and annual reports.

In this episode, Scott shares his personal experience with Lyme Disease, discussing his 2019 Spotlight series on tick-borne disease.

01:46 S Heiberger

I was asked to talk about my experience with Lyme disease, and so I'll preface by saying I'm not a scientist and I'm not a medical doctor, but I've had Lyme disease and so have family members and pets. That article talked about a incident in 2001, where I got Lyme disease and it made it to the second stage, which brings on a new array of symptoms and problems and the point of the article was is that it's often very hard to connect the dots.

In that case, I noticed a rash the morning after sleeping in a tent in our yard and We're just doing a little backyard camping. And so I thought, oh, something bit me the night before a spider bit me. Or, you know, who knows what? Eventually I figure out after very high fever, several days of that several days of the worst headaches I've ever had. After about a week I had these pink, if you call them lesions but, sort of silver dollar sized pink round circles All over my body. I figured out that what I was seeing was the rash that you get after a tick bite when you when you have Lyme disease. It wasn't the classic bullseye and I later found out that that bullseye rash or the rash you get after being usually get after being infected by a or, you know, by a tick bite that takes 3 to 30 days to develop. And so

when I backtracked, I remember 3 or 4 weeks prior I was at a family reunion in the northwest part of Wisconsin there was ticks everywhere. That's probably where I got it.

Back to my point though, I didn't connect the dots. I didn't think Lyme disease when I was sleeping in this in this zipped up tent and I didn't remember being bitten by a tick. That was the basis of that article. And just you know cautioning people providers as well as any of us who live in rural or suburban areas. Who camp, who are outdoors, work outdoors to really be aware of Lyme disease and to think line when you have fever and body aches and fatigue and some of the other symptoms that go along with it instead of thinking well, it's the flu or you know these days it's COVID, whatever. Think Lyme, because oftentimes doctors are getting better now about providing antibiotics. You know, being proactive and not waiting for the tests just kind of assuming it's Lyme.

Even if a deer tick gets so far as embedding itself in you it's got to be in you at least 36 hours, is what the experts say, in order to be able to transmit Lyme disease because the Lyme transmission is only at the end of this feeding that they do so we've got a you know a number of places where we can stop this, you know.

Number one, you try to be aware of your surroundings, you maybe tuck your pant leg into your socks. Which you might look geeky, but if you're in a in a tick infested area, you might want to do that something with at least 30% deep is helpful. Ticks get on you and then they go upward. So, if you kind of keep an eye on the on your legs and then even if they do get on you at the end of your activities for the day, you're in a, you know, an area with Lyme disease, a shower, you know, take a shower. Really go over yourself carefully. That's another line of defense. And then if they make it through those lines of defense you can still catch them, you know, before 36 hours of feeding and becoming engorged, and then even if that happens, it's only a very small percentage of the takes that feed on. You are going to have Lyme disease.

So, when you put it that way, you say, gosh, how does anyone get Lyme disease but there's steps we can take to protect ourselves. Another interesting thing, it is the Lyme disease is the most common vector borne disease in the United States. Vectors we're talking about blood sucking insects, fleas, ticks, mosquitoes. You know the types of diseases we're talking about are malaria, West Nile, stuff like that of that group in our part of the country here. Lyme disease is the number one vector borne illness. It's also very underreported. You are supposed to report it. You know, medical providers are supposed to report it to their health departments. But it's underreported. A lot of times it's not even diagnosed it's, you know, mistaken for a flu or something. The official CDC estimates of Lyme disease cases in the United States are about 30,000 a year. But there's studies to indicate that the true number of Lyme cases is probably closer to a half million. I would believe the closer to the half million part because just word of mouth around here located in central Wisconsin, seems like a lot of people have had it.

06:01 E Presnall

I know a lot of people who have had it and you know that's one of the questions that I wanted to ask you about because I am, I was aware that it's underreported. My question there is how, because if you don't, if it goes untreated it will progress so. You know, even if people initially mistake it as the flu or something else, don't they eventually end up figuring out that it's Lyme disease as it progresses? Or how does that under reporting kind of come into play?

06:34 S Heiberger

You're right, is it the fact that it's in some cases never diagnosed? Which is, I would think possible because you know symptoms do, over the long term, kind of come and go and maybe you don't even make the connection back to. You know, when the person visits the doctor. They don't even make the connection way back to when this when this all started. And I'm not being a medical provider. I don't know what the process is for reporting these diseases and where the ball might be dropped. I don't know that. But it is, yeah it's pretty routinely acknowledged that that this is underreported.

You know my wife, this past summer. So here I am. I've got this story. We live in this area. My wife in the middle of summer, trying to think of the first symptoms. Oh well, she had a tick on her and I, you know, had practice and I got the tweezers and it was kind of on her rib cage here in the front and I took it out and I was very proud of myself. And like, you know, I got it all. I got its jaws and the whole deal here I'm, you know, as a clean extraction, and he wasn't, he wasn't engorged. So, in our minds that that's it, we're, you know, Lyme disease is. You know, we dodged a bullet. A few days later, she starts getting really bad headaches. A couple days after that started getting excruciating nerve pain. Sciatic nerve pain. She can hardly get out of bed. But we. never thought Lyme disease because we thought, well, we got that tick. It's, you know, it can't be that it's got to be something else. We tested her for COVID. We were at a loss.

She finally went into urgent care. And we said, look, you know we didn't see a tick or you know there was a tick there but it was it didn't leave a rash. It was just a little mosquito bite. It was a clean extraction, we don't see how it could be Lyme. But you know, here we are with these symptoms. So, the doctor there did prescribe. Which is the standard treatment. Sent her home and then she's kind of looking around again, you know, she's been really sick and she hadn't really examined herself. She lifts up her T-shirt and it's kind of around the backside, she says. Look there, you know, that was kind of itchy. Look there. It's the classic bullseye. There was a second tick.

The second tick. And it's the classic it was faded. It was the classic bullseye like. That's like it was drawn on you. Oh my God. So, we reported that then to the to the doctor, and they kept the reports of antibiotics going, I don't know if it's. I think it's a couple of weeks that usually do the trick, and if you can, you know, catch it in what they call stage one, which I suppose would be that first month, it's usually going to do a great job. You know, there is an acknowledgment now in the medical community that there is such a thing as long-haul Lyme disease. People could have arthritic pain for years afterwards. Other issues you know, years afterwards and no one knows exactly why some people are long haulers and others are not. Thankfully, most are not. But the medical community is at least finally acknowledging that it's not just your imagination that you know, some people do have long term problems.

Guy used to be our medical director here practiced in northwest Wisconsin, which is a real hotbed of Lyme disease, he had a family practice. He treated dozens of cases. He got Lyme disease, and he didn't recognize it until it got to stage two. He had the worst headaches in his life. He had the high fever. And he thought it was pretty ironic that somebody who had diagnosed it and so many others could not see it in themselves. It's really it can be a tricky thing and it doesn't sound like it as we're talking about it. But to connect all the dots, it's just amazing because there's some of these variabilities like, hardly anybody I think gets nerve pain. So. My wife had this terrible static pain. We didn't. That didn't add up to Lyme for us. But it's really remarkable how it's how it's so elusive.

There's, you know, with our health system, there's ongoing education, there's a there's a work group getting the word out to physicians, you know, to think line when they see some of these symptoms and the medical community has gotten a lot better. This idea. Not every medical provider maybe does this, but in our health system, there's, you know, they go ahead and prescribe if there's reasonable cause. I know that physicians don't want to over prescribe antibiotics, but. But in this case, if there's reasonable cause, we're in an area that's hot with Lyme disease, you know, you got a fever in the middle of summer. Even if you don't remember seeing the rash, they're getting a lot better about just going ahead and prescribing antibiotics. And because the test, this is where my lack of knowledge shows, but if you do the test too early, it's not going to show the antibodies and so that's kind of limited value early on in the Lyme disease.

Another thing going on right now – there's a study. It's nationwide. They're enrolling participants and Marshfield is one of the sites or our health systems, [one of the sites], testing a vaccine and I don't know how it works. I don't know the particulars. There had been a vaccine like 20 years ago. And I don't know why it was pulled. It might have been ineffective as I think it was called limericks. And so, I don't have any updates on the effectiveness of this vaccine that's being trialed right now, but we could certainly use a Lyme vaccine in this area.

The rash, according to our researchers here, at least 80% of the time there will be a rash. The rash is not always the classic bullseye. My wife had the classic bullseye, perfect symmetrical lines and everything. My rash is more of a blotch, and that's another thing that kind of threw me off. So, another, I guess, you know, word to folks would be it's not always the classic bullseye rash. It can be a little misshapen and or asymmetrical.

And yeah, speaking of animals that carry them. We should mention, too, that the white footed mouse and white-tailed deer are two real common ways that that takes get around. Those are kind of their popular host animals and so, things you can do maybe landscaping wise or things that would discourage the rodent population. Keeping grass maybe trimmed a little lower where you can or at least around the house are all things that could kind of tamp this down.

12:46 E Presnall

In town or other places like that, we wouldn't think about it. And now you really have to because you can get them anywhere it seems.

12:56 S Heiberger

Great. Great point. I'm holding an old map of the state of Wisconsin and what used to be the range of the ticks. It's exactly what you're saying. It was always thought to be something that you know you had to worry about in the North Woods and it's, you know, every county in the state has Lyme disease cases. Now the suburban areas, but the tall grass and it's, you know, it's not just trees. It's my

understanding is like they'll kind of sit there in tall grass and they'll keep their claws out or whatever and animal brushes by and they latch on for a ride. Definitely have to be vigilant everywhere. And they carry other diseases now as well, and I'm not well versed as far as keeping up on diseases other than Lyme, but sometimes it's a headline grabbing story. They talk about the tick bite that gives you a meat allergy. I think that might be the Lone Star tick and then you have the range of ticks. Climate change has probably contributed to this expanding the range of some ticks that we didn't used to see here. And then just making for a milder winter and an easier time for the, you know, the ticks that we've always had.

Some of those early symptoms typically include fever, headache, fatigue, the skin rash we talked about. It can then spread to joints, the heart, the nervous system as was the case with my wife. Might have the facial palsy. You might have heart palpitations, and this is a real minority of the cases, but you might have heart palpitations or an irregular heartbeat because of it messing with your electrical signals in there.

It's kind of this grab bag of symptoms and no two people are precisely the same, but hopefully with awareness we can stay on top of it. And like you say, get out and enjoy everything that's good about the outdoors.

14:36 E Presnall

It is important that everyone is aware of the symptoms of Lyme Disease, particularly individuals who work outdoors. Some of the common symptoms of Lyme disease include erythema, migraines, rash, malaise, headache, and fever. The incubation period for ticks is between 3 to 30 days, meaning that, in general, for Lyme disease to spread, the infected tick needs to be attached to your skin for at least 36 to 48 hours. Early symptoms appear within 3 to 30 days.

If you believe that you have contracted Lyme Disease, it is important that you immediately notify a medical professional to receive proper treatment.

15:17 E Presnall

To help prevent Lyme disease and other tick-borne disease, make it a routine to practice a self-check protocol after being outdoors. As soon as you come indoors, tumble dry your clothes on high heat for at least 10 minutes to kill any ticks that may have latched onto your clothes. Make sure to examine any clothes and equipment that you bring indoors. Shower within two hours of being indoors to help wash off any unattached ticks and remember to check your body, looking in the places ticks commonly attach, including under your arms, in and around your ears, inside your belly button, on the back of your knees, in and around your hair, between your legs and around your waist.

16:00 E Presnall

To explore more information on reported Lyme Disease cases in the US, visit the Lyme Disease Surveillance Data resource under this episode. For additional resources on identifying ticks, download the Tick ID Business Card and the Tick ID Card from the Marshfield Clinic included in the resources for this episode.

16:20 E Presnall

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We want to hear from you. Share your stories about health and safety issues on the farm, about injuries that made you change the way you work, or about the ways you keep yourself and others safe on your farm. Also let us know if there's questions you have or topics that you want to hear about on the air. You can visit our website, gpcah.org, or email us.

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Episode Resources

- **Lyme Disease Surveillance Data:** <https://www.cdc.gov/lyme/data-research/facts-stats/surveillance-data-1.html>
- **Lyme Disease, Marshfield Clinic:** <https://marshfieldresearch.org/nfmc/lyme-disease>
- **Tick ID Business Card:**
<https://marshfieldresearch.org/Media/Default/NFMC/PDFs/Tick%20ID%20Wallet%20Card%20doc%20052019.pdf>
- **Tick ID Card:** <https://marshfieldresearch.org/Media/Default/NFMC/PDFs/Tick%20ID%20Card%20doc%20052019.pdf>

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