Why Lyme Disease Treatment Is So Controversial Transcript

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Opening Patient Recovery Story

I can't tell you how many patients have come in and said, you know, I've been told this is just what it's like to get old. In your late 40s and early 50s.

I mean, all argue even in your 70s or 80s, like it is not normal to feel that way. It's not just life. We had an 80-year-old this week that had been to quite a few doctors, but it only took two months and she's already well on her way to recovery.

And so she was thinking, you shouldn't give up at 80 either. But she shocked and pleasantly surprised that what could have been sort of like a sentence, a long stretch, turned around so quickly.

It's so satisfying to be in practice and take somebody like that on and turn their life around. 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 is not. We share the facts that most people miss, challenge outdated thinking, and give both patients and practitioners the tools to heal smarter.

Podcast Introduction and Lyme Treatment Controversies

So let's get into it and change the way we heal Lyma. Welcome to another episode. I'm your host, Dr. Mariah Hinchy. And today we're focusing on a particularly challenging aspect of Lyme disease, the controversies in its treatment.

This topic stands as a significant point of debate in the medical community. Why? Because Lyne disease and tick-borne illnesses in general present as a complex puzzle in terms of presentation, diagnosis, and treatment.

Different medical experts have varying opinions on the best course of action, leading to a diverse range of treatment methods and strategies, some of them simply not effective.

In this episode, we will delve into why these controversies exist and what they mean for patients and practitioners alike. So stay with us while we explore these issues in depth with Lyme expert Daniel Cameron MD.

Dr. Cameron has led the International Lyne and Associated Diseases Society, or ILADS, as their president twice. And he's widely recognized as the author of the ILads Practice Guidelines.

He's the Author of Book, An Expert's Guide on Navigating Lymedisease. And he has a private practice in Mount Kisco, New York. Welcome Dr. Cameron. Please tell our audience how you became or why you become a Lyme specialist.

Well, thanks. It's nice to join you. I grew up on a farm, which most people know by now and went to medicine, thought geriatrics would meet my need. grew up with a lot of elderly people that were integrated.

And as soon as I left in Alzheimer's practice at a teaching nursing home, that first year I saw three Lyme disease patients and not something I ever saw in medical school or my geriatric training or even in the nursing that I was aware of.

In those three patients, I had a lotta time my first-year in and not practice to get to know them. The treatments that were out at the time, which is mainly just doxyclone, wasn't working so well.

I was making progress. So I didn't understand the range of issues that I facing, but as a doctor, you have to start somewhere. And were these, so these were chronic Lyme patients, obviously, at the time, if they already had Alzheimer's, correct?

Dr. Cameronu2019s Path to Lyme Specialization

Well, these didn't have Alzheimer, but because I had so much training in Alzheimer and dementia is that I could pretty soon recognize the cognitive issues, the memory problems, and the focus.

And so it was more of that awareness through my geriatric training that had a better sense of the Cognitive issues. Cephalopathy was common, but not dementia.

And so it's that fine line between dementia, you know, patients I see all the time are worried about will this turn into dementia? Could it be dementia and until they realize, well, actually Lyme can mimic it sometimes.

I have to pull back and say, well, you're only 52. You can't be thinking dimension now. There's a lot of other issues involved. So I thought that foundation and on the farm with the people I took care of in my family and then geriatrics, all of a sudden is that I had some unique insight.

And also I was item masters in public health and epidemiology. I sort of had a coalition of lot things that just allowed me to take those three patients on, get to know them, take what little literature was and work with them.

That's great. And so how did that then continue into you specializing in Lyme? Was that something that happened kind of right away or did it happen farther down the road?

No, it happened pretty quickly because there were a few people in 1987 that worked with Lyne. Dr. Brescona was out there, a Dr. Ligner had just started practicing in the same area at the hospital.

And after three years of work in that field, the New England Journal of Medicine article came out by Drs. Zajidjian, Steer, and Kaplan, where they were seeing the very same things.

So I thought, gosh, it wasn't just what I was seeing. It wasn' just a passing observation, but that's where the described the Severe fatigue, poor memory, and poor concentration.

The lightheadedness, which later on we realized that was sort of a POTS type problem. Neuropsychiatric issues, like irritability was showing up. There was anger and rage, we now know as lime rage.

We know that some of the confections can cause a lot of anger and irritability. Even suicidal issues were showing up in Dr. Bransfield's practice. And so it went on and on.

There's a broad range of issues that were published. I thought, boy, that's going to be a whole team working on how to do something with Lyme. Now, there was nothing in that paper about coinfections, but they were finding that if you treated for two weeks of intravenous subterraxone, that two-thirds improved.

They did say there a problem because a third relapsed, and some of them failed treatment. And they even had the insight that they weren't sure they we're eradicating the organism at that.

time with those two weeks of IV. So everything you could possibly think of was there on paper. And the other thing I thought was fascinating from that paper was they were sick up to 14 years.

I was already seeing people that were for years and for me to see a validation in a published paper of what I'm seeing, the symptoms I am seeing is that I joined the community of people working with Lyme and there was

diversity, but it was certainly a good start, good foundation if I look back on it.

Yeah. So where do you think the big divide came from? Well, I think that there was, there's uncertainty, so it's all speculative that. There was a lot of interest in acute Lyme.

It's when that paper came out in 1990 where the chronic Lyne disease came up, it shook the foundations. You know, Dr. Stier, who discovered acute lyme or at least wrote the first papers on acute line was part of that chronic neurologic Lyman paper.

Why Lyme Treatment Became Controversial

And so I thought that would be the opening for. everyone on board. But no, it seemed to be people that went down the line of it's gotta be acute, there's no such thing as chronic Lyme.

That came out in a paper published a guideline published that product line doesn't exist as a unique entity and it's nothing more than aches and pains of daily living.

So already by the year 2000, guidelines come out saying no such thing and they're not sick, sort of divided the community and declared that there was a big division.

And so there is a widening gap between the kind of work I was doing and some doctors who said that they weren't going to go there and if anything, They were going to frustrate doctors like myself.

They're going make tests that were harder to get a positive test on. And they were to make every step of the way difficult. So a lot of my colleagues that I worked with stuck it out and continued to work on the chronic issues.

They didn't like the word chronic Lyme disease, but they didn' realize that a paper said chronic neurologic Lyne. And so there was this fight over semantics, over words, over language, 5 out of 10 Western blood bands.

There was more discussion and fighting and arguing over that than, what would I do with my patient? That's what I want. What do I see? What to do? From where I started in 1987, I'm still focusing on what my patients need, not on on the semantics.

Well, I'm glad you are. So why do you think there's such a controversy? Well I am still trying to sort that out now. Lyme disease is not so easy to take care of.

Somebody like I, like, am an intern, somebody who's been sick with diabetes or or high cholesterol, they're not sick for 20 years and even then you just refer them to a cardiologist or a neurologist.

In this case they come in quite sick, you know, with severe symptoms, their function poor, there in pain, They have failed like you stand at three week or four week of antibiotic and it's a pretty intense time and so many co-infections have been discovered, so much so, many different approaches have emerged that it You know, some doctors aren't sure where to begin, and some patients aren' t where they begin.

So the question I always work on is how can we tone down and get focused and on to patient care instead of getting caught up in controversy? Because my job is to take that visit and try to get rid of all of the baggage and all the conflict and problems out there.

Where are you now? How beat up are are? What can we do to try to straighten out, not the persistent infection, but all the baggage and conflicts and problems and war that you've been seeing and living through.

And that's a challenge for doctors. Yeah. I mean, I became a doctor to help patients and it troubles me when it seems like a medical practitioner isn't more concerned with treating their patient and the patient in front of them.

But I thought that this topic was really interesting because a lot of patients get caught in the crossfire, as I'm sure

you see all the time, and they don't understand why does the infectious disease society say that chronic Lyme doesn't exist and that depending on which doctor you talk to, X amount of days of doxycycline is going to basically cure you.

And then anything after that is like this post-treatment syndrome. So I think it's important for patients to have a fundamental understanding of why there is such a divide in the medical community.

Are you ready to transform the way you diagnose and treat complex chronic inflammatory illness? Because what if everything you've been taught to treat separately is actually deeply connected?

At the Limebite Symposium, we're bringing it all together. Join us November 13th and 14th at the Fort Lauderdale Pompano Beach Resort in Florida, or attend virtually from anywhere for the premier functional medicine conference on complex chronic illness.

This year, we're diving deep into the interconnected drivers of chronic disease, including neuroinflammation, immune dysregulation, COVID spike protein related pathology, mold and mycotoxin illness, breast implant illness pans pandas, and of course, Lyme and other vector borne infections.

Acute Lyme, Testing, and Early Treatment

Because the reality is, your patients don't have just one of these. They have several. And if you're not trained to recognize how these layers interact, you'll continue to miss the root cause.

If you are a patient still searching for answers, this is the information that your doctor may be missing. This is how we move from symptom management to true healing.

So join us in Pompano Beach or from anywhere in the world. Don't get left behind. Register now at LymeBytes.com. That's L Y M E B Y T E S dot com. I think with the standard of care, which was not to treat or not do much for treatment, is that that's what led to me to work with ILADS as a professional society to write the guidelines, to set the standards, that instead of only one set of guidelines that There's a professional medical society that exists that looks at the literature different and comes to the conclusion that chronic Lyme issues are important, that it's severe and there's various treatment strategies available and that persistent infection is a big problem.

Now, there is still a challenge of how do you get better, but that already in 2006 was trying to establish some comfort zone and some space for doctors like myself to work in.

We did this repeat guideline 10 years later, clarifying issues. we used a more of a traditional evidence-based medicine type of scoring, and it came to the same conclusion that we have a problem in Houston.

Yeah. So do you think that part of this divide, especially with the infectious disease society, is it the lack of knowledge? Is it not wanting to deal with this whole sort of can of worms and this complex patient?

Or is there some political or other underlying reason? Good question. There, in my area, I feel that doctors know a lot more about Lyme disease than you might think.

And they know the controversy, but they also know patients who have these issues. So it's very easy, and I see this all the time, where the doctor sees it coming within three or four sentences, they're already misdirecting, changing direction and going and picking maybe the headaches or maybe pots for maybe, the cardiologist.

They'll very quickly make a referral for a piece of the problem. The patient wants to get past multiple specialists and multiple referrals to what does it all mean?

How do I begin this issue? And so the relationship falls apart really quickly for some doctors and some patients. Even primary care doctors have known you for years.

If you end up with a Acute Lyme, that's fine. If you end up with any chronic issues or neuropsych issues, any of these that we're talking about, it very quickly, they see it.

They know what's out there, what could be done, but it's almost like it is too hot a subject, politically too hard a a topic to go there. And so even though they might be trained, gone to good medical schools, They have experience.

That one topic they'd rather go off in the fibromyalgia, chronic fatigue, or a chronic viral syndrome or without any psychiatric training, just say, well, I think you have psychiatric problems.

First, when they go to psychiatrists, they're not sure that, often don't think that's the issue. You know, it may be tough to be sick, you know. There's post-traumatic stress disorder type symptoms, but it's a lot of things that happen until you get better.

And then even if you can get, start getting better, there's work to get your health back and your wellness, your function back. It takes a lotta counseling, I find, to help somebody that's sick to, get them back to health and wellness and get over this crisis.

Yeah, it's a lot of work and usually it entails an entire holistic treatment plan with everything from addressing the autonomic nervous system and mindset and obviously the infections, but everything else that the infection has done to the terrain of the person's body and all of systems and organs and the body.

Do you think now that CDC has acknowledged that, you know, Lyme can become chronic or however it is that they've worded it. Do you think that that's going to change anything?

Well, the CDC recently included Lyne disease in lists of infections that led to chronic symptoms. So they were very careful in how they wrote it, not chronic infection, chronic symptoms.

So when you look at the site, readers want to look up what happened. They gave an example, which is it could be an immune response to the Lyme infection.

I'm concerned that a patient might grant that there's symptoms, yes. They look at the website, Yes. But if the only thing they mention is that it's immune related, there is a chance that somebody who has a persistent infection might get overlooked.

Okay. So in an acute case, What do you think the reluctancy is to treat appropriately? And I mean, I'm using that for lack of a better word. So in Connecticut, where I practice, there's a multitude of medical practitioners in either family practice or walk-in clinics that are still following that one dose of doxy at the time of the tick bite is going to stop you from getting Lyme disease or 14 days of Doxycycline is sufficient.

I guess I understand, maybe, not really, but let's just say for the sake of argument, I can understand why maybe a physician or a medical practitioner wouldn't want to get involved in the very complex treatment of chronic Lyme disease.

But in an acute case, Like, why are doctors so reluctant to follow the science of how many days of the appropriate antibiotic, such as doxycycline, to prevent this whole chronic Lyme situation to begin with?

Well, there's a fair amount of doctors who in our area who do take on Lyme and for early Lyne or they might even have chronic issues, but they take an early line approach.

So they're very limited in what they do. Let me address that first tick bite issue is that this study that's about 20 years old was able to show that two doctor's second pills, a one-time dose could prevent rashes.

They weren't able to show that it prevented any of the other manifestations of Lyme. They didn't look at chronic neurologic issues, neuropsych issues or autonomic.

All I could show was you could prevent a rash, which is not the main point anyway.

Babesia, Coinfections, and Broader Protocols

And so my concern is I see patients where, yes, they didn get a rest, but they got sick and nobody ever told them, Yes, we're giving two docs second pills, We don't know if it's going to prevent anything other than a rash.

And the study was tiny. There was eight rashes in the placebo group and one in treatment group. They were people in a study that went on to have Lyme, but they call it probable Lyne.

You know, they didn't want to declare it was Lyme because it's somewhat of a clinical judgment. So I was frustrated that, and I still oppose to a single dose of doxyclin without informing the patient.

I'd rather treat or watch carefully. The other issue when it comes to, I like four weeks or six for early Lyma, acute Lymen with a rash. And the reason I picked four is then I make sure I have a follow-up.

because I need to determine how they respond to the treatment. Sometimes they'll present with the chronic issues, recurrent issues or even the sweats of Avesia.

And so there's so much diversity in what's in a tick is that if I plan on at least a four-week follow-up, then I can reassess the things. I also, at that point, get a chance to make sure that there's no other illness that's emerged that I have to address.

And so I think the most important part of Lyme is that follow-up visit. If there are issues, everybody follows hypertension endlessly. But with LyME, you don't get patients who are following up.

They might get phone call from the office saying the tests are negative, but the real job of medicine when it comes to LyMe is, that one-on-one clinical exam right in your face discussing where you're at, where are you going.

Because some of these patients say, oh, I think I'm okay. And then they just go on and months to years later, they're rather sick without anybody saying, well, you should have followed up.

Right. Yeah. I Think patient education is one of the most important pieces of this and really telling patients like what they need to be on the lookout for because a lot of the symptoms are so cyclic and intermittent, right?

That like, it's just not obvious, especially to someone that doesn't know what they're looking for. Yeah, I think I find that protocols may have to change because there are some many people with Babesia in the area.

And if the doctor is always right, you know, for Dr. Cyclin, that does not do a thing for Babiesia. So I found that I'm on the lookout for a Babsia at the beginning.

mostly looking at it for four weeks. I don't trust the babesia test because the Babesie tests are going to show parasites in the red cells only for the first week and the antibodies aren't so complete.

And so I think that I might be interested in a protocol where doxycycline and something for Babese at the same time, day one might actually be better than just hoping for the best and letting a patient have, have the risks of a chronic illness.

So I don't think that the protocols of doxycycline is one size fits all. Also, if you're under eight, amoxicillin is the treatment. Above eight the CDC said that they're not so sure if I'm more flexible and don, and I more flexibly use doxicycloin.

Doxyclin takes care of quite a few things, but it doesn't do anything for rubesia. Right. So are you talking about doing like a TovaQuone and azithromycin or something like that with Babesia?

And then how would you cover, like, do you think azothromysin is sufficient for Lyme as well? I mean, without getting into specifics, although I'm asking you specific, sorry.

Well, but I think I'd want to address that just a second. The, sometimes if I want, to treat for rubesia right away, because there's sweats, they can't catch their breath.

And, and I, think that I better add rubiesia treatment, yet I wanted. kill, like I want to do something for anaplasmosis or ehrlichia, I need doxycycline.

So I will sometimes wave the Zithromax, take the docycyclone with the Babesia treatment, you know, and then I can always add the zithermax later. Because the original study only picked zitromas, they didn't say what was the best, They just said this worked.

Okay. I'm not always married only to Zitser Max. And when it comes to babesia treatment with the Atobacone, even though a lot of my colleagues tend to use the liquid version, which is 750 milligrams per dose, I find that I get comparable results with malarone which has 250 milligrams.

So instead of always muscling to the highest dose that often does the trick. Then for people who are really fragile where their Herxheimer reactions are that are possible, then I will often start with the pediatric dose, which is 62.5. So that's quite a bit less than 750. And if I start that way, some of the stormy types of treatment that I get through the beginning, I can handle and make decisions later on with responses.

I'm not a big fan of muscling through to the highest dose I could possibly do, but I'd much rather one-on-one work out what to do to ameliorate the side effects and help with that person under control rather than just always the big dose.

I may never get to the higher dose and get the results I want. Right. So how can patients navigate the vast amount of conflicting treatment advice out there?

Well, I think it's pretty easy to read and find out that there's a divide because there are not too many people in between. I try to take somewhat of an in-between, but at the end, it is hard to see that it doesn't exist, that is no symptoms.

It's hard take anything from that view. So, with patients, there is so much to be read now. What I find is a lot of patients read much when they know about Lyme and they've been diagnosed.

My concern is all the ones who have been lost in the system or been told it's not Lyne or that Lymen doesn't exist in a chronic form. And so a lotta my work is trying to target those who haven't even started reading.

Once they read, they… You can learn pretty quickly and then sort of see where everybody is and what works for you. But it's all the ones in between and ones that haven't taken on the system, haven' read, have realized they have to do something.

They've gotten lost in some other diagnosis like related to a virus or fibromyalgia, chronic fatigue or totally MMS or something else. And it'll get back to looking at Lyme.

Right, I've had a lot of patients come in where it's like the one thing that they know that don't have is Lyme because they've been tested for it like 20 times and like, that should tell you something.

Navigating Conflicting Advice and Patient Education

If you've went to all these different experts and they all thought to test you for Lyne, clinically you're presenting as Lymen, you know? Are you suffering from Lymedisease 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 Lime 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 LIME Core botanicles. 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. Lymecore Botanicals, herbal medicine you can trust from a doctor who lives this work.

Learn more at LymencoreBotanicles.com Yeah, that's why I said that doctors know much more about Lyme and can see it coming. And so they don't want to touch that subject.

At least it appears that they want touch the subject so very quickly they'll steer the conversation in other areas. So you can get lost in the system very quick.

I see that all the time. How do you get that person who's heard that it doesn't exist to open up and discuss what to do if they have a perfectly good doctor, a perfect good internist?

Family doctors say, look in your face and say. I don't know what it is, but I just know it's not lying. And once you hear that, it very hard to question an authority answer.

It's almost like a politician to look in your eyes and say, listen, that's all I know. That often slows down the process, delays treatment, and months pass before they get back and realize maybe that was the problem in the first place.

So do you know of any emerging treatments that are generating any sort of debate? Well, I think that a lot of the confusion has to do with what to with the test tube work in the mice.

You know, so the combination treatment seems to be working or triple therapy seems working. But the challenge there is some of triple therapies all intravenous.

And so, you know it may be useful for someone who's failed some other treatments, but I hate to go into intraveinous first or second or third. I'd rather try some others issues.

There are some great research on biofilms, which You know, their biofilms are from Staphylococcus streptococcal infection, but they're certainly difficult to find clear cases that you can study in people.

You could certainly study them in a test tube. And even persisters, I think I like that theory that there's some infection that's sent in the tissue. that's in the body that is not resistant.

So when you start looking at all those things, it gets confusing to the doctor. I look at that and try to figure out where to begin with all that great knowledge, all the great information as to what to do.

You have to start somewhere with something they can tolerate, oral if I can, and then build from there. But a lot of times when you read ahead, you've read everything that's ever been known about biofilms and persistors, then you never get there because you get better with a simpler strategy.

And so it's a, I tell people it doesn't hurt to know all those things. You just may never need to known those thing, just as, but keep reading. It's great challenge to understand what's going on with.

Lyme and all the cone infections. Yeah, I would say there's a vast majority of patients that know just as much, if not more, than most doctors out there regarding treating Lyne disease, you know.

Oh yeah, well in fact that's, that you just touched on something important, which is that doctors in certain diseases don't read and make decisions as well as you might think.

There's something in medicine called thought leader. where you're waiting for that doctor to make a decision before you do something. So whereas patients or myself is I'm not tethered where I have to do exactly what that thought leader says.

In fact, I haven't, you know, for 36 years I hadn't cooperated about that theory that chronic Lyme doesn't exist. There's nothing more that makes a pain in the daily living.

So there's a lot of people waiting for those thought leaders to change their mind. That's why you can read ahead, and I can, patients do all the time.

And they wonder, why is the doctor stuck? Well, they're waiting for a thought leader to change their mind and be open to it. So I'm hoping that the next generation of doctors or healthcare providers, the nurse practitioners can look past that thought later to have a different thought letter or be more flexible or even have the freedom themselves to use judgment instead of just waiting a for thought.

Yeah, I think that one of the most important things that I learned in my training to become a physician is how to think, you know, how do you be a critical thinker, look at studies, read things, apply that to the person sitting in front of you, and it's a little disheartening when a lot of A lot of things going on in medicine these days is more cookie-cutter, and it's like, well, it is like a decision tree.

If there's this, do that. And if there is that, then do this. There is no more learning and applying the knowledge and the emerging evidence that's coming out and looking at that particular patient in front of you and figuring out that complex puzzle of what's going.

Well, when I went to the University of Minnesota to medical school and learned an awful lot of facts and directions and focus, much of it still was based on a thought leader, like what the rheumatologist said to do with these situations, what that medical resident said do.

Persistent Infection vs Post-Treatment Syndrome

And so when went I to graduate school at the university of minnesota in epidemiology. That's turned into the thinking part. You know, Madison introduced me to what are trials, how do you evaluate trials?

How do, you know to take care of biases and how you interpret research when it's never completely clear. And so that foundation helped me with geriatrics, but then it helped with understanding.

my patients and the literature. And so that's that questioning authority. The other thing is that just having the nerve to question authority isn't everybody's DNA.

It might be, but it's just not necessarily so easy to do the DNA when you have medical bills to pay. You got insurances to pay, you got medical boards, and you've got all these other things.

And so, how do you, if those other years aren't helping much, How do yourself say, Hey, my patients are first. I have to do something where my patient, I had to read and it's so clear cut out to something.

and I'm going to follow up my patience anyway. stick with them until they get better. But ultimately they're my task, what I Yeah. So in your opinion, when it comes to chronic Lyme being an active infection versus being a cluster of symptoms, right?

That is, that are left over from having an act of infection that has been, you know, complete or completely treated or eradicated. What, what do you think about that controversy?

Like how much of chronic lyme is active, infection, versus ramifications of having a long-term infection? Well, I'm more on the side of that's a persistent active infection that hasn't been resolved.

Others disagree. So just want to talk about semantics for a second, because the group that says chronic Lyme disease doesn't exist for years, that was their mantra.

post-treatment Lyme disease syndrome. And so it ended as a syndrome and it's post treatment is once you have three or four weeks of antibiotics, that's about it.

So even though they grant the literature that yes, it could be a persistent infection is that most of the doctors I ran into are saying, well, post treating must mean it is over.

It's a syndrom, its over and so other than approaching as immune issues, then there's quite a few doctors who grant finally there is issues as long as you're willing to say they're not going to treat because they are assuming its damage done.

I find that it's so common to take that person, no matter how many months and how may years they've been sick, and look a second time. Sometimes it is going longer on duct cyclone because the persistent theory said, well, they're not really resistant, but they are just persistent.

The persistent is based on tuberculosis research. Then there is no nothing there about the bees, you have a parasite that requires a totally different treatment.

And the whole Bartonella issue is showing up in the people who have Lyme, and that isn't even worked out exactly as to what is the role of Bartronella because it's in a cat, or at least the mites on a, on cat and the poo of the mights of a the cat.

Where is that role? And so to be saying, dismissing these important topics so quickly, I find personally in my practice that handling that as persistent infection works for most patients.

I do intravenous antibiotics if they need to, but most of the time I never get there. I hardly ever get to intravenous now that I take a broader approach and include Babesia treatment.

Also, I'd take broader approaches and take slower dose rather than always muscling through at the high dose. I do a lot more counseling. You know, if I don't sit there and write a prescription, then I have to engage them, find out how they've been beaten up.

what they've said, how their fears, the conflicts in the family. Sometimes you'll get a mom and dad and a kid right there and they all have different opinions and how do you engage them?

And also with the flare-ups that people get, you know, their parent might see something, but the kids, as long as they have any flare ups, are pretty frustrated and so how you get to control over the situation?

And I find that helps a lot rather than just relying on a prescription. That takes some time, but usually if I get control over it, it's much quicker and easier than one thinks.

If you just take them very methodically, take it on. Yeah, I think it is big just to have a physician who will listen and who'll validate how they're feeling and validate that what they are experiencing is real and it isn't in their head.

you know, and validating it for the family members because I know a lot of times it's actually the close immediate family that just doesn't get it and doesn t understand.

So I think counseling with the entire family is invaluable. Yeah, you captured that very well, that dialogue, the engagement. Sometimes that the family, one of the members is more resistant to lime and it's hard for that kid or that 30 year old to try to get better when there's such opposition in their own house and their on the roof.

at their own blood and they're thinking, well, how do I, I can't get a consensus here, but I got to do something. I cannot stay sick for this long. So that's why I come back to the persistent theory works for so many patients.

Now if they fail, then I go a certain length of time and while I'm working with them, making sure they don't overlook another specialist that can see what's going on.

But failure, are you surprised how I don' have near as many failures as I would think? I certainly have people that are wrecks. I have people that are in between, they're not all wrecked.

They're sick from what I would think is sick, but they are not quite as sick as they perceive what they hear from other people. they've just gotten so moderately ill for so long that they kind of accepted that that's just sick.

You know, there are 52 in there. I guess I'll just coast from here. It's, I only got 48 years left or whatever it is, is I'm just going to live with that and accept that until you realize, listen, you shouldn't give up and, uh, accept, that that's your lot in life.

You have to take charge again, get this under control. Yeah. I can't tell you how many patients have come in and said, you know, I've been told this is just what it's like to get old.

Like, in your late 40s and early 50s. You know? I mean, i'll argue even in you 70s or 80s, like, it is not normal to feel that way. It's not just life.

We had an 80-year-old this week that had been to quite a few doctors, but it only took two months and she's already well on her way to recovery.

Family Counseling, Hope, and Patient Outcomes

And so she was thinking, well, she knew there were doctors in the family that that shouldn't be, you shouldn' give up at 80 either. But she shocked and pleasantly surprised that what could have been sort of like a, a sentence, long stretch turned around so quickly.

Now we still got to work together to try to get the bottom, It's great, it's so satisfying to be in practice and take somebody like that on and turn their life around.

That standard one and done treatment course of four weeks didn't work. This one happened to have abesia, which is, they never acutely sick like you do where you see the parasites in the red cells.

But that was the trick. She had been on plenty of treatments, but never that part. I'm sure you see it all the time, the blessings when you get somebody better who is lost in the system.

Yeah, it's absolutely amazing. I honestly don't think there's any better feeling than knowing that you've truly helped someone and literally changed the course and the outcome of their life, no matter how old they are.

So Dr. Cameron, how do you think these controversies in treatment specifically impact patient care and their outcomes? Well, I think that my biggest concern with patients is delays.

Months and years can go by. And so part of it is that who wants to be sick, that sick with that many symptoms and having trouble working for that long.

So just the morbidity, the suffering, the despair, the family dynamics that is destructive, just delays alone. Then when you finally get treated, it gets more challenging if you wait months to years.

But even then, even though I said it's rewarding and so many people get better anyway, is it a process of how do you get more and more patients to accept that there is hope and that the persistent infection theory, if that's the correct one for them, that can turn things around quicker than they think.

It's been an ongoing theme of the summit, right? This, like, don't give up hope, there's hope. Have hope and really just what having that hope does with mindset and how having not just a positive mindset, but, you know, the whole mindset piece, how that feeds into the physiology of body, and the ability to actually recover your immune system.

Yeah, so I'm on the same page as your panel, which is great that we're all coming to a consensus on one of the core themes, you know, hope. I talk about that all the time.

So are there any steps being taken to address these controversies? I mean, obviously being a member of iLADS, going to iLADS annual meetings, staying up to date on all of this information.

But I, mean you, know it's a small select group of medical practitioners that go to ILADS, I would argue, out of all of the medical professionals, even just in our country, that even know what ILAdS is.

Like, what can we do? What can be done? what is being done to address all this division? Well, as long as the ILads exist, and as well as doctors who are treating are out there talking, there's There's a gradual shift.

Right now, the media almost always gives at least a balanced story about Lyme instead of being dismissive or negative. It brings the dialogue up to a better level, higher level.

I think that the social media brings more of understanding of Lyne to the reader than we were used to in the past. And what I've been doing is I have been involved in the social media lately, instead of the just guidelines and being president of ILADS, which is great.

But now I'm more focusing on how do you get some movement through the Social Media, through TikTok, Instagram, and YouTube. How do get more people shifted to asking the right questions, to knowing there are doctors, there's nurse practitioners out, There's other professionals out there.

they're out there. Oftentimes they have trouble finding what they can find them eventually. But how do you get the people to have interest and understanding at a higher level quicker, I think will help.

And it's also easier to treat if you take on a persistent infection earlier. Yeah, absolutely. I think spreading more awareness about what does and doesn't happen more importantly, right, when you have that acute infection, because I thing so many people are still under the misunderstanding that they're going to see this rash, this bull's-eye rash if they have Lyme disease.

And obviously, you know, that happens in under 40% of patients, and then you're not going get a bulls-eyes rash. If you one of these co-infections that we've been talking about.

So I think combating that misinformation right up front, which I Think social media, a lot of doctors on social Media, yourself included, do a really good job with that.

And I've had patients come to me that have seen someone's post on Social Media and said, you know, I figured this out because I saw X, Y, and Z. I had two patients Come to Me with PANS who had underlying tick-borne disease that came to their own diagnosis of Pans by watching various social-media posts.

Yeah, so that's more immediate in their face where they get to at least start the process of learning. And I think that my suspicion is that there are clinicians out there who have patients that they take care of where, they watch social media sometimes also.

Reducing Delays and Building Awareness

And I wouldn't be surprised if once in a while they might see something of interest for their family member. And so all of my work is partly to raise the bar up for a dialogue and a discussion.

It just happens to be something not as scientific as more of just communication and awareness of what's going on

with Lyme, that people can engage personally by themselves to start the process of understanding Lyne disease.

Yeah, that's great. So what would you say would be your top three pieces of advice when it comes to vector-borne disease for our listeners, for patients out there that are listening that think they may have one of these infections or know that they do?

Well, I think the most important thing is to cut out the delays. You know, even if doctors say it's not a problem, or at least be aware that Lyme is such a common problem.

It's so pervasive that if you can cut off delays, you shouldn't suffer so long and you'll increase your chances of getting better with pills and more quickly.

The second thing, is that just being aware, that there are doctors out there that and nurse practitioners and other providers who are who are out there fighting the same battle as you're fighting and I'm fighting in this seminar series.

There's out-there fighting, and discussing things, just be aware they're out, they don't feel like they are not there. And I think lastly, keep reading because there's a fair amount of science out here, there are a lot more publications out and there is a more available.

You're not all alone. and trying to understand Lyme is that it is, that hope that they're going to find some breakthroughs is still there. And so I would, I'd love to read it.

I continue to be a lifelong learner and I'm sure you're fine and you got plenty of things to learn along with me. and i think that's a hope, That way is also helpful.

Yeah, definitely. I think it's important to never stop learning, for sure. So Dr. Cameron, let our listeners know how and where they can reach you, if they would like to become a patient, and if you have anything new coming out or coming up that you would people to be aware of.

Well, I'm practicing in Mount Kistle, New York, which is about an hour north of Manhattan for 36 years. Same town, same place. My number is 914-666. 4665, and my email is info at DanielCameronMD.com.

That makes sense because my website is Daniel Cameron MD, so that's why it's info. DanielCamerronMd. Com. And lastly, I'm showing up in social media because I've put out 800 posts since March.

You could tell that I am having a lot of fun and a new direction, new focus. Part of my life is one-on-one with patients and the other part is taking on social media, the communication at a broader level.

And so I might be turning 70, but I'm having a good time. It's obvious that you're having good times. I told you the first time I met you, I love your social medias.

So tell our listeners, what is your Instagram handle? I think it's DrDanielCameron. My YouTube is Dr Daniel Cameron or the MD at the end. And my tip talk is thalime underscore doc.

Thaline underscore Doc. I know, I guess one more thing is I'm having a fun project this past couple of weeks is that because people see one post at once, maybe two, is, that I took the top 400 posts from the year and put them in a picture book.

It's going to be an ebook, picture book that I'll have on my website quite soon. I'm actually looking for a few people who can, who are going read an advanced copy and give me feedback because it's, and as soon as you click on any of the pages, you go right to the YouTube video, but you can look at all of them, pick out which one.

Where to Find Dr. Cameron and Closing Remarks

But I've clustered them into like. You know, frustrations, the symptom patterns, difficulty working, all kinds of issues. So it's, I'm trying to take new beginners that are learning Lime through one post and saying, well, how can you look at four posts and get a better feel for Limes through a social media style rather than publication from PubMed?

That is a great idea. So that's, that'd be out soon, but I'm having people read so that if you have an interest, let me know and I'll send you an advance copy.

Yeah, I'd love to send it my way. Absolutely. I will send that personally to you too. So you can see where I am at. And I haven't seen any picture book like that, where you look at forwarded posts.

Me neither. Did you come up with that? Yeah. That's great. All right. Well, thank you so much for taking the time to discuss all of this with our listeners and with myself.

I sincerely appreciate it. And to all our of listeners, Thank you for joining us. I truly hope that this helps you on your path to healing Lyme. We'll see you at the next episode.

Thank you for having such a wonderful interview. If this episode gave you an answer, brought you new insight or made you think differently, subscribe to the Lime Bites podcast and share with someone who's ready to take control of their healing journey.

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