Opening Lyme Story and ILADS Discovery

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And it was a case study. And I contacted the researcher who referred me to the International Lyme and Associated Disease Society, otherwise known as ILADS.

And that was the first time I ever heard of ILADS. Hi, and welcome to the Lime Bites podcast, where we shine a light on the misunderstood science of Lyme and other vector borne diseases, as well as the truths that many still miss.

I'm Dr. Mariah Hinchy, naturopathic physician and fellow of the Medical Academy of Pediatric Special Needs. I specialize in treating chronic Lyme disease as well as other complex inflammatory conditions.

In this podcast, we break down what's working and what's not. We share the facts that most people miss, we challenge outdated thinking, and we give both patients and practitioners the tools to heal smarter.

So let's get into it and change the way we heal Lyme. Hi, this is Dr. Mariah Hinchy and welcome to another episode. Today we're going to talk about what I see as a big issue with a lot of my patients and it took me a long time to recognize the link.

So a lot of these stealth infections like Lyme disease because of the level of, you know, incompetence or immune dysregulation that these infections cause, we end up with a lot of other What I would even consider to be opportunistic infections in the body that a lot of times the cause and effect link isn't really discovered.

So today we're going to be talking about the incidence of chronic UTIs in a Lyme patient and really why that connection is there and what we can do about it.

So here to discuss this topic with me today is Dr. Pamela Cipriano. Dr. Cipriano began her career as a certified critical care nurse in 2011. She then became an acute care nurse practitioner working as a hospitalist.

Podcast Introduction and Episode Overview

And after recognizing the need for quality preventative care, she got her doctorate degree in 2016, focusing her research on preventing the progression of prediabetes to type 2 diabetes.

And she was one of the first practitioners in Connecticut to open her own independent practice. So welcome Dr. Cipriano. It's an honor to have you here.

Tell our listeners a little bit more about yourself and how you came to specialize in treating chronic Lyme disease. Thank you so much for the introduction.

Thank you so much for having me on your show. So I became involved with Lyme disease when my son was 19 years old. We went scuba diving. He had some pressure in a lower abdominal area, turned out to be a tiniest

hernia that I could find.

When he had surgery though, when they opened him, they found his entire abdominal wall to look like Swiss cheese. And at the time I had no idea what that was.

A surgeon didn't know. They called in specialists and no one could figure out what it was. He didn't have any risk factors. He was tall and lean, very muscular, and no real reason to have something like this.

And at the time, the surgeons never saw anything like this either, which was really concerning. It was right after the surgery that all the symptoms started.

So that was his trigger. So make a long story short, he was six years old when he was bitten by a tick. Never saw the tick, but we did find the bullseye rash.

Brought him to the pediatrician who put him on, if I have to guess, about 10 days worth of antibiotics. And he never had any symptoms at all. At 19, now you could think, well, maybe he got bit by other ticks because he's teenagers and all that kind of stuff.

At 19, when he had the surgery and all the symptoms started, it was the brain fog and testicular pain and joint pain and exhaustion. The exhaustion was overwhelming.

And at the time, we honestly didn't know what we were dealing with. None of the doctors seemed to know. He went to so many different doctors, different surgeons, I contacted the surgeon to make sure that he did isolate the ilioin will nerve to make sure that that wasn't the cause of the problem.

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How Lyme Led to Chronic UTIs

And then at 29, I found one research article, took me that long. to find one research article that had his symptoms, exact symptoms. It was in the Journal of Urology, and it was a case study.

And I contacted the researcher who referred me to the International Alignment Associated Disease Society, otherwise known as ILADS. And that was the first time I ever heard of ILADS.

I never even knew they existed. And so I became a member. I found Dr. Horowitz. I went away for training. I did a preceptorship with him afterwards and got my son on treatment.

And luckily he's 36 now and so much better than he was. But it's a real epidemic, especially in Connecticut. And the sad part is the Mainstream doctor doesn't know anything about Lyme disease.

You know, my second meeting was in 2019, and I had asked just doctors sitting next to me, how did you get involved with Lyme disease? And it was always a family member.

It was always somebody in the family that had all these very vague symptoms, and they took it upon themselves to try and figure out what was going on.

Yeah, that's such a common occurrence. I think most people that I speak to that specialize in Lyme disease and really get it, it's because themself or their family member had an issue that they literally were just trying to solve and came across it.

But that's amazing that over a decade went by before you finally got answers. Are you ready to revolutionize your approach to diagnosing and healing complex chronic inflammatory illnesses in both adults and children?

The Lime Bites Symposium is your gateway to cutting-edge education, groundbreaking research, and innovative therapeutic solutions. Join us at Lime Bites Symposium.

at the Fort Lauderdale Marriott Pompano Beach Resort and Spa. Lion Bites is the premier functional medicine conference on complex, chronic, infection-driven inflammatory illnesses.

This year's meeting is jam-packed with leading industry experts discussing lung COVID, mycotoxin illness, PANS Pandas, as well as Lyme and other vector-borne diseases.

This conference will arm you with the knowledge, clinical pearls, and practical solutions that you can implement immediately into your practice Monday morning that will literally change your patient's lives and get them on their path to true healing.

So join us at Pompano Beach or virtually from anywhere. Register now at LymeBytes.com. That's L-Y-M-E-B-Y-T-E-S dot com. It was horrible. So fibromyalgia, I'd never believed in the diagnosis of fibromyalgia.

I believe obviously of the symptoms. But if you think about when fibromyalgia and Lyme disease first came out, it was exactly the same time when it really became more popular.

And fibromyalgia is diagnosed because everything is negative. So you just get labeled with a diagnosis without anything to support it. And my son would have fallen right into that category.

if it weren't for me just delving in to figure out what's going on because he looks fine. People would think you're lazy. You don't feel like working because you don't show the outward signs of the disease process until it gets really advanced.

Then you'll see some of the outward signs. But in the beginning, especially in the first 10, 15 years, you really don't have a lot of external signs. A lot of it is more subjective.

rather than objective findings. And that's really upsetting for some patients that just don't get diagnosed correctly. It is. And it's a shame because, you know, patients, mostly people don't realize that fibromyalgia, chronic fatigue syndrome, are kind of like catch-all diagnoses.

They just feel so much better that they have a diagnosis. But it's like, what does that diagnosis actually mean? And when it doesn't really mean anything, there's really no treatment that works.

Again, like you said, the symptoms are very, very real. I don't want anyone listening to think that I'm dismissing or saying that it's not. The symptoms are real, what they're experiencing is real, but the diagnosis is kind of BS.

It's like, what is actually going on? What is the mechanism of action or the pathophysiology behind those diagnoses? And I always, when I'm training other practitioners, say, look, like those are two huge red flags.

Like if you have a patient that's been diagnosed with either of those two things, there is something else going on, get to the bottom of it. And I have never had a patient with either of those diagnoses who hasn't had an underlying vector borne disease as well.

All right. Well, we could keep going down that road forever, but for the sake of time, let's dive into the chronic UTI. So let's start with a little bit of background.

So tell our listeners in your opinion, like how does Lyme disease impact the immune system in a way that might dispose them or predispose them to having recurrent urinary tract infections?

So the bladder specifically is a reservoir, and that is where a lot of times the spirochetes or bacteria of Lyme disease will migrate to. And because they are corkscrew-shaped bacteria, they can actually corkscrew themselves past the bladder membrane and embed themselves into the bladder wall.

And a lot of times patients are misdiagnosed as having interstitial cystitis because it's all the signs of it. It's the inflammation, it's difficulty urinating, it's pelvic floor dysfunction, it's chronic urinary tract infections.

You know, you go on an antibiotic and your symptoms feel better, but they never actually go away. And so I think more and more people having chronic urinary tract infections don't realize that it's actually because of a vector-borne disease like Lyme disease.

Yeah, absolutely. So why do you think they are recurrent?

Why UTIs Recur and Why Tests Miss Them

So the way the bladder works, you know, if you have that protective membrane covering the bladder wall and you take antibiotics, the antibiotics are going to be able to get rid of an acute urinary tract infection.

If your postmenopausal and things start to thin out in the vaginal area and the urethra is exposed now, the area where you urinate from, That's when you'll have more urinary tract infections, you know, doing something like estrogen therapy or estrogen cream vaginally will help to decrease those and usually gets rid of them.

It's when they don't go away. It's when you've tried those preventative options and you still have the same kind of chronic urinary tract infection. That's when we know that there's something else going on.

And it's usually when it is embedded in the bladder wall where we have to do some specialty testing to figure out, you know, what type of bacteria is it because local testing isn't going to show you the DNA of the bacteria and what are the best types of antibiotics to use.

And then also like when you have the disruption of the normal flora and the normal microbiome inside of the urethra and the bladder, and that's being disrupted because of immune dysfunction, because of inflammation, because of the actual spirochetes, as well as using chronic antibiotics, now you're also taking away part of the body's defense to actually keep that bacteria from migrating as well.

So we have like the actual spirochetes causing inflammation, causing what can feel like symptoms of UTI, but then also the disruption of the microbiome, allowing other bacteria to migrate up and cause persistent infection as well.

And then we also have the role of biofilms, right? Do you want to explain that a little bit more? Yes. So when my son had all these urinary tract problems, I found Ruth Kriz, who's an nurse practitioner and specialized in chronic urinary tract infections.

And it wasn't until I started seeing patients with chronic urinary tract infections that I started testing for Lyme disease because of the biofilms. So any bacteria can create biofilms.

But when it's related to Lyme disease, it just seems to be a little bit more aggressive. They do pretty much everything to try and hide. Now you have somebody who is on antibiotics frequently for sometimes several months at a time, several years on and off.

And now not only are we destroying the microbiome of the bladder, but the microbiome of the gut. So now we're having even more issues with trying to get rid of the symptoms and the bacteria itself.

And so generally what I'll do is micro gen DX testing because they'll do the same culture that a local lab would. But then they go a step above, they do phase two testing where they do DNA analysis.

And that's when you can actually find out what is actually going on in the bladder. And, you know, I could treat patients for those bacteria that I found in the bladder, but until I actually test them for tick-borne diseases is when I really am able to treat them and get rid of everything that's affecting the bladder itself.

A lot of times they don't realize that it's not only the bladder, but it's the brain fog and it's a joint pain that they were

contributing to something else.

Right. Yeah. And a lot of times other medical professionals too could say, oh, well, you know, you have a low grade chronic infection. And so that can explain some of like the fatigue and not feeling well in the systemic symptoms, but really, you know, you're kind of missing the boat.

And again, like for our listeners, Lyme infects every single cell in the body and therefore has the potential to affect every cell and organ system in the body.

So, you know, when you start to feel like you're having a problem in almost every part of the body, that's a huge red flag too, right, that something else is going on.

So when we're talking more specifically about UTIs, I know that part of this can be like a neuropathy, right? Or like there's also other nervous system symptoms that can be going on with chronic UTIs.

Can you talk a little bit more about that? Sure. So with Lyme disease or other vector-borne diseases, there's a lot of inflammation throughout the entire body, including the central nervous system.

And because of that, sometimes the message from the brain to the bladder just doesn't get there the proper way. And the bladder in those cases simply can't contract.

So the patient has a full bladder and sometimes they just can't urinate because the bladder is not contracting properly. And you'll see something like this a lot with multiple sclerosis, otherwise known as MS, which unfortunately my son got tested for literally everything before we figured out it was from a tick-borne disease.

If I could backtrack for a second, you know, I was talking about how he had had this for such a long time. I think the biggest thing that I could say about the bladder is that the bacteria will continue to grow.

The bacteria, because it does affect the entire body, including the central nervous system, your symptoms are so vague that I think that the mainstream provider doesn't even know where to start.

And I think that's where people will have, you know, somebody telling them that all the testing is negative. They can't really find anything wrong with them because local testing isn't very accurate.

And that it's all on their head, which is a terrible thing for anybody to ever hear from a professional that they respect and trust. Absolutely. So I think, yeah, bladder though, it's just that one area that, you know, cystoscopes, I mean, no matter what you do, you're not going to find this bacteria that is embedded in that bladder while…

And no one's looking for a spirochete, no one's looking for Borrelia, right? So that's another reason why they're missing it.

Neurological Causes of Bladder Symptoms

And if you can't culture it out, then it's like, oh, well, nothing's there. Do you find a lot of times that there are, because I have found this, so you do a traditional urine analysis, you know, you work a patient up for a UTI and it comes back negative.

And I've had so many patients come with this like in their history and it's like they have all the symptoms of a UTI but nothing will culture out, you know, the urine analysis does not look like it should.

Do you see this a lot with your… patients where it's the symptoms are there, but they're testing negative for a UTI. They're testing negative, and what I'll see is from the lab that they'll say that there was less than 10,000 bacteria, and so it's not something you would treat.

Or they'll say it was contaminated. That's the biggest one I get, is that it's contaminated. Well, it's not contaminated.

It's because they're seeing a low level of bacteria that they can't culture out because it's only looking for the bacteria and the urine.

And not in the bladder wall. And I think that that's the biggest thing. I don't think I've ever had gotten a negative culture. I tend to get the contaminated or the less than 10,000, whatever.

I can't remember exactly what the measurement is, but that's generally what I'll see. And that's usually my cue that this is going to be something more tick-borne related.

So can you explain the mechanism of action or the pathophysiology behind why patients are having these symptoms when they have Lyme? Is it neurological?

Is it a neurological phenomenon? Is it an inflammatory phenomenon? What's actually going on there where there isn't a secondary infection, but you're having all of the symptoms of a UTI, like the urgency, frequency, pain, tingling, et cetera?

Are you suffering from Lyme disease or another complex chronic illness and aren't sure who to trust when it comes to herbal supplements? Hi, I'm Dr. Mariah Hinchey, founder of Lyme Core Botanicals.

As a naturopathic physician specializing in complex chronic infection-driven illnesses like Lyme disease, I needed herbal medicine I could truly trust.

That's why I formulated Lyme Core Botanicals. where our herbal tinctures are handcrafted in small batches right here in Connecticut. We use the whole herb, never isolates, to preserve the full spectrum of medicinal compounds.

Every single step from sourcing to extraction is done with precision to ensure maximum purity, potency, and consistency. These are the same herbal formulas I used to heal myself and have used for years to help my patients and family members heal too.

And now I'm making them available to practitioners and patients everywhere. Lyme Core Botanicals, herbal medicine you can trust from a doctor who lives this work.

Learn more at Lyme Core Botanicals. That's L-Y-M-E-C-O-R-E dot com. So I think it's multi-system. I think it affects, I think it's because of how the brain is affected, how the nervous system itself is affected, how the nerves in the bladder are affected, how the inflammation that is in the bladder affects the nerves inside the bladder itself.

I think it's multifactorial where there's not one simple reason why this is occurring, but a compilation of everything. So you have somebody who has a tick-borne disease, usually Lyme disease, what I'm seeing from my patients with chronic urinary tract infections.

And I think it's also because of the shape of the bacteria itself, how it's able to literally corkscrew its way out of a vein and into the tissue and out of the bladder and into the wall, but then also into the nervous system.

So I think it's a little bit of everything. We haven't had a patient yet. that only had chronic bladder pain or chronic frequency or urgency. I think what happens is that's their main problem and that's what they'll focus on.

And then when you start them on treatment for the chronic urinary tract infection, then all of a sudden their brain fog gets worse and their joint pain gets worse.

And all of a sudden they're like, well, I started with this antibiotic and now I have all these other symptoms that I didn't have before, but they did have them.

But the bladder was such a significant part of it that they kind of ignored everything else. That I think is the biggest thing that people don't realize is Humans, in general, ignore a lot of things.

There's a lot of things that are going on in our body that we tend to just ignore. I'm thinking they're going to just get better on their own, and sometimes they definitely do.

But whenever you have brain fog, joint pain, difficulty urinating, chronic urinary tract infections, if your provider has not been able to find the root cause, I would definitely try and find either somebody who is with the International Ambulance Associated Disease Society or functional medicine, naturopaths, homeopaths, chiropractors.

Integrative Treatment for Lyme and UTIs

They think differently. They treat based on the root cause of the disease process. After my doctorate degree, I did go back to school for functional medicine.

You can't imagine what I didn't know. You can't imagine what I didn't know. Nursing school, like my diploma in nursing as a registered nurse, that was actually three years and it was much more like functional medicine than when I became a nurse practitioner.

It was very medical and just what medications you prescribe for what disease process. Nothing like when I was in nursing school, how to prevent the disease process, how to get to the root cause of the disease process.

And they were talking 30 something years ago that I graduated. So I don't even know if that kind of curriculum even exists any longer in nursing school.

Yeah, you know, unfortunately, it seems like today's world of medicine is more based off of like diagnosing and matching up the correct pharmaceutical with that diagnosis.

But I think you're right. I think functional medicine is where it's at and getting to the root cause and helping to heal the person sitting in front of you by investigating their terrain and their process and their body and then helping them to basically turn it around.

So I'm excited to hear you tell us about the various integrative and holistic treatments that you're using to get your patients better. So it's pretty much the same thing I do for Lyme disease.

First of all, I always do the microgen testing first because I want to see what bacteria are we dealing with in the bladder wall and I'll treat the patient that way.

Their symptoms never are completely gone after that. Then we start, you know, I usually have to convince them to test for Lyme disease because none of them have ever seen a tick or I have patients in Australia right now that their government told them that their ticks do not carry any Lyme disease or other type of bacterias, which I don't know if they had a little caucus with all the ticks to make sure that they didn't, but you know.

I don't know how you know something like that. It's a tick, so it's going to be pretty much anywhere that a bird can go. There's no logic behind it, I guess.

That's the best way to say it. Unfortunately, there's a big political thing going on with Lyme disease, regardless of what country you live in, which makes it even more difficult for a patient.

I kind of went off on a tangent. Could you repeat your question for me? Sure. Yes. And no, but I mean, I think that's really important. And for, you know, everyone listening who, you know, I know you've heard this in other episodes, but, you know, since I know y'all pick and choose which ones you listen to, you know, Lyme disease has been found in every state in America, and it's also all over the country.

It's in all of the countries. So, you know, you can't Just don't fall into that trap of thinking there's no Lyme where I live because it's all over the place.

And we all travel to different states and different countries and vacation and et cetera. So, you know, just don't

listen to any of that. But my question was, what are your integrative or holistic treatments that you like to use?

So once I do know that it's Lyme disease, then we go on to the treatment of Lyme disease. And so I combine antibiotics with antimicrobials from nature.

I don't do it at the same time. I did do that in the beginning and I found patients got really sick when I was treating their Lyme disease. So what I do now is I'll do between one and three months of antibiotics, depending on if they only have Lyme disease or if they have co-infections as well.

And as soon as they get a little bit more stable, then I switch everything over to all natural. While they're on the antibiotics, I incorporate liposomal glutathione to try and clean out the liver so that all of that inflammation is going to be out of their system a lot quicker.

The liver is supposed to make glutathione, but with a diet in the United States, it's very difficult no matter how hard you try and eat to actually have a healthy enough diet where the liver can function like it's supposed to.

I incorporate liquid stevia and seropeptase. Liquid stevia was found by Dr. Eva Sapi. She's a researcher at the University of New Haven and tried pretty much everything to break open biofilms in a petri dish, including gasoline and bleach.

She was very comical when she gave her talk and found that the liquid stevia was the one thing that was able to break it open. So botanists by trade and plants by nature are supposed to be able to fight off biofilm.

And using that information, she found that it was stevia that had the ability to break open the biofilm. And then incorporating that with seropeptase, which is a derivative of silkworm.

For a silkworm to be able to break out of the cocoon and become a moth, it has to excrete something called seropeptase. And seropeptase, taken internally, will help to get rid of any non-living structure in your body.

So it's lipomas, cysts. I'm trying to like scar tissue, sometimes coronary artery disease. It kind of depends on how long you've had it for, if it's still in the soft phase or if it's turned into calcium.

Now it's a little bit too late for that. But it's an amazing thing that you can take to try and just get certain things out of your body. I get those cysts on the head.

And actually, I haven't had to see a surgeon since I started taking seropeptase because that's how Amazing, it works. It really, really does. And before that, it was probably every three to four years, I'd wait until I got a ton of them and then go in to have them removed.

And it's been, gosh, well over 15 years since I've had to do that. Wow, that's amazing. Yeah, yeah, it really is. I also recommend apple cider vinegar with the mother, organic apple cider vinegar.

It's going to help to alkaline the body. In an alkaline environment, it's very difficult for any cells to really survive that are not supposed to be in the body.

So cancer cells, Lyme disease, viruses, anything that really shouldn't be there, it's really hard to survive in an alkaline environment. On the contrary, if you have a diet that is very acidic, that's going to have a lot more issues with your health and a lot more problems getting rid of Lyme disease.

So when I treat, I really treat the entire body. I give them the antibiotics. I have patients who don't want antibiotics, so I do all natural. I'll do that as well.

And your talk at the summit was fantastic. I have all of your notes as well. I do for how to treat without antibiotics. I was very appreciative for that.

And it's a combination of everything, including diet. I have an anti-inflammatory diet that I created for my doctorate degree to get people off. reverse their pre-diabetes.

I have an infrared sauna at the office. I encourage if you can't come here and you're a patient that's somewhere else in the country, I encourage you to find someplace that has an infrared sauna.

You can purchase it yourself. And then we have halo therapy as well, which also helps to alkaline the body and really get rid of a lot of different types of infections.

So for our listeners that don't know what halo therapy is, can you explain that a little bit? Sure. It is Himalayan salt that is dispersed for us. It's like, it looks like a telephone booth dispersed into the air and it is gets into your body when you're inhaling.

It also goes through your hair follicles, um, your skin cells. So the less clothing you have on in there, the better you're going to have. It's your own private room.

Nobody gets, you can lock the door, you can do whatever you want in there. And it's anything to just get somebody. you healthy without having to use a lot of medications.

I'm not a fan of medications. I mean, if you need an antibiotic, absolutely. I'm just tired of band-aids as medicine. That's what I'm really trying to avoid is just giving a band-aid.

If I get you on a band-aid and you follow my advice, now we're talking like more primary care, I would promise I'll get you off of that band-aid. But if you continue on your path, you're going to stay on a band-aid, unfortunately, because it's the only thing that's going to be able to help you.

Well, and sometimes patients need band-aids. You know, I'm sure you see the same thing, but sometimes patients come in and they're just so, so sick in the beginning that they can't do anything.

So sometimes these band-aids are necessary to hold them over, you know, while we're treating the underlying cause. You know, I always tell patients like, look, If you break your leg, you're still going to use a crutch, right?

Like while you're getting your leg to a certain point of healing, you know, we're not going to just throw the crutch away because we're doing other things to accelerate the healing of that broken leg.

That I have to definitely agree with.

Practice Info, Seminars, and Prevention Tips

Yeah. So it sounds like you do a lot of lifestyle medicine, a lot of functional medicine as well. So you're doing the whole integrative approach. I am I am, you know, I had the, I had the best possible 1st job after high school.

I took off 2 years before I went back to school. Back to college and it was with a local chiropractor. Dr. Robert. And at 18 years old. he was an amazing person to work for and learn from because he was young, he was in his 30s, and everything with him was all about all natural.

That was probably the best thing that happened to me to get me on the path of health and wellness without medications. So pretty much, I have to say, since I've been 18 years old and because of his guidance, I've really You know, if I've had medical problems, it's because of things that were outside of my control that I couldn't, had no control over.

But other than that, my diet has always been healthy. I've always exercised. I can't remember when I didn't exercise. Always had an anti-inflammatory diet, always the nag with my family and my friends, which is kind of funny.

I got so excited when I became a nurse practitioner and started doing seminars and things like that and called my sister and said, I actually have people paying to hear me talk.

Because my thing is everybody's teasing me because I talk so much. Yeah, that's amazing. You have a lot of knowledge to share. So that's great. Thank you.

Yeah, I love what I do. It's a passion of mine to keep people healthy. It's really a passion. I love it. So if we have listeners that want to see you as their physician, as their doctor, how would they get a hold of you?

Are you accepting new patients? I am. The name of the practice is the Practice of Health and Wellness. We are in Thomaston, Connecticut. The phone number here is 860-802525.

And we have a website, thepracticeofhealthandwellness.com. And you can send us an email through the website too, for any additional information that you'd need.

I have amazing staff here. They're so knowledgeable. I really can count on them so much. It's been wonderful. That's great. And having a great staff is the key to having a successful practice, really.

Yes, and it wasn't always like this. Okay, so do you have any upcoming events that you'd like to share? So once a month, we do free seminars here. We took the month of December off because it's a busy month.

But starting back in January, we do free monthly seminars open to the public. We can usually accommodate between 20 and 30 people. We have a beautiful foyer in my office here, and it's all PowerPoint so that people can follow along.

And we talk about everything from tick-borne diseases, vector-borne diseases, Parkinson's disease, health and wellness. nutritional counseling, exercising, anything that the people are requesting.

So on my Facebook, I just started posting the videos. I just started videotaping them. So I started posting them on Facebook and then I have a YouTube channel too.

It's Dr. Pamela Cipriano. Wonderful. So if there was one piece of advice that you could give the listeners about anything regarding Lyme or chronic vector-borne disease, what would it be?

don't get bit. That's easier said than done. It is. It definitely is. However, I really promote this. It's essential oils. It's through Nantucket Spider.

And I use it all the time when I'm mowing my lawn because I live on four acres, we have our front of our house, it's all wetlands. You know, I do all the, you just can't find a tick.

There's also a company called Insect Shield that I first found out about when I was, my son went to University of Rhode Island, my younger son, and they were there.

And they not only, you can purchase clothing from them that is impregnated with permethrin, which works so much better than to spray the promethine on your clothing yourself.

It lasts up to six months of washings until it has to get retreated, but you can also send your own clothing to them. That is going to be the best way to really prevent a tick bite.

So if you're somebody who's a hunter or a fisherman or you love to hike or you're outside all the time, regardless of where you are, I would really recommend being very proactive to try and prevent a tick bite.

If you end up with chronic symptoms and you go to your provider and they're unable to figure out what's wrong with you, don't ever stop trying. Go on ilads.org, try and find somebody who's local to you who does know how to treat tick-borne diseases.

because there's so many of them. Lyme disease is only one. Right now I'm doing a research project right in the process of submitting it to a peer-reviewed journal and it's more about what the experiences I've had with patients going to walk-in clinics, urgent care centers, emergency department, their own primary care with a bull's-eye rash that most people don't get and having it misdiagnosed as you know, ringworm or cellulitis or something else.

Always listen, you know, make sure your provider is listening to your story. You know, for me it was, this one was really kind of got me on this path.

It was a young woman in her 20s who was working at a local overnight camp for kids and two other counselors had gotten Lyme disease. And she went to a local urgent care center and they looked at it and she said, I'm a camp counselor.

I'm outside all the time. We have two other camp counselors who have Lyme disease right now. And they diagnosed her with ringworm. I mean, if that was a board question.

Yeah. You know, it's funny. It's not funny. I mean, it's, it's, it's terrifying. And as a medical practitioner, it's humiliating, but I had a patient who, you know, had not the classic rash, but I mean, it was an EM rash for sure.

She went to the doctor. She was told that she had cellulitis from an insect bite. but it definitely wasn't a tick bite. Within 24 hours, it had doubled in size.

She went back. They still insisted that it was cellulitis, not a tick bite. I mean, it's maddening. Fortunately, they put her on antibiotics for the cellulitis and then she was on vacation when this happened.

She was able to come home and we ended up taking care of it.

Misdiagnosis, EM Rash, and Closing Advice

It's just I don't know what it is. I don't know if it's ignorance or if it's just, you know, a lot of medical professionals just don't want to be involved in treating Lyme disease.

They don't want to be involved in the controversy, which is just a shame and disgraceful that it's even a controversy. But what you're saying happens more often than not.

And it's just, it's terrible. So for me, luckily, Her girlfriend is my stepdaughter, and she sent my stepdaughter all these pictures, and you're right.

You know, it started off as a small, hers looked like a bull's eye. I mean, it wasn't even something that didn't look like a bull's eye, which most of them don't.

Hers was a perfect bull's eye, and it was expanding and expanding and expanding, and now she's feverish, she has joint pain, she has all these symptoms, and Emily showed me the pictures, and we got her in the next day.

I think I actually did a telehealth visit with her because she couldn't even leave the camp. The poor thing, I put her on minocycline to try and decrease the sunburn because it's middle of summer, she's outside all the time.

And you can't call out sick. You know, you can't, it's not something like you could take a sick day with your camp counselor and she had to work through it.

But she was on antibiotics for about six weeks before we switched everything over to antimicrobials because it was so acute. And it was unfortunately misdiagnosed.

And luckily, you know, my stepdaughter is her friend and sent me the pictures immediately. Yeah. So I think two important things to point out to listeners.

Number one, if you have an EM rash, it is diagnostic of Lyme disease. It doesn't matter if you test negative, even using one of the specialty labs. If you have an EM rash that is diagnostic of Lyme, the ILADS treatment recommendations are four to six weeks of doxycycline if doxycycline is not contraindicated.

Number two, the absence of the rash does not exclude Lyme disease. So depending on the source, it is stated that the rash is present only 20 to 40% of the time.

And again, that's only with Lyme, that's only with Borrelia. You're not going to get an EM rash if it's Babesia, Bartonella, Anaplasma, Ehrlichia, Rocky Mountain spotted fever, Powassan virus, right?

All of these other bacteria and viruses that these ticks can carry. All right. Thank you so much for being here with us. I really appreciate it. Absolutely.

Thank you to all of our listeners. I hope that this was helpful and it helps you on your journey to healing Lyme and we'll see you next time. If this episode gave you an answer, brought you new insight, or made you think differently, subscribe to the Line Bites Podcast and share with someone who's ready to take control of their healing journey.

And if you can, please leave a review. It helps others to find the show. Thanks for listening and we'll see you next time.