Introduction to Lyme Treatment Controversies

Welcome to another episode of the Healing Lyme Summit. I'm your host, Dr. Myriah Hinchey. 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 Lyme 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 Lyme 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 Lyme disease." He's the host of the podcast Inside Lyme, and he has a private practice in Mt. Kisco, New York.

Welcome, Dr. Cameron. Please tell our audience how you became or why you became 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. I grew up with a lot of elderly people that were integrated, and as soon as I left an Alzheimer's practice and 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 a nursing home that I was aware of.

And those three patients, I had a lot of time in my first year and in practice to get to know them, the treatments that were out at the time, which is mainly just doxycycline, wasn't working so well and I was making progress.

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

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

How Dr. Cameron Became a Lyme Specialist

And so it was more of that awareness through my genetic training that I had a better sense of the cognitive issues. Oh, okay. I feel apathy 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. And so that I have to pull back and say, well, you're only 52. You can't be thinking of dementia now.

You know, there's a lot of other issues involved. So I thought that foundation and on the farm with with the people I took care of in my family and in geriatrics, all of a sudden is that I had some unique insight.

And also I had a master's in public health and epidemiology. And so I had sort of a coalition of a lot of things that

just allowed me to take those three patients and 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 that happen farther down the road?

No, it happened pretty quickly because there were very few people in 1987 that worked with Lyme. Dr. Bruce Garner was out there, a few others. Dr. Lehner had just started practice in the same area, at the same hospital, and after three years of work in the field, the New England Journal of Medicine article came out.

By Dr. Sijin in, Dr. Steer and and Kaplan, where they were saying the same things. So I thought, gosh, it wasn't just what I was saying, wasn't just a passing observation, but that's where they described the severe fatigue, poor memory, poor concentration, the lightheadedness which later on we realized that was sort of a part type problem.

The neuropsychiatric issues, which are like irritability was showing up. There was anger and rage, which we now know as kind of Lyme rage. We know that some of the co-infections can cause a lot of anger and irritability.

Even suicidal issues were showing up in Dr. Brown, Phil's practice. And so it went on and on. There's a broad range of issues that were published. And and I thought, boy, that was going to there's going to be a whole team working on how to do how to do something with lyme.

Now, there was nothing that paper about co-infections, but they were us finding that if you treated for two weeks of intravenous subtraction, that two thirds improved.

They did say there was a problem because a third relapse and some of them failed treatment. And they even had the the insight that they weren't sure they were eradicating the organism at that time with those two weeks of IV.

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

And so I was already seeing people that were sick for years. And for me to see a validation in a published paper of what I was seeing, the symptoms I was seeing is that that I joined the the community of people working with Lyme.

And there was diversity, but it was certainly a good start, good foundation, the pilot back on. Yeah. So where do you think the big divide came from? Oh, 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 that chronic Lyme disease came up, it shook the foundations.

You know, Dr. Steere, who discovered acute Lyme or at least wrote the first papers on a cute Lyme, was part of that chronic neurologic Lyme paper. And so I thought that would be the opening for everyone to come on board.

But no, it's seem to be people that went down the line of it's got to be acute. You can't there's no such thing as chronic Lyme that came out in a in a paper published the a guideline published that broke Lyme 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, no such thing. And they're not they're not sick sort of divided the community and declared that there was a big division.

Origins of the Chronic Lyme Divide

And so there was 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 were going to make tests that were harder to get a positive test on and they were going to make every step of the way difficult.

And so a lot of my colleagues that I worked with stuck it out and continued to work in the chronic issues. You know, they they didn't like the word Lyme disease, but they they didn't realize that it papers that chronic neurologic line and so they there was this fight over semantics over words over language over five out of ten Western blot bands and there was more discussion and fighting and arguing over that.

Then what I do with my patient, that's what I want. What's what? What do I see? What do I do? From where I started in 1987? I'm still focusing in on what my patients need, not on the on the semantics.

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

You know, somebody like I'm an internist, somebody who's been sick with diabetes or or high cholesterol and 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. They function poor, they're in pain. They they have failed like a standard three week or four week antibiotic.

And it's a pretty intense time. And and so many co-infections have been discovered so much so many different approaches have emerged that it's you know, some doctors are unsure where to begin and some patients aren't where we're again.

So it's a it's it's the question I always work on is how can we tone down and get focused and get on the patient care instead of the you know, instead of like getting caught up in in controversy, you know, 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 and Well, where are you now?

I'll beat up the are you what can we do to try to straighten out not the present infection, but all the baggage and conflicts and problems and and and war that you've been seeing and living through.

And that's a challenge for doctors. Yeah. And I agree. I think you know really what I mean. You know I came 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, you know.

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, you know, they they don't understand, you know, why does the Infectious Disease Society say, you know, that chronic Lyme doesn't exist and that, you know, depending on which doctor you talk to, X amount of days of doxy cycling, you know, is going to basically cure you.

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

Yeah. I think, you know, with with the standard of care, which was not to treat or not to do much for treatment is that that's what led to me and to work with adds 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 that it persistent infection is a big problem.

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

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

Yeah.

Why Lyme Treatment Remains Controversial

So do you think that part of this divide like especially with the infectious disease society like is it just like not is it the lack of knowledge? Is it the not wanting to deal with this whole sort of like can of worms and this complex patient or like is there some political or other underlying reason?

Good question there in in my area, I, 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 that are already misdirected, changing direction and going and picking maybe the headaches or maybe the parts, you know, for maybe the cardiologists, they'll very quickly make a referral for a piece of the problem.

And the patient wants to get past multiple specialists, multiple referrals to, well, what is it all mean? How do I begin this issue? And so you 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 the acute line, that's fine. If you end up with any chronic issues or neuropsychologist, any of these that that we're talking about it very quickly, they see it.

They know what's out there, what could be done. But it's you know, it's it's almost like it's too hard a subject politically to out of subject to go there.

And so even though they might be trained, they've gone to good medical schools. They have experience that one topic they'd rather go off and the fibromyalgia chronic fatigue or a chronic Byron viral syndrome or without any psychic training, just say, well I think you have psychiatric problems.

You know, first when they go to a psychiatrist, they're not sure that they don't often don't think that's the issue. You know, it may be tough to be sick.

You know, there's 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 get start getting better, there's work to be done to get your health back in, your wellness, your function back.

And it takes a lot of counseling, I find, to if somebody is that sick to get them back to health and wellness and to get get over this crisis. Yeah, it's it's a lot of work and usually it entails an entire, you know, holistic treatment plan with everything from addressing the autonomic nervous system and mindset and obviously the infections.

But you know, everything else that the infections have done to the terrain of the person's body and all of the systems and the organs in the body. So do you think now that the 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 Lyme disease and lists of infections that led to chronic symptoms. So they were very careful in how they wrote it. Not chronic infection, chronic symptom symptoms.

Right. So when you look at this site, you know, people readers want to like look at, well, what what happened? So they gave an example, which is that it could be an immune response to the line infection they didn't mention that could also be a persistent infection.

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

Hmm. Okay. So in an acute case, what do you think the reflux potency is to 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.

You know, one dose of doxy at the time of a tick bite is going to stop you from getting Lyme disease or 14 days of doxycycline is sufficient. Like I guess I understand, right?

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 line and for early line or they might even have chronic issues, but they take on an early Lyme approach.

So they're very limited in what they do.

Acute Lyme, Testing, and Early Treatment

So let me address that first tick bite issue, is that this study that's about 20 years old was able to show that two doctors taking pills, a one time dose, could prevent rashes.

They weren't able to show that it prevented any other manifestation of Lyme. They didn't look at chronic neurologic issues. This is autonomic. This is all I could show was you could prevent a rash, which is not the main point anyway.

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

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

You know, they didn't want to declare was lying because it's a somewhat of a clinical judgment. So I was frustrated that and I still opposed to a single dose of doxycycline 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 Lyme, acute Lyme with the rest. And the reason I put four is then I make sure I have a follow up because I needed to determine how they respond to the treatment.

Sometimes I'll present with the chronic issues, recurrent issues, or even the sweats of a visa. And so there's so much diversity. And 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 what's important part of the Lyme is, is that follow up visit, if physicians, everybody follows hypertension endlessly. But with Lyme, you don't get patients who are following up.

They might get a phone call from the office saying the tests are negative. But the real job in medicine where it comes alive is that one on one clinical exam right in your face, discussing where you're at, where are you going to Some of these patients say, Oh, I think I'm okay.

And then they just go on and and months, two 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 so many people with BRCA in the area that a doctor is always right, you know, productions like and that doesn't do a thing for babies. You.

So I find that I'm on the lookout for a busier at the beginning, mostly looking at it for four weeks. I don't trust the baby the test because the visitors 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 that's a cycle and something for really at the same time, day one might actually be better than just hoping for the best and letting a patient have and have the risks of a chronic illness.

So I don't think that the protocols of doctor cycling is a 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.

So I'm more flexible and done and then more flexible and use that as like on dioxide and takes care of quite a few things but it doesn't do but anything probably easier.

Right? So are you talking about doing like a Tovah clone and is that for myosin or something like that with the bees? Yeah. And then how would you cover like do you think it's a three myosin is sufficient for your Lyme as well.

Yeah. I mean without getting into specifics, although I'm asking you specifics, sorry, but I. Think I would want to address that just a second. The sometimes if I want to treat from easier right away because it sweats they can't catch their breath and and I think that I better at the easier treatment but yet I want to kill it I want to do something for anaplasmosis.

Or. Look, I need Dr. Zeitlin, so I will sometimes wave the zithromax. Take the doxycycline with that would be the treatment, you know. And then I can always add as as much later, because the original study only picked Zithromax, they didn't say what was the best.

They just said this worked. Okay, but not always married. Only two to Zithromax. And when it comes to a visa, a treatment with the protocol, and 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 the Maron, which is 250 milligrams.

And so instead of always muscling to the highest dose, that often does the trick. And then for people who are really fragile where they're hurt, some reactions are that are possible, then I will often start with the pediatric dose, which is 62.5, and 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 and make a decision later on what the response is.

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

Co-Infections, Dosing, and Treatment Strategy

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

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

So I think with patients, does that that so much to read. Now. You know what what I find is a lot of patients read much when they know about Lyme and that they've been diagnosed.

My concern is all the ones who who have been lost in the system who are been told it's not Lyme or that Lyme doesn't exist in a chronic form. And so I a lot of my work is is trying to target those who haven't even started reading once they read the A, 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, haven't taken on the system, haven't read, haven't realized that to do something they've gotten lost in some of the diagnosis like related to a virus or play around with chronic fatigue or totally a mess or something else.

And I'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 they don't have is Lyme because they've been tested for it like 20 times.

And like, that should tell you something. If you've been to all these different experts and they've all thought to test you for Lyme, clinically, you're presenting as Lyme, you know?

Yeah, that's why I said that doctors know much more about Lyme can see it coming and so they don't want to touch that subject. At least it appears that they don't touch that subject.

So very quickly they'll steer the conversation and in other areas. And so you, you have you can get lost in the system very quickly. And I see that all the time.

And 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, 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 line and want to hear that. It's very hard to question an authority answer.

It's almost like a politician. The look in your eyes and say, listen, it's not like that's all I know. And so that often slows down the process, the delays, treatment and then months pass before they get back and realize, oh, maybe that was the problem in the first place.

Right. 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 do with the test tube work in the mice.

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

And so, you know, it may be useful for someone who's failed some of the other treatments, but I hate to be going to intravenous first or second or third.

I'd rather address and other issues. There are some other great research on biofilms, you know, which you know, the biofilms are from staphylococcal streptococcal infections, but they're certainly difficult to find.

Clear cases that you can study in people you can certainly set in a test tube and even persistence, I think I like that theory that is and there's some infection that's in the tissue, that's in the body that's not resistant.

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

So I usually figure that instead of jump into the, the latest, latest thing is that you have to start somewhere with something they can tolerate oral if I, if I can and then build from there.

But a lot of times when you read ahead, you read and you know everything that's ever been known about biofilms and persistence and you never get there because you get better with a simpler strategy.

And so I tell people and doesn't hurt to know all those things. You just mean never need to know those things. Just it's but keep reading. It's a great challenge to understand what's going on with Lyme.

And I would co-infections. Yeah, I would say there's a vast majority of patients that know just as much, if not more than than than most doctors out there regarding treating Lyme disease.

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

And in fact, I have it, you know, for 36 years I haven't operated filed that theory that chronic Lyme doesn't exist. There's nothing more expensive than living.

So there's a lot of people waiting for their thought leaders to to change their mind. So that's why you can read ahead. I can read that patient, too, 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 to it.

Navigating Conflicting Advice and Patient Advocacy

So I'm hoping that the next generation of doctors or health care providers that nurse practitioners can look past that thought leader to have a different thought leader or be more flexible or even have the freedom themselves to use judgment instead of just waiting for a thought leader.

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 to be a critical thinker, how to look at studies, how to read things, how to apply that right to the person sitting in front of you.

And it's a little disheartening, you know, when a lot of a lot of things going on in medicine these days, it's more cookie cutter and it's like, well, it's like a decision tree.

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

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

And so when I went to graduate school at the University of Minnesota in epidemiology, that turned into the thinking part. You know, medicine introduced me to what are trials, how do you evaluate trials?

How do you know, take your biases and how do you interpret research? One is never completely, never completely clear. And so that foundation helped me with geriatrics.

But then it helped me with with understanding my patients and the literature. And so that that questioning authority. The other thing is that just having the nerve to question authority isn't in 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, the chances to pay the medical board, you get all these other things.

And so and how do you if the lawyers aren't helping much, how do you yourself say, hey, my patients are first, I have to do something where my patient, I have to read and it's so clear cut, I have to do something and I'm going to pilot up my patient anyway.

I'm going to stick with them until they get better. I'm going to send them to specialists. But ultimately, they they're my task, what I have to do. 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 active infection that has been, you know, complete or completely treated or eradicated.

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.

It's a persistent active infection that hasn't been resolved. Others disagree. So just want to talk about semantics for a second. There's the group that says black Lyme disease doesn't exist for years.

With that was their mantra. So somebody came along and says, why do we call post-treatment Lyme disease syndrome? And so it's ended as a syndrome and it's post-treatment as once you had three or four weeks of antibiotics, that's about it.

And so even though they grant in the literature that, yes, it could be a persistent infection, is that most of the doctors I went to are saying, well, post-treatment must mean it's over as a syndrome.

It's all over. And so other than approaching is immune issues, then there's quite a few doctors who agree that finally there is issues. As long as they're willing to, as long as you're willing to say they're not going to treat because they're assuming it's damage done, I find that it's so common to take that person no matter how many months and how many years they've been sick and look a certain time.

Sometimes it's going longer in that segment, as the persisted theory said, well, they're not really resistant. They're just persistent. The persisted the resistance theory was based on tuberculosis research.

Then there is no nothing there about the BS. But this is a parasite that requires a totally different treatment. And the whole Bartonella issue is is showing up in the people that have Lyme and that is being worked out exactly as to what is the role of a bartonella because it's in a cat or at least a to a cat and the poo of the mites of the cat.

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

I do intravenous antibiotics if they need to, but most of them never get there, hardly ever get the intravenous. Now that I take a broader approach and include but easier treatment also I take a broader approach and take a lower dose rather than always muscling through at a high dose.

I do a lot more counseling. You know, I don't sit there and write a prescription. I have to engage them, find out how they're being beaten up and what what, what they've said, how their fears, the conflicts in the family.

Sometimes you 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, the you know, the parent might see something, but the kids, as long as it any flare ups are pretty frustrated.

And so how do you get 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.

Persistent Infection vs Post-Treatment Syndrome

If you just take them very methodically, take it hard. Yeah, I think it's big just to have a physician who will listen and who will validate how they're feeling and validate, you know, that what their experience saying is real and it's not 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 dialog, that engagement sometimes that the family one of the family members is more resistant to Lyme and it's hard for that kid or that 30 year old to try to get better when there's that opposition in their own house, under their own roof, that their own blood.

And they're thinking, well, how do I, I can't I can't get a consensus here, but I got to do something. I can't say that for this long and I got to do something.

So that's why I come back to the persistent theory works for so many patients. Now, if they fail, then they go a certain length of time, and while I'm working with them, I'm making sure that they don't overlook another specialist that can see what's going on.

It's a it's but failure is suppressed. I don't have near as many parents as I would think. I certainly have people that are wrecks. Yeah. People that are in between.

They're not all wrecks that sometimes they're, they're in between. They're sick from what I would think is sick, but they're not, they're not quite as sick as they perceive what they hear from other people.

They just gotten so so, you know, moderately ill for so long that they've kind of accepted that that just sick, you know, they're 52 and they're think I guess I'll just coast from here.

You know, it's I only got 48 years left or whatever it is. I'm just going to live with that and accept that until you realize this, you shouldn't give up and 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 at like, you know, in your late forties and early fifties, you know I mean I'll argue even in your seventies or eighties, like it's not normal to feel that way.

You know it's no it's just life. You had an idea all this week that was I 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, well, she knew there were doctors in the family that that shouldn't be you shouldn't give up at 80 either. But she was shocked and pleasantly surprised that what could have been sort of like a, you know, a sentence long stretch turned around so quickly.

Now we still got to work together to try to get to the bottom. But it's great. It's so satisfying to be in practice and take somebody like that on and turn that life around. That that started one one and done treatment course of four weeks didn't work.

This one happened to have a BS year, which is. But they never acutely sick like you do where you see the the parasites in the red cells but that was the trick.

She had been on plenty of treatments but never a never that part. So that it's one of our trees it all the time that the blessings when you get somebody better who was lost in the system.

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

Yeah. So, Dr. Cameron, how do you think these controversies in treatment specifically impact like 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's sick with that many symptoms and having trouble working for that long.

So just the mere morbidity, the suffering, the the despair, the family dynamics that are destructive, just delays that alone. Then when you finally get treated, it's, you know, gets more challenging if you went months or years.

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

Yeah. It's been an ongoing theme of this 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, you know, how that feeds into the physiology of the body right and the ability to actually recover your immune system.

Yeah, So I'm on the same page as your panel, which is that 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.

Yeah. So are there any steps being taken to address these controversies? I mean, obviously being a member of islands going to islands, 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 islands.

Impact on Patients and the Importance of Hope

I would argue out of all of the medical professionals, even just in our country, that even know what islands is like, what can we do, what can be done, what is being done to address all of this division?

Well, I think as long as the islands exist and as long as doctors who are treating are out there talking, there's there's a gradual shift like right out of the media, almost always gives at least a balanced story about Lyme instead of being dismissive or negative so that it gets it brings a dialog up to a better level, higher level.

I think that the social media brings more understanding of Lyme to to to the reader than than we what we're used to in the past. So and what I've been doing as I've been involved in the social media lately, instead of the just guidelines and being president of islands, which is great.

But now I've been more focusing on how do you get some movement through the social media, through Tik-Tok, Instagram and YouTube? How do you how do you get more people shifted to asking the right questions to knowing their doctors?

There's nurse practitioners out. There's other professionals out there. You know, they're they're out there oftentimes they're they have trouble finding, but they can find them eventually.

But how do you get people to have an interest and understanding at a higher level quicker, I think will help. And it's also easier to treat if you, you know, take on a position infection earlier.

Yeah, absolutely. I think spreading more awareness about what does and doesn't happen more importantly, right when you have acute infection because I think so many people are still under the misunderstanding that they're going to see this rash, this bull 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 to get a bull's eye rash if you have one of these coinfection points 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've had two patients come to me with patients who had underlying tick borne disease that came to their own diagnosis of patterns by watching various social media posts.

Yeah, so that's more immediate in their face where they get these that the process of learning. And 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.

And I wouldn't be surprised that once in a while they might see something of interest for their family member. And so all my work is partly to raise the bar up for a dialog and a discussion that just happens to be something that not as scientific as more just communication and awareness of what's going on with with Lyme in that people can engage, you know, personally by themselves to start the process of understanding Lyme disease.

Yeah, that's great. So what would you say would be your top three pieces advice when it comes to vector borne disease? You know, 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 a loss, at least be aware that Lyme is such a common problem, so pervasive that if you can cut out delays, you shouldn't sufferers along and you'll increase your chances of getting better with pills and more quickly.

Social Media, Awareness, and Final Advice

The second thing is that just being aware that there are doctors out there that nurse practitioners and other providers who are out there fighting the same battle as you're fighting and fighting.

And and there's a there is there's out there fighting and discussing things and just be aware they're out there. Don't feel like they're there. They're not there.

And I think lastly, just just keep reading because there's a fair amount of science out there. There's lot more publications out there, there's a lot more available. You're not all alone.

And and trying to understand Lyme is that it is that hope that they're going to find some breakthroughs is still is still there. And so I would I love to read that I continue to be a lifelong learner and I'm sure you're fine and you've got plenty of things to learn along with me.

And I think that 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 any anything new coming out or coming up that you would like people to be aware of.

Oh, well, I'm practicing in Mt. Kisco, New York, which is about an hour north of Manhattan for 36 years, same town, same place. I then or my number is 914 666 4665 and my email is info@danielcameronmd.com.

That makes sense because my website is danielcameronmd.com. and so that's why it's info@danielcameronmd.com. And lastly, I'm showing up on social media because I put out posters since March and so it's you could tell that I'm having a lot of fun and and a new new direction in focus.

So part of my life is one on one with patients and the other part is, is taking on social media that communication at a broader level. And so I'm having I might be turning 70, but I'm having a good time.

And it's obvious that you're having a good time. I told you the first time I met you, I love your social media so tell our listeners what what is your Instagram handle?

I think it's @drdanielcameron. My YouTube is @danielcameronmd at the end and my Tiktok is thelyme_doc thelyme_doc and I don't like 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 post from the year and put them in a picture book. It's going to be an e-book picture book that I'll have my website quite soon.

I'm actually looking for a few people who can who can read an advance 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. But I clustered into like, you know, frustrations, the symptom patterns, the the difficulty working, all kinds of issues.

It's a it's I'm I'm trying to take new beginners that are learning Lyme through one post and saying, well, how can you look at foreign posts and get a better feel for Lyme through a social media style rather than publication from PubMed?

That is a great idea. So that's that's. Awesome. So that's that'll be out soon. But 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. I'll send a person or two so you can see where I'm at. And that's a I haven't seen any pitch book like that where you looking for reposting and.

I haven't either. Did you come up with that long post? Yeah. That's great. Yeah. All right. Well, thank you so much for taking the time to to discuss all of this with our listeners and with myself.

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

Thank you for having having such a wonderful interview.