

Dr. Jill

Your Functional Medicine Expert®
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[#56 Dr. Jill interviews Dr. Dan Kinderlehrer on Recovery from Lyme Disease](#)

Dr. Jill 00:12

Hey everybody! I'm so glad to be here this afternoon with Dr. Dan Kinderlehrer. As we were just speaking before we got on, we both happen to be in the Denver-Boulder, Colorado, area. And yet Dr. Kinderlehrer, as you'll hear today, is a world-renowned expert in Lyme disease. And I'm going to do a few housekeeping things and then introduce him and we'll dive right in. But I am so honored to have my colleague.

Dr. Jill 00:36

We've known of each other and worked with mutual patients on quite a few cases for almost the last decade. But I have such great respect. And here he is, in my own backyard and yet a world leader. He's been part of ILADS. And, again, I will introduce him formally. But you're in for a treat today because this epidemic of Lyme disease is only getting more complex and more common. And we'll talk about some of the causes of why we're seeing more cases and those kinds of things today.

Dr. Jill 01:02

But if you are just joining us now, this will be recorded. You can go back and watch it. You can also find this and all of my other interviews on my YouTube channel and if you just search my name, Jill Carnahan, my YouTube channel will come up. And, again, you can watch this. You can share it. If you want any other information about me, I have a blog and frequent content on my website, which is just my name: JillCarnahan.com. And our product page is DrJillHealth.com. So those are places where you can find more information.

Dr. Jill 01:33

I will be sure to include [links] in all of the spaces where this video plays. If you look below, you'll see links. We're going to talk about two articles that Dr. Kinderlehrer recently published. And we're going to talk about his book that just got released, *Recovery from Lyme Disease*. I will include links to all of these things here and

everywhere you see this video. So if you didn't catch it as we're talking, you will be able to see those links below.

Dr. Jill 01:56

So I want to first introduce my guest, Dr. Dan Kinderlehrer. Like I said, he is a colleague, and [I have] such great respect for him and his work. I think, Dr. Kinderlehrer, in this area of both mold and Lyme and all these complex chronic infections and illnesses, there's no more difficult area of medicine that we could have chosen. Let me introduce you and then I want to hear your story.

Dr. Jill 02:21

Dr. Kinderlehrer is a nationally recognized physician with expertise in the fields of nutrition, allergy, environmental medicine, Lyme disease, and the healing of mind-body-spirit as a unified whole. He co-founded the New England Center for Holistic Medicine in Newbury, Massachusetts, and has taught extensively, including practitioner training courses at the Omega Institute, the National Institute of Behavioral Medicine, and the International Lyme and Associated Diseases Society. He created and organized the Lyme Fundamentals course, which is presently at the International Lyme and Associated Diseases Conference. He's the author of several review articles and of these two new ones that we're going to talk about today. His integrative medical practice in Denver, Colorado, focuses on the diagnosis and treatment of tick-borne illness. And, again, that doesn't do you justice. You are such an expert in this field. So welcome, Dr. Kinderlehrer. Thank you so much for joining me today.

Dr. Dan Kinderlehrer 03:14

Thanks so much for having me, Jill.

Dr. Jill 03:16

You're welcome. So where I always like to start is that we all have a story. We all have a journey. It gives us a framework for where we practice and even the compassion and mind-body pieces that we bring to our patients because we've all been in situations. I'd love to hear a little bit about your journey to becoming a world expert in Lyme disease.

Dr. Dan Kinderlehrer 03:39

Okay. First of all, it's hard for me to imagine myself as a world expert, but I have developed a certain amount of expertise over the years. It's interesting. I have to say that that journey really started with my training in internal medicine. I had a very classic training in internal medicine, and I felt it gave me a foundation on which I understand the human body. But I never wanted to practice internal medicine. I finished my residency in 1979 and instead of opening up an internal medicine practice, I actually opened up what was then referred to as a holistic medical practice, one that you would know well. We didn't have the name integrative practice or functional practice. We were called holistic MDs and were generally considered quacks, quite frankly. I thought that I would see people who are just interested in treating things naturally. But, in fact, like you, I ended up seeing people who fell through the cracks and just weren't getting help through mainstream doctors.

Dr. Dan Kinderlehrer 04:50

So I was drawn to [the idea that] I want to be the person who can really help this person who hasn't gotten help anywhere else. It sort of satisfied my desire to help but I also really enjoyed the detective work. So that's what I was doing back then. There were not very many of us. I mean, we knew each other—those of us who were doing that kind of work. We did not have journals. We did not have big conferences. We had small groups. So that's the work I was doing. I was doing a lot of environmental medicine.

Dr. Dan Kinderlehrer 05:27

Then in August of 1996, right in the middle of the summer in Massachusetts, I came down with a high fever, shaking chills, sweats, diffuse aching, and fatigue. I was in bed for two or three days and then it was gone. Now, I did live in an endemic area for Lyme, although it hadn't spread that much at that point. It was weird. But there were epicenters of Lyme at that point and there was an epicenter about 10 miles [away], as the crow flies. In Ipswich, Massachusetts, there was an epicenter. I worked in the emergency room there. So I had these three days of high fever, chills, and sweats. It goes away but recurs the next week. After another couple of days, it goes away and recurs for the third time.

Dr. Dan Kinderlehrer 06:25

At that point, I said: "I can't ignore this anymore. It's not just some sort of virus." I never saw a tick. I never saw a rash. So I go to see a colleague of mine. He does a

physical exam and tells me I have an enlarged spleen. He does some blood tests, and it comes back positive for Lyme. "Great, okay, I have this simple bacterial infection." Heh, "simple," right? And then I figured, "I'll go on antibiotics for two to four weeks and I'll be fine." But I wasn't. I got worse. I developed severe insomnia. I went from being a great Olympic sleeper to being up most of the night. I would take 100 milligrams of Benadryl to try to make myself unconscious. It was pretty terrible. And anxiety—I had been someone who most people would consider reasonably calm and collected. I was in a state of nine out of ten impending doom all the time. I just wanted to hide under the covers; everything overwhelmed me. It was just abject terror, really.

Dr. Dan Kinderlehrer 07:37

So after a month on antibiotics, we tested again. It really was a slam dunk for Lyme and it was a strongly positive Western blot. At that point, I called a physician at the Tufts-New England Medical Center, which is my alma mater, who is considered a world expert. And back then, you could call another doctor and they'd call you back. It's not so easy now, right? But he was very gracious. He called me back and very politely listened to my story. And then he said, "Well, you don't have Lyme disease." I said, "Why not?" And he said, "Because if you had Lyme disease, you'd be better by now. You've been on a month of antibiotics." And I said, "But what about the tests? I mean, they were a slam dunk." He said, "Well, false positive. They were wrong." And I said, "Well, what do you think I have?" He said, "Something else."

Dr. Dan Kinderlehrer 08:36

My head was spinning, so I called up a colleague of mine in upstate New York who I knew was treating Lyme disease, and I really had not been. I described what had happened and he said, "Dan, welcome to the Lyme wars." So that was my introduction to Lyme. And it got bad. One comment on the expert is that although he was categorically wrong—I clearly had Lyme—he was right that I had something else, which you probably recognize from that story. There's no question I had Babesia. It was under the radar back then. But if any Lyme-literate doctor were taking my history now, they'd say, "Oh, you've got Babesia."

Dr. Dan Kinderlehrer 09:21

Then later, probably from another tick attachment, I got Bartonella. So my main symptoms were neuropsychiatric, but really bad neuropsychiatric. I mean, I was

severely depressed. I was suicidal. The anxiety was over the top. I was having panic attacks. It was really hard to get through the day. But when I did finally recover—and it took years—I said: "All I want to do is treat people with Lyme disease. There are very few doctors who really have a handle on this and hopefully I can help people not experience what I went through," because it felt worse than death to me. And that's, in fact, what patients are often like when they come to see us, right? So it's really been a calling for me: "What can I do for each patient who comes in?"

Dr. Dan Kinderlehrer 10:18

But also, I came to Lyme with what we'll now call an integrative medicine background, even though we didn't have that language for it. It was 'holistic' then, [or] 'complementary medicine,' [or] 'alternative medicine.' Eventually, it became integrative and functional medicine. But I came with that background. Back then, ILADS, which was a fledgling organization, was actually very straight physicians. But almost all of us—virtually all of us—were there because either we or a family member had had this devastating illness and we were tuned into it. But I was one of the very early doctors who came in with this other background. I was the first one to present at the conference on: What else can we do from that integrative medicine direction to help these patients? So that's what I've been doing ever since.

Dr. Jill 11:17

Wow, some salient things jump out at me. First of all, you didn't have the classic bull's-eye rash. A lot of our colleagues still think that's required. And what is it, about 30% of patients who get Lyme get the rash and the other 70% don't? Is that about right statistically?

Dr. Dan Kinderlehrer 11:32

It's really an open question. Some people say it's as low as 15%. Some studies suggest as high as 70%. I would say the rash itself might happen in 20% of my patients but less than half of them actually have a bull's-eye rash. The most common rash is sort of an oblong, salmon-colored, homogeneous rash. But your point is very well taken. Doctors say, "Well, if you don't have arthritis, you don't have a rash, you don't have Lyme disease," which of course is totally false.

Dr. Jill 12:12

And what we're talking about is that there's a chronic inflammatory thing that

happens with this. And the acute infection—that febrile kind of illness that you have—may come and go. So conventional doctors are, kind of like with mold, thinking it's just an allergy when it's an immune-inflammatory thing. It's much bigger than we were taught in medical school. So again, most people who are listening are very, very Lyme-literate; they're aware of this. Probably they're suffering from this or know someone who is. However, if you're not, there is still a dichotomy between what is taught in medical schools and what Dr. Kinderlehrer and I are seeing in clinical practice—actually, the reason why we're passionate about doing what we're doing.

Dr. Jill 12:48

Dan, my story is that I always said, "I'm never going to do Lyme disease." Never say never, right? I was like, "Oh, it's so complex and I don't want to hurt the gut." But what I found is that if I really am dedicated to being a healer, which both of us are and I want to help people, I cannot ignore this. And then, like you, I was diagnosed with Borellia, tick-borne relapsing fever, Bartonella, Babesia, and Ehrlichia. And what we're seeing now is that it's way more common to have the conglomeration of, especially, Bartonella, Babesia, and Lyme. Those are like the trifecta, right?

Dr. Jill 12:48

It's confusing because Lyme has—I always call them footprints. And what I find too is that clinically, I have to be really good because, usually, it's a clinical diagnosis that I prove with the best labs in those areas. So we can talk a little bit about that too. But often you have to really be astute because insomnia, anxiety, air hunger, and disequilibrium might be more towards Babesia. So by listening as a clinician, we can usually have a pretty good idea of what direction to go without even testing—although you and I both appreciate and use laboratory and scientific validation testing. So your journey obviously opened this door. Gosh, it's like, where to begin? Let's talk about when you first see a patient and how you would navigate. Do you ask questions about their clinical symptoms, make a clinical observation first, and then test? Or what's your order of operations for figuring out what you're dealing with?

Dr. Dan Kinderlehrer 14:18

Okay, well, unfortunately, there's a bar to even getting into my practice. Either they have to have a Lyme test, or if it's a negative Lyme test, I'll talk to them on the phone to make sure their symptoms suggest that they might have a tick-borne

illness. So, if they're in my office, there's usually already an ironclad diagnosis that at least they have Lyme disease. And that's probably all I know about them when they first sit down. And then the initial intake takes about three hours for an adult patient. I don't start with, "Why are you here? What's your chief complaint?" which is how we were taught. I start with: "Where do you grow up? And tell me about your childhood."

Dr. Jill 15:04

Yes, I love it. Me too.

Dr. Dan Kinderlehrer 15:07

So first, I want to know: Did they grow up in an endemic area? I want to know what their family life was like. As you know, adverse childhood experiences can have a significant impact on your immune system. Did they also, by the way, happen to get a lot of tick bites? Did they have chronic runny noses and recurrent ear infections that suggest they have food allergies? So I start there, and then we just slowly work it up chronologically. Even though I ask patients to write all this down before they get to see me, we end up filling in all sorts of stuff as they remember, as I take them up through one set of years at a time. And we watch how this illness evolves because it's rarely: "I was fine until [I was] 32 years old, and then I fell off the cliff." It's usually this stuttering and gradually worsening situation where people become less and less dysfunctional and more and more symptomatic.

Dr. Dan Kinderlehrer 16:10

So that's what we're doing. We're documenting this odyssey of illness. And while we're doing it, [I ask questions like]: "Okay, what doctors did you see?" "What did they do?" "What was your response?" "When you went on amoxicillin for your sinus infection, what did you notice? Did you have a Herxheimer reaction? Did you feel better?" "What happened when they put you on steroids for poison ivy?" All of these are clues, as you know.

Dr. Dan Kinderlehrer 16:40

And you're right, it's not just the medical test. In fact, I don't use medical tests nearly as much as one might suspect. I do order it, depending on insurance coverage. It's always nice to get that backup or the objective findings. But particularly Babesia and Bartonella, which, as you said, are the most prominent of

the co-infections, I'll usually diagnose them clinically before I ever get a lab test. And the lab tests aren't that good for those anyway, right? But then, as you know, since you're so well trained in integrative medicine, I'm looking for all the downstream issues associated with chronic inflammation, autoimmunity, and immune suppression. So, as you said, we're looking at mold. This goes back like 10 years, for sure; I used to think: "Well, maybe mold's a problem in some people and if they're not getting better, I'll look at it." Now, day one, I'm—

Dr. Jill 17:52

Right? Way back when I had the mold and I started to understand that, I was like, "Oh, not everybody has mold, Jill." But especially for our patient population, the toxic burden is a big piece of it, isn't it?

Dr. Dan Kinderlehrer 18:05

It sort of blows me away, especially since we live in a relatively dry climate. It turns out that it's sometimes hard to find a house or an apartment without mold right here in Colorado, right? And the person with Lyme in the family gets sick from it; the people without Lyme in the family don't even notice that there's mold growing on their ceiling. So yes, that's a huge issue. So we're asking all of these questions to see what the heck else is going on that might be impacting this person's health. And that's why, in my book, I use the term 'Lyme disease complex,' not 'chronic Lyme' or just 'Lyme disease.' We're talking about people with chronic infections.

Dr. Dan Kinderlehrer 18:56

But it's never just Lyme. It's been 20 years now that my practice has been limited to seeing people with Lyme and tick-borne infections. Other than some cases of acute Lyme disease, I never see anyone with chronic Lyme disease who only has Lyme. They all have co-infections. And this is more and more accepted in the literature. There's actually a study [from] not that long ago [where] they actually looked at sera from 420 people who were CDC-positive for Lyme, and they found that there was an 85% probability of a co-infection. And that's from looking at the sera. You and I both know you're going to find a lot more if you just look at the patient.

Dr. Jill 19:45

Right, exactly. I love that you say that. I always say that functional medicine is really simple: It's toxic load and infectious burden, and the merging of those two—now, that of course oversimplifies it—the idea that these two things play together. And I

have seen cases where, if you take away the environmental toxic burden and help their immune system, you don't necessarily have to be as aggressive in the treatment of the infections because their immune system does what it should do naturally. Now, that's the exception because a lot of these people have dysfunctional immune systems.

Dr. Jill 20:18

Let's talk just a little bit about Babesia, Bartonella, and Lyme because they are so common. And then I want to talk specifically about tick-borne relapsing fever. But those three in particular, because I think those are probably the three that we see the most, especially together. Can you give us just a little bit of a footprint? We talked a little [about] Babesia, but let's just review. What would you see clinically for each of those so that the patients listening are like, "Oh, yes, that's me; I may have Bartonella"? What would you say their picture is like for those?

Dr. Dan Kinderlehrer 20:47

So if we're going to put together a Venn diagram in the middle where they overlap so that all the infections can do this—and probably when there's more than one infection, they do it even more so—you're going to see fatigue, headaches, joint pains, muscle aches, cognitive impairment, and mood disorders. I think it's more likely than not that patients are going to have those symptoms. Now, as you mentioned before, let's say someone wakes up with anxiety, shortness of breath, and night sweats—slam dunk, they have Babesia. Now, all these other things might be worse. They might also have migraine headaches and neck pain. So that's how we diagnose Babesia clinically. But I have to point out that not everyone with Babesia has those symptoms.

Dr. Dan Kinderlehrer 21:41

Okay, then Bartonella is known for causing these neuropsychiatric problems. Now, it's not the only one that causes neuropsychiatric problems, but it is the one that does it the worst. When we see not just anxiety but panic attacks, when we see not just irritability but rage attacks, [when] we see bipolar, [when] we see psychosis, we think: "Hmm, I bet Bartonella is an issue." There are certain symptoms that strongly suggest Bartonella in addition to the neuropsychiatric symptoms. I would say peripheral neuropathy: Sharp pain, burning pain, electric-like pain, stabbing pain, as well as numbness and tingling. Again, not only Bartonella, but particularly

Bartonella. Pain on the soles of your feet, particularly when you get up in the morning. Joe Burrascano described this to us like 12 years ago. I remember it well. That's almost always Bartonella. Even as I say that, I have seen Babesia do it. It's a neuropathy; it's a peripheral neuropathy. It's not only Bartonella, but it sure as hell suggests it. And then there are the Bartonella striae, these lines—

Dr. Jill 22:58

Yes. That's the one I was going to say we should talk about because it's a young person with no other risk factor and they have huge stretch marks.

Dr. Dan Kinderlehrer 23:04

Yes. So people think that they are stretch marks. And this is interesting. I have another article that I'm going to submit for publication for review. It's on a 16-year-old who presented with anorexia nervosa. She clinically refused to eat and felt she had a weight problem. She was purging and had a distorted body image. She was in and out of eating disorder units and was getting all of her nutrition through a nasal gastric tube when I saw her because she refused to eat. Among other things, she had these striae that she thought were stretch marks and were "evidence of the fact" that she was "overweight", except they weren't stretch marks. They were [inaudible].

Dr. Dan Kinderlehrer 23:51

Also in December of 2020, just three months ago, Ed Breitschwerdt in North Carolina, who's a world expert in Bartonella and his colleagues had a paper in which they saw 29 people who tested positive either serologically or PCR-positive for Bartonella. Twenty-four of them developed neuropsychiatric symptoms and these skin issues at the same time. Bartonella, by the way, also causes a lot of eye symptoms and gastrointestinal symptoms, and it does cause other kinds of rashes as well.

Dr. Jill 24:32

Like the skin stuff—often is... And I was just thinking the other day, because I've seen a few patients with this and I always associate it with Bartonella, that they feel this random sore throat flu coming on just a little bit of something and then it goes away. But is that pretty classical for Bartonella too? It feels flu-ey and then it goes right away. And it's usually a sore throat and kind of a malaise.

Dr. Dan Kinderlehrer 24:52

Thank you for reminding me. It is very common. Often, people say, "Yes, I have a sore throat almost every morning" and get the swollen glands. Sometimes it's not just cervical nodes; it might be axillary nodes and inguinal nodes. But it never amounts to anything. But you absolutely nailed it; that's usually Bartonella.

Dr. Jill 25:12

And one other thing I remember from my youth... I think my infections go back to probably eight or ten. I grew up hiking in the woods of Wisconsin and Illinois. Of course, we pulled ticks off ourselves all the time, so no surprise. But the thing that was interesting was that when I started menstruating and cycling every month, I would have a weak immune system. I'd get kind of sick around my cycle. And I've seen that with women now. I don't know if it's particularly Bartonella; it might be all of these, a trifecta. But I would see that in young women now or older women—that the cycle was very related to how they felt with the illness and immune system.

Dr. Dan Kinderlehrer 25:47

Yes, I see the same thing. The Lyme bug, *Borrelia burgdorferi*, tends to cycle about once a month. Usually, in females, it's associated with the menstrual cycle. As I'm sure you know, once women start menstruating, their immune system is suppressed to some degree, and that's when the bugs flourish. Babesia tends to cycle every one to three weeks or one to two weeks maybe more often. Not always. And Bartonella—I don't see a consistency with Bartonella, to be honest. But those are clues, like you're describing, of like, "Well, what's going on here?"

Dr. Jill 26:32

Yes. And we'll talk next about a little bit of the lab testing that's out there. Nothing is great. There are continued new tests—PCR and FISH and stuff—that are better. But it's hard. Really, truly, you have to have a good clinical diagnostic skill, because I can't tell you the number of times I hear the symptoms and I'm like: "I'm positive this person has Bartonella." And I may never have a positive test, but I have to have enough confidence to move forward because that's the only way they're going to get better.

Dr. Dan Kinderlehrer 27:00

Absolutely. I would say only a low percentage, at most 20%, but probably closer to

10% of the patients that I diagnosed with Bartonella have positive Bartonella serologies or PCR tests.

Dr. Jill 27:14

Yes, I totally agree with you. So if you're out there as a patient and your doctor is like, "Well, you're all negative," or you do a Western blot on Labcorp or Quest and it comes back negative, this is one strain of East Coast type of Lyme. This leads us into tick-borne relapsing fever. This has been a massive aha for me because I am seeing so many people... First of all, out West here, [such as in] Texas, it's actually more endemic with these soft-bodied ticks. So I think in our state, tick-borne relapsing fever and some of the other rickettsial or Ehrlichia are actually more common than the classical Lyme, although we see them all. I feel like this is a hidden epidemic because most doctors don't know how to test. And right now, I think the only one really testing well is IGeneX. But what are your comments on testing tick-borne relapsing fever? Are you seeing it? Let's talk a little bit about that.

Dr. Dan Kinderlehrer 28:03

Well, I'm glad you brought this up. Relapsing fever used to have this standard clinical description in which people would feel fine and then once a week or so they would have this program and run a high fever, sometimes high enough that they'd have a seizure. And then they would quickly defervesce. [There were] all sorts of symptoms associated with that. And then they'd go another five or six days and feel fine. That's the classic relapsing fever. Well, it turns out that at least one and probably more than one of the species of bugs that are genetically in the relapsing fever group doesn't cause relapsing fever; it causes Lyme. The most prominent one is *Borrelia miyamotoi*, which has been recognized within the last decade—not that long—initially in Russia and so on.

Dr. Dan Kinderlehrer 29:04

So at any rate, what's important and I think you're bringing this up, is that the standard tests for Lyme are going to be negative even though someone is presenting with Lyme. They don't get a rash, but as far as we can tell, they get everything else that Lyme does. And we treat it the same as Lyme. So I don't actually test for it if I know they have Lyme because we're going to be treating it anyway. The treatment is the same for *Borrelia miyamotoi* as for *Borrelia burgdorferi*, the Lyme pathogen. But if there's someone who has a Lyme-like illness and tests totally negative, then I'm going to start looking for it. And by the way, I

don't know if you get the New York Times magazine. But a couple of months ago, Lisa Sanders—she's a Yale doctor who does these clinical "what is this?" [or] "Who done it?" kind of thing—there was a case of *Borrelia miyamotoi* that was diagnosed by Brian Fallon, whom we know at Columbia [University].

Dr. Jill 30:07

Wow, that's amazing. Well, I have to tell you, when I interviewed Dr. Horowitz, I told this story. It's really personal, but it's very telling. I had cancer at 25 and Crohn's at 26. I have overcome both. You're going to totally get this as a clinician. So first of all, I had cancer, [was] immune compromised, and then [underwent] three-drug chemotherapy that totally trashed my immune system. Six months later, I presented with cyclical fevers. That's it. I had no gut symptoms. I had cyclical fevers and they were up to 102/101. They weren't 99. I was in my third year of medical school. I was working in the ER shifts and I wouldn't even tell anybody because I knew I'd not be able to work. And the standard, as you well know, for medical students is almost abusive. You work. So I would work through these shifts with fevers and I felt horrible, but I just went through.

Dr. Jill 30:31

Six months later, I had an abscess and was diagnosed with Crohn's. But that was my only gut symptom. And there's some evidence now that not only *Bartonella*, which can cause granulomas, which looks like Crohn's but that tickworm relapsing fever and all these infections at that time in my life after the chemo started to pop up. And I probably really did have Crohn's. I have the genetics, but could it have easily been... We'll go to your article on autoimmunity in just a moment because this is all going to fit together. But I believe that that tickborne relapsing fever, maybe the *Bartonella*, were actually popping up and creating a syndrome that looked like Crohn's, like identical. And again, doesn't it make a lot of sense that that might have been at play?

Dr. Dan Kinderlehrer 31:40

Oh, absolutely. Someone we don't hear from anymore, but a pediatric gastroenterologist by the name of Martin Fried is in New Jersey. He presented at ILADS. And he's written articles—this is in the medical literature—where he took kids both with non-specific gastrointestinal complaints and some with Crohn's and ulcerative colitis. And he would biopsy their intestines and he would find Lyme and he would find *Bartonella*. He was one of the first people to actually describe

Bartonella striae. So I can tell you that Bartonella, as you know, is associated with a wide range of autoimmune illnesses, including Crohn's and colitis.

Dr. Dan Kinderlehrer 32:30

And just a year ago, I had a paper published on Bartonella causing primary sclerosing cholangitis. And this is so interesting. So what happened was that I saw this kid when he was about 10 years old and he had a bunch of non-specific symptoms. It certainly looked like Lyme, and he tested positive, but it felt like Bartonella. He did not test positive to it. It's just "no big deal," of course, right? He responded well to treating the Lyme, but every time I tried to give him something for the Bartonella, he would get a bellyache. Well, if we didn't give him something for Bartonella, he felt 100%. So we just stopped. And we stopped treatment and he was happy. I always thought he had Bartonella.

Dr. Dan Kinderlehrer 33:19

Well, three years later, I get a call from his mom: "He's been diagnosed with primary sclerosing cholangitis." And just so the listeners understand, this is a very serious illness. It's actually associated with cirrhosis of the liver, early death, and a bunch of different cancers. It typically happens in adolescent males, most commonly. It's inflammation of the biliary tract, both outside the liver and inside the liver, and is often associated with colitis. So what happened was that he presented with bellyaches and some blood in his bowel movements. They scoped him and said, "You have colitis," and they did blood tests. And then they saw [and realized], "Oh my God, this kid's got cholangitis." They did the scans and they made that diagnosis.

Dr. Dan Kinderlehrer 33:59

Okay. So the mother goes to this specialist in California and they're really having good luck with oral vancomycin. And she told me—and I looked it up, a bunch of case histories and small case series—how well vancomycin is working. I said, "Well, why do they think vancomycin is helping these kids?—because it's not getting into the biliary tract." And she said, "They have no idea." And I said: "I know why. It's hitting the Bartonella in the gut, and there was an autoimmune reaction from the Bartonella causing the cholangitis." So I call up Dr. Fried and I presented the case to him. I said, "Here's what I think is happening," and he said, "Bingo!" So anyway, I wrote that article. It's got a lot of attention. But as you point out, the Bartonella, oh

my God, can do so many things. Of all the bugs, I actually think it's the worst one and the hardest to treat.

Dr. Jill 34:59

I could not agree more. I could not agree more. And I think it's persistent. I don't think we really have a handle on exactly the very best. And we have some good treatments. And you and I, I know, have had some good successes. But the bane of my existence is the recurrent Bartonella. Now, interestingly, another thought on this is... Years ago, I read the research out of New Zealand on Mycobacterium avium species in correlation with Crohn's. Because I've had Crohn's, I draw a lot of inflammatory bowel patients. I love treating them. Whereas everybody else is like, "I don't want to see you," I'm like, "Crohn's and colitis, I love treating." So I started testing all of these infections, including Lyme. And what I would find often as a co-infection is MAP, this Mycobacterium avium.

Dr. Jill 35:40

Well, guess what the treatment regimen for MAP is? It's clarithromycin and rifampin or rifabutin. That treats Bartonella very well. And sometimes I'll add on a third drug that is actually not available in the US right now. But what I found is that I was getting cures for Crohn's disease by using this regimen that I thought was for MAP. Well, about four or five years ago, like you, I was like: "I think I'm treating Bartonella. I don't know for sure because a lot of tests were negative." But that same regimen would treat the MAP. And then I wondered, [after] all this research on MAP, were they just seeing this co-infection and saying, "Let's treat it," and obviously they got results just like I did? But I wonder if, at the core... This is just my postulation, I have no science to back this except my clinical experience: I think that most of us were treating Bartonella.

Dr. Dan Kinderlehrer 36:24

I suspect you're correct. I know about the atypical Mycobacteria and that association. I really don't know how well it's documented. I've not perused that literature. But I have a patient just like what you're describing. And she was put on a regimen just like you described. But what really made the biggest difference was Cipro. When she went on Cipro, not only did her gut get better, but she was better all over. To me, it was like: "Yes, this is Bartonella. This is really Bartonella." If you guys want to treat Mycobacterium avium, that's fine because they're the same—

Dr. Jill 37:02

I totally agree. And I agree that the evidence isn't that strong either. So I was always like, "Ah, am I really on the fringe?" And you know what you and I have to do too: We have to be really good detectives—you mentioned this in the beginning—and observe. And we're really hopefully making inroads because we're doing stuff that isn't necessarily standard of care yet. And that's okay. I'm fine being there because I know that I'm using good science and my patients are getting better. But we have to be willing to push the envelope a little bit sometimes because otherwise nobody is treating or thinking outside the box to get new answers and solutions to these people.

Dr. Dan Kinderlehrer 37:35

Well, you're being polite, because I would say the standard of care sucks. These people are not getting appropriate attention. I think one of the gifts we give them is just giving them time and validating their experience. They go to their family doctor and they're in and out in five to ten minutes. They go to the gastroenterologist who looks up them, looks down them, doesn't look at them from a functional perspective, and certainly doesn't know anything about tick-borne infections. In fact, it's only recently, it seems, that gastroenterologists are diagnosing SIBO. Excuse me! So, yes, we could spend a lot of time talking about how Western medicine has failed people with chronic illness. It's really sad.

Dr. Jill 38:23

So the other thing I want to talk about is that you came from a holistic background and I did too, and I find that either a purely medical pharmaceutical approach doesn't usually work or a purely herbal approach doesn't usually work. Although there are exceptions to both. What are your thoughts?—because I feel like we have to have the most tools in our toolbox and really, really pull these all in. There is an appropriate use of hydrocortisone. There's an appropriate use for these other things. [Please share your] thoughts on that and let's talk just a little about how we need these tools and what you use.

Dr. Dan Kinderlehrer 38:57

Yes, it's a big question. As you know, every patient is different. There's no cookbook that we can just say, "Okay, here are steps one, two, and three." If a patient is really fragile, I'm going to be spending time on infrastructure before we even consider hitting the infections and as you're suggesting, looking at adrenals, other food

sensitivities, gut issues, and all the stuff that we do as integrative physicians to try to get people into balance, particularly with their hormones. And then, in terms of antimicrobials, if they don't seem that fragile, I will probably start with pharmaceuticals. I always start things one at a time, and I always start things at half dose because I really don't want to give them a Herxheimer or a die-off reaction, which are to some extent unavoidable and can be helpful diagnostically, but they're not good for you. As you know, they're causing a lot of inflammation in the body, which is the problem. So we don't want to cause undue Herxheimer reactions. Okay, so I'm adding things one at a time.

Dr. Dan Kinderlehrer 40:15

And ideally, what happens is that I get people fairly well at that point and then I start adding botanical antimicrobials. So now we're hitting it from two different directions. And I think that's ideal. If we can get both of those on board, I think we have more killing power. And the botanicals, as you know, also support the immune system all the time. We're doing whatever we need to to make sure the gut stays healthy. And then, over time, people go into remission. I'll start peeling away the pharmaceuticals and just leave them on the botanical antimicrobials for a while. Then, over time, some people say, "I just want to stay on this [for the] rest of my life." And other people, after a while, say, "I'm ready to stop." And knock on wood, I have patients in prolonged remissions. But as you pointed out, that's not going to work. It's interesting to me that, of course, there are people who don't tolerate pharmaceutical antibiotics. I have more people who don't tolerate botanical and herbal antibiotics.

Dr. Jill 41:28

I totally agree with you. I feel like there's such a broad range of activity that sometimes it's too much for this—too much noise and static. Even though they're beautiful and whole as an herb, I totally agree with you. I think sometimes that just hitting... And a decade ago, before I did this, that was my fear: "I don't want to hurt their gut. I don't want to use the drugs." And then I realized the drugs actually really work and there's a place for them—a perfectly appropriate place.

Dr. Dan Kinderlehrer 41:52

Yes. And people will say, "Well, is it okay for me to take these drugs? It's going to undo my microbiome." And I'm like, "We can do a lot of things to help protect that,

but I can tell you what's going to happen if you don't take the drugs." There's a benefit-risk [relationship] there that is really obvious.

Dr. Jill 42:07

I totally agree. So, a few last things. This is so fun! It's so fun to talk to someone who understands this so well. And really, you are an expert, Dr. Kinderlehrer. Transmission—we have tons of questions. I always find these a little hard to answer because, for some of them, we don't have a ton of science, but I want to know your opinion on mosquitoes, spiders, and bed bugs, which I have a story about. And then, between couples, can it be sexually transmitted or in utero? Let's talk about those kinds of transmission questions. And some we may not have answers for but for what you do, share with us your wisdom.

Dr. Dan Kinderlehrer 42:42

Okay. So the most common form of transmission is, of course, the deer tick, long-legged tick, or Ixody's tick, or whatever you want to call it. But there are these tiny ticks, which are hard to see. Okay. That's the most common. What's very well documented is that Lyme can be transmitted in utero to an unborn fetus. And that's not just Lyme. It's also Babesia and Bartonella. That can cause serious issues. It's often not noticeable in newborns, but by the time these kids reach toddlerhood and so on, they're manifesting some really significant issues, often manifesting as a PANS-like syndrome. So that's two ways people can get it.

Dr. Dan Kinderlehrer 43:32

In terms of other biting insects, I don't think there's great documentation, but then we hear these anecdotal stories. I have a patient who swears that he got Lyme disease from a horsefly, which caused some painful bites. And I have another one who swears it was from a mosquito bite. Who am I to say, "No, it didn't"? I mean, we do know that *Borrelia burgdorferi* does inhabit other insects; we just don't know how well it transmits. So it's certainly not impossible that you can get it from these other biting insects. And I'm interested in hearing your story about bed bugs.

Dr. Dan Kinderlehrer 44:15

And then, can it be sexually transmitted? Of course, Lyme is a spirochete. And guess what? Syphilis is a spirochete. Syphilis can be sexually transmitted. Can Lyme be? This is still a really great area. There's three animal studies. Two of them suggested it could be. One of them found no transmission. There was a really

well-known study where they actually tested vaginal swabs from females and semen from males who were actively infected and they found Lyme. Now, does that prove it can be transmitted sexually? No. They did find antibody strains—this is by antibody testing—similar in spouses to suggest, "Well, we think it was." It may have been.

Dr. Dan Kinderlehrer 45:12

I know other doctors have described this as well, even though I don't know if that has been reported: I do see spouses of patients, and usually the male is asymptomatic. But if you test him, he's positive. And sometimes [he is] even more positive than his wife. Now, as you know, [being] more positive doesn't mean he's sicker. It could mean he's got a better immune response. So maybe it's like a vaccination. I don't know. Maybe he's got a low-level exposure through his mucosa and now he's got antibodies to it, which, of course, as you know, doesn't mean he's protected if he gets a tick bite. But in general, those people have remained asymptomatic. And if they're asymptomatic, I don't treat them. I don't know what my endpoint would be if I treated them because the serologies don't tell us whether they're cured or not. So that's still a gray area. And there are people on both sides. Oh, they're convinced. I'm not convinced, but I can't say for certain.

Dr. Jill 46:20

I totally agree 100% with everything you said. It's kind of like, "Could it be possible?" Yes. "Do I have convincing evidence for sure?" No. "Do I have clinical experience to suggest, maybe?" Exactly. So for the bed bugs, I had a patient who had a massive infestation of bed bugs in their beautiful town. It's a penthouse on Michigan Avenue. So this is no respecter of persons. And she got very, very ill with anxiety and insomnia—what I thought was Babesia afterwards. And I went looking in the literature. I thought, "Could there be an association?" These are the little arachnoids. And we know that lice carry tick-borne relapsing fever. So I was like, "This seems like it could be."

Dr. Jill 46:57

And I found that there is evidence in bed bugs of Babesia being found in the bug, but there's no clinical evidence yet of transmission to humans. But I tested her—[she was] FISH-positive, off the charts—for Babesia. And I'm treating her and the bed bugs are gone. This is, again, just N of 1 clinical experience. But it was so

timeline-related to the bed bugs, and we know that they do carry it. I have a suspicion that might be the first case.

Dr. Dan Kinderlehrer 47:21

You should publish that. I'm curious. And if you want, I really enjoy writing up stuff for medical journals.

Dr. Jill 47:28

Oh, I hate that. So I'll share the info. I would love to have you help with that.

Dr. Dan Kinderlehrer 47:32

I think that's a great case. And I think it should be presented at ILADS too. Yes.

Dr. Jill 47:38

Let's talk about that. And I called a few of the experts around and everybody said the same thing: "We don't have any evidence." But is it possible? And then, when I looked, there's clear evidence—they found the Babesia organism in bed bugs and lice. So it is seemingly possible. Well, this is interesting. Well, in the last few minutes here, we didn't get to talk a lot about your articles. I'm going to share those. One is on could Lyme be associated with PANS/PANDAS? We talked a little about Bartonella and in utero. So maybe touch on that. And then—and these are huge topics so we'll just touch on them—autoimmunity. So let's talk about PANS/PANDAS and autoimmunity.

Dr. Dan Kinderlehrer 48:15

Okay. So back in 1994, Susan Swedo and colleagues described these neuropsychiatric symptoms in kids who had previously been healthy. They got a strep infection and they fell off the cliff with really significant mood and behavioral disorders, particularly OCD and anxiety. They named this PANDAS—pediatric autoimmune neuropsychiatric disease associated with streptococcal infections. Well, it turns out that many of these kids also had eating disorders. And then it turned out it wasn't only strep. In fact, [they had] a bunch of different viruses, including the common cold, influenza, and HIV. And then, in addition, mycoplasma and Bartonella have been documented as causing PANS. Lyme has not been documented by itself as causing PANS.

Dr. Dan Kinderlehrer 49:21

They changed the name from PANDAS to PANS because it's not just strep. PANS stands for pediatric acute-onset neuropsychiatric syndrome. And now we have an umbrella for all of these syndromes that basically result in autoimmune encephalitis, that is, they have brain inflammation, brain on fire—these poor kids. So I explained to my patients: "Think about a strep throat and rheumatic fever. Antibodies to the strep attack the heart valves because there's some sort of structural similarity and the antibodies pick up on the heart valves and attack them. It's both an infection and an autoimmune reaction. We're talking about the same thing with PANS, which is that it's an infection."

Dr. Dan Kinderlehrer 50:09

Even as I say that there are nonmicrobial causes of PANS like mold, for example, right? But usually, it's an infection. And then it's triggering these antineuronal antibodies and activating certain enzymes that cause all sorts of inflammation in the brain. And these poor kids, in particular, tend to have OCD, anxiety, and depression. They become obstreperous. I mean, these kids go into rage attacks and try to destroy the house. Really, there are stories of where the father has to hold the kid down when they go into these places. They're oppositional. They can develop ticks and choreiform movements, which are sort of involuntary stuff. These poor kids. And they usually end up being diagnosed as ADHD or bipolar—and [with] eating disorders, of course. So that's what PANS is.

Dr. Dan Kinderlehrer 51:04

And I wrote this article; the article is entitled, "Does Lyme Disease Cause PANS?" And when I go through the data, Lyme disease is associated with all the same neuropsychiatric symptoms associated with PANS. But when we look at all those neuropsychiatric symptoms with Lyme, it really doesn't pull out what's caused by co-infections. We don't know how much is caused by the *Borrelia burgdorferi* microbe and how much may be [caused by] *Bartonella*, which admittedly is hard to diagnose with blood tests. And usually, they don't even try. But there is clearly this parallel in symptoms.

Dr. Dan Kinderlehrer 51:47

And then Brian Fallon and Cunningham had a study about a year ago where they took people and found that those with a prior history of Lyme disease, some of whom are still symptomatic, tended [inaudible]. So a positive Cunningham panel

means that they have these antineuronal antibodies, right? And these are adults. The mean age was around 56. Okay, I won't go into anymore. I cited a whole lot of different studies. There are probably a hundred citations. But basically, we don't have the evidence yet to convict *Borrelia burgdorferi* as a cause of PANS, even though it's clear that other tick-borne infections, such as mycoplasma and Bartonella, absolutely can. But my whole proposition at the end of the article is that we need to change the name. PANS, which is pediatric acute onset, doesn't apply to the greater range of people. Adults get PANS and it's often not acute onset; it's often a stuttering onset. My suggestion was that we change the acronym to MANS, which is microbial-induced autoimmune neuropsychiatric syndrome. So that's what that article was about.

Dr. Jill [53:10](#)

Ah, brilliant. And I couldn't agree more because I see all kinds of adults. And we're doing the Cunningham, and we see the same pattern. And it's not just a childhood illness. So this is brilliant. Dr. Kinderlehrer, this has been just so much enjoyment for me to talk and to talk to you—all your information and wisdom. I know that our listeners have enjoyed it. And thank you so much for sharing your wisdom with us.

Dr. Dan Kinderlehrer [53:33](#)

Oh, it's my pleasure. I'd love to do it again.