Autoimmune Encephalitis & PANS/PANDAS - A Child Psychiatrist's Experience Transcript

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Introduction to PANS, PANDAS, and Autoimmune Encephalitis

Everyone. Welcome back to this episode of The Healing from Lyme Disease Summit. I'm Dr. Tom Moorcroft, and I'm so excited to be having this interview today and bringing to a near dear friend, Shannon Delaney, who is a medical doctor and an assistant professor of psychiatry at Columbia Medical Center.

And as you know, the people that I like to bring in to talk about this are folks that are on the front line of treating patients with tick borne illness, Lyme, Bartonella, Babesia, and all these other things, but also specifically Shan and I work together on a lot of we share some patients primarily focusing on patterns and pandas.

And what we're looking at, infection induced autoimmune encephalitis. I think there's a lot of misconception out there, and that's why we really wanted to have this conversation today.

And I think one of the cool parts is when I work with other people and I refer people out, I want to make sure that I'm sending you or your kiddo over to someone that I would trust to see someone in my own family or myself, but also someone who's diving so deep into the literature and has the clinical experience that when we work together, I'm learning new things.

And so with Dr. Delaney and I collaborating on a lot of different folks here, I've learned so many different things that I've been able to share with the physicians at our mentorship program, to share with my patients who may not be able to see her.

And it's really been revolutionary to think about the way people with autoimmune encephalitis may be presenting and even metabolizing and using medications in a different way than the standard population.

And this is such a misunderstood kind of conversation. So, Shannon, thanks for joining me. And I'm looking forward to a conversation about this. Yeah, thanks for having me today, Tom.

Great to be here. Yeah. So, I mean, just kind of a little bit of background mean what gets someone into like, you know, studying people with patterns and pandas and working with them?

I mean, is there like some big old back story here that really got you that, you know, passionate about this topic? There is actually a little bit of a back story.

So when I during my intern year, I think it was two back in 2009, it was right when the condition NMDA receptor antibody in South colitis was just being discovered.

And what was really cool about that condition is that here we had a very specific autoimmune condition that had a very specific pathophysiology to it and what was happening is that these patients typically were first presenting with psychiatric symptoms.

So something like 70 to 80% of the patients who have NMDA receptor antibody encephalitis present with psychosis. So I was very intrigued that because most of the psychiatric conditions, as you know, we have no idea really about the underlying neurobiology to the disease.

And so here's this condition where we specifically know that an autoantibody is targeting this and the receptor and producing psychiatric symptoms. So I was really interested in thinking, a, if we if we kind of understand this condition a bit better, we can understand psychiatric problems probably better.

But then also it got me thinking, what if there is this huge cohort or subset of patients out there who have psychosis or schizophrenia and they're like their whole lives.

They're they're told that they have schizophrenia and they're in a psychiatric hospital and they actually may have this auto immune disease, which would amount to a completely different treatment pathway, instead of giving them traditional psychiatric meds.

So I was very motivated when this condition was first discovered, and it is pretty fascinating that we're still learning about new medical conditions in this day and age.

So I actually was very interested in kind of so that was part of the thing that spurred my interest in research in this area. And then the other aspect was that from a clinical perspective, as psychiatrists in the field, whenever we so during our training and residency and also during fellowship, what would happen is that when we worked in the hospitals, we would serve as the consult liaison doctors so that somebody would come in with a complicated illness or potentially chronic illness and they would get the million dollar workup and everything would come back negative.

And the doctors often wouldn't know what to do with these patients because they needed to help them in some way. And so typically at the very end, they would call in the psychiatrist to see the family or the patients.

And you can imagine, like what the reaction is of the patient who's coming in with like left sided weakness. And now they have to talk to a psychiatrist about their problem.

How Dr. Delaney Became Interested in the Field

So they were never the patients were never happy seeing the psychiatrist, but we would have to go as the psychiatric team and evaluate this patient. So I found myself both in residency and then in child psychiatry fellowship.

After hearing the patient's story, I would be very compelled and I would definitely think that there was some underlying medical cause going on. But oftentimes the attending psychiatrist would take more of a psychoanalytical approach to the problem, and they would, you know, sometimes it was honestly very ridiculous.

They would say, whoa, that move from seven years ago is definitely like contributing to why you're having these sudden onset like new medical symptoms.

So basically they would kind of diagnose a conversion disorder type illness and a patient who's having active medical symptoms. And it just was not logical to me.

So I would get very frustrated with seeing that. And I felt like I was always on the side of the patients being like, No, no, there's a medical problem here.

And we just don't have like the right answers and we just, you know, from a scientific perspective, there are so many unknowns and that's why we need to do more research.

So I think both of those things coming together, the discovery of NMDA receptor antibody encephalitis and then my clinical experience that made me very passionate to sort of find out better answers for this patient population are the two things that motivated me.

Yeah, I mean, I think it's so interesting. It's so nice when you meet people who are really thinking about, hey, like what is and is there any identifiable medical condition underneath?

Because it's like, I always hate when it's like we're left of, you know, the, you know, just kind of like the fibromyalgia. We don't know just what is label you and then just that's okay.

And as you were talking, I'm like, wow. So almost like leading the witness here, you know, it's like, oh, so do you think it was that time in your life back?

That's what it felt like for me. Also, as the physician, it did not feel like a scientific approach to the problem. But I think in those circumstances, oftentimes the doctors who are taking care of these patients, it's very difficult for them to say like, listen, I don't know what's going on.

You know, we don't have answers for you. You know, it's interesting, as you say, that like I remember in residency, someone's like a family member said to me, you were the first doctor ever to say, I don't know.

Really? And they're like, We trust you. So what do we need to do next? Right? It's like amazing, right? That we're taught to, like, be gods or something, as if we know.

But like you said, 2009, I mean, it's crazy that we're just discovering something like, you know, I actually didn't know that. I thought that we had known that for like since before I was born, because it's just like to me, you know, the NMDA receptor encephalitis and like just seems like so obvious now, you know?

But anyway. But we've made so much progress in that domain now there's so many different autoantibodies that can cause autoimmune instabilities, and they're discovering more every year, which is pretty fascinating.

Yeah, that wasn't even a thing prior to that. So with this, I mean, I think for a lot of folks watching, I think they're kind of going to be somewhat aware of Pans, Pandas, right.

And this sort of what I like to call toxin induced autoimmune encephalitis and many other people, especially, I think, Dr. Charles Ray Jones is the one who really told us like to step back from the label of pediatric acute onset neuropsychiatric syndrome and say, hey, look, it's an infection induced autoimmune encephalitis or encephalopathy.

But from a broader perspective, what is sort of can you kind of like maybe generally define what this sort of autoimmune encephalitis type of thing is, just so people have a general understanding and then maybe zero in on a little bit of what patterns in pandas is and how they may be similar are different because I think I think there are some nuances here that will be really helpful for folks.

Well, I mean, I would love to kind of delve into some of those details. I mean, I wish honestly, I understood the condition a little bit better. Traditionally, autoimmune encephalitis, like the one I was referring to in terms of NMDA receptor antibody encephalitis typically presents with very significant neurological symptoms as well as psychiatric.

I mentioned that they're presenting symptoms are often psychiatric in the form of psychosis, but typically people who have straightforward autoimmune encephalitis will then develop seizures and they'll have very profound neurological impairments.

And so these are not subtle kind of findings like often times as the illness progresses, they're so sick that they end up in ICU, they're often, you know, on ventilation and things like that.

So, you know, that's that's not an illness presentation that people can ignore or doctors can ignore because they need they need help. And, you know, all of their organs are problematic at that point.

But the difficult thing with Pans Pandas is that most of the time and we do see neurological symptoms associated, but most of the time we see primarily psychiatric symptoms that are presenting as the most problematic.

So you can imagine that when we see a constellation of psychiatric symptoms that a lot of doctors will start questioning the underlying diagnosis. So that's one of the most difficult things for, in my opinion, as a as a practitioner and a provider in this space, is sometimes dealing with other colleagues who basically de-legitimize this illness because they look at these patients who present with new onset OCD or even psychosis or severe depression, suicidal ideation, even if they have underlying neurological problems like tics or other things like that,

the doctors often just dismiss it and think everything is entirely psychological in origin.

I mean, I think that's a challenge because it's like it's almost like if it looks psychiatric, it must just be psychiatric. Right? And it's like so I mean, it sounds like the, you know, the mainstream medical viewpoint is like it's got to be ultra severe, neurologic and and otherwise.

It's kind of like, you know, my frustration is always it's the all in your head situation, right? Or like with the food restriction, the acute food restriction, that can happen with pans.

I mean, like we just chalk it up to anorexia, you know, and you're like, I don't know, what do we do? I mean, like, how do you figure out the difference then?

I mean, is there any diagnostic, you know, testing that actually can help in this arena or are we just kind of left to try it out or. I mean, it is very frustrating.

I mean, just to speak to that, I had describe a negative interaction that I had with a colleague yesterday, just yesterday, about a patient that has a 12 year old patient of mine who has a clearcut history of Lyme disease in the past, presenting with numerous patterns type symptoms over the course of his illness.

And he presented with mania, emotional dysregulation, severe OCD tics. So this is kind of a classic patient that I will see who also has a history of Lyme disease.

And through throughout the years she had sort of discordant dated care where he went to a lot of different doctors.

Why PANS/PANDAS Is Often Misunderstood

So he briefly got some IVIG, briefly got antibiotic treatment, had some plasmapheresis and one of his doctors was concerned enough in the last week to tell them to go to the emergency room, which unfortunately is, you know, probably as a physician, that that can be one of the worst places for for patients to go to get help, even though you think that it should be one of the best places.

So this doctor ends up calling me up on my cell phone, basically to express his opinion that he felt as if this kid he said he was appalled and outraged by the treatment that this kid was getting.

He said it was a disservice to the kid and his family and so I started talking to him a bit more. And, you know, this like I mentioned, this kid had received IVIG and plasmapheresis.

And so I explained to him that in terms of treatment guidelines, when it comes to pans, pandas, if you encounter somebody who has severe moderate or severe degree disease, that's the guidelines specifically say that immunomodulatory treatment is part of the treatment plan.

And I explained to him that the conception of of doctors who are experts from multiple different disciplines have come together from multiple different institutions throughout the U. S.

to develop these guidelines. And he wasn't really willing to have a conversation with me. And in fact, he heard that and said that these doctors are whack jobs, quote unquote.

So it was a very difficult conversation to have because he was just calling me to kind of, you know, just give me all of these negative opinions. And there was no like two sided conversation to be had at that point.

And it was frustrating because the patient, the parents had reached out to me asking me about what testing that I would recommend because this kid was going to have to undergo a lumbar puncture.

And so I made the typical recommendations in terms of comprehensive Lyme disease testing and Bartonella testing and testing for autoimmune encephalitis panel and everything that we would normally do for a kid who's

presenting with very severe neuropsychiatric symptoms and then during the conversation, the doctor told me that he absolutely refused to do any of the Lyme disease testing because that's not what this kid has.

And the only thing he would test for was because this this child was on rare toxin. He would check to make sure that he doesn't have a fungal infection because of the medication that he's on.

But he refused to do any Lyme testing. So it's just incredibly sad from my perspective and quite frustrating because here is this family in complete crisis.

And, you know, over the course of years, they've been to multiple different doctors. You know, nothing has really helped properly. And it's a very difficult area for parents to navigate.

And so then they're caught between these two systems. They come to me and ask for advice and I tell them what I think needs to happen. And then they encounter this pediatric neurologist in the emergency room who's basically saying that all of these problems are psychological and there's no reason to even do a comprehensive medical workup.

You know, I mean, the frustration that I'm sure so many people listening have and I certainly have, like I'm just like taking a lot of deep breaths over here because, like, I feel like, you know, as we've talked in the past with a lot of people we work with, I mean, the medical community seems so closed minded.

And but but what I hear you saying is you're doing all the standard medical stuff. And because there's other new emerging research, which really isn't all that we're learning more.

But I mean, just to step back, the patient is working group. It's not like a bunch of schmucks in their basement. I mean, this is like, you know, Sue Sweden is like at the National Institute of Mental Health, like pediatric department.

There's people from Yale, Mass, General, Boston Children's, all these hospitals in Minnesota, all these places in California. These are big name, well-respected researchers.

I mean, Jim Lichtman's on there. I mean, these are not asses and these are not people whose credentials are being called into question. In fact, these are people who stand up at conferences and somebody says, oh, no, that's not the way it is.

And they're like, Oh, really? Have you looked at the research? Let me just rattle off 90 billion like since widow puts people in their place because they're so close minded.

And when I'm seeing a patient, I don't want to have to have that conversation. I think it's okay at a medical conference for doctors to debate. That's where that's one of the places we should debate.

But when you're saying, hey, I want to do all the right medical workup and also let's be open to this other possibility and just evaluate it. What's the problem with getting a test?

Because if the test is negative, great, but what if it's positive? And that's the scary part. They're closed off that you know. That was I felt like that was it was one thing for him to call me and just like spew his opinions, you know, despite me not even asking for them, but different.

So close minded as to say like no, I'm not doing it. Tests for this kid who's presenting like the sick kid who's presenting in front of him. It's just like I have such a difficult time with that.

And I think like, I'm sad because wouldn't you prefer it to be a treatable cause? I mean, this is like the thing I never understand. It's like, why? And the other part of it is, if you're an egomaniac, doctor, which there are a few of us out there, I may or may not be one of them.

I hope not. But. But, like, why wouldn't you just say, hey, I'm going to get the testing and prove you wrong rather

than go, Oh, let's screw that. Like, why wouldn't you be curious?

I mean, I think I've heard you talk about that a lot in the past. It's like it's the curiosity. And I'm so depressed, not really depressed, but I'm a little frustrated with the system that you and I work in.

That curiosity is kind of out the window. Isn't that why we got into this? We wanted to help people get better. That's what I thought. But I think he was sort of thinking that he was taking the moral high ground because he started talking about doctors in private practice who don't accept insurance and describing them as like predatory and basically saying that any of the doctors who prescribe this, these treatments to this kid were acting in a predatory fashion.

And so, you know, it's his job to sort of correct all of this. Oh. Yeah. It's a shame. I mean, I think that I mean, I think that collaboration and stepping back to say, hey, are we doing the right thing?

But it was like, I never heard you say it, like not doing it. And I think that that's what people misunderstand about a lot of us is like for me, if I were in the system because, you know, I'm sure that if, you know, they were talking about me, I'd run and I'd end up in that cat lumped in that category. But it's like we're not given enough time to see patients.

We're not being reimbursed for our time, the patients aren't getting their stuff covered, and all we're trying to do is get them better. And the number of kids I see, like I have a kid who was doing exceptionally well, she, you know, basically her hands on set, you know, was hallucination.

And, you know, suicidal ideation had been in the hospital after multiple suicide attempts. We started working together. She was doing great. All of a sudden, no more hospital visits, no more suicidal ideation, the whole nine yards.

But it was like 12 or 14 months later. The family just had a lot of things going on and they kind of fell off the wagon with treatment. And next thing you know, the kid's trying to kill herself again.

She's back in the E. R.. I talked to the doctor there and they're like, Oh, because I got a copy of their note that like Dr. Marco said, they were previously treated.

There's nothing more to do. It's psychiatric, which is totally not what the conversation was. And as of this conversation right now, today, this kid's been in a psych hospital for two and a half months and she's 14. Wow.

Challenges in Diagnosis and Medical Gaslighting

And I'm like, could you just try a little bit of antibiotic therapy and and or maybe call me one more time and be clear because it's like, I don't understand how to how it's appropriate to leave a child in a psych hospital.

And the other problem and so maybe because I mean, it's nice to have a rant, I think about these things because so if people know that it's not just the patients who are getting shit on, it's us too and the people who are willing to do this work.

And I do think there's probably predatory people. But I'll tell you, if you you know, how many people just tell you to get vaccinated for no reason and they don't know why.

They just were told this and they spoon feed it to you or get your Lipitor or whatever. So, I mean, it's this happens on all sides, right? I mean, do we really need a colonoscopy every 25 minutes?

Probably not. So. But I think more importantly is like I should have not distracted myself, but. Exactly what what area of the body are we on now. Yeah, right.

Or it's that. Well I think it's the heart and that's the part the doctors are missing. I mean, I think we're afraid to say

we don't know and but we're open to working on it.

I mean, when we look at these people, though, like I just, you know, feel like we need to step back and give them an opportunity to heal whatever that is.

So if you're seeing a kid with plans, what are kind of the general treatment approaches? Because I think one of the things that the other side, which I can't even believe we take sides in medicine but think is that we're withholding certain treatments in lieu of others.

But I mean, like if you were to look at a person depends what are the kind of general categories of of treatments they might expect to kind of have considered even like not even that they need.

But like, you know, are there groups of treatments that you might consider offering them or evaluating them for? Well, to be honest, I think that patients with pens, you know, they you have to have a very individual visualized approach with each patient, because even though it can be a similar constellation of symptoms, oftentimes I, I see very different like treatment algorithms working for different people.

And the frustrating thing when you're a provider trying to tease apart like what's actually happening with patterns also is that it can be triggered by a lot of different infectious, infectious triggers like we know.

So a patterns that's triggered by mycoplasma or strep can look very different than one that is triggered by Lyme disease and Bartonella in my experience.

So I think number one thing to do and approach that I have is to do a very comprehensive like initial evaluation, which involves getting a lot of, you know, laboratory data because I think the combination of getting a very comprehensive clinical history and combining that with the laboratory data does really you can go quite far in having a very thorough initial appointment.

But I've seen kids that like who are diagnosed fairly early with patients and can be put on a combination of, let's say a few months of antibiotics and vitamin D and fish oil and probiotics and do quite well and never have to go on antibiotics again.

I can see others that have a history of Lyme disease, for example, and maybe just got the initial treatment in the beginning and then had their initial sort of pans presentation maybe months or years down the road.

And once it becomes a chronic illness, that can be very, very difficult to treat in my in my experience. But so, so again, it's I can't say that I have a typical approach because I've seen patients there's such an individualized response to antibiotics as well with patients.

But I will say that a combination of antibiotics, herbs and for very severe patients, immunomodulatory treatments have been the most effective like on the whole.

I don't know what your experiences. Yeah. I mean I feel the same way. It's, I mean, I think we need to look at the in fact, we need to look at the triggers.

You know, and one of the things that I found, too, that's so interesting is the infections are typically the initial trigger, which leads to the autoimmunity and that inflammation.

But the other side of it is later on, other things re trigger people, you know, so once that inflammation is set up and so I see a lot of stressful events re trigger patterns but I personally at the moment that we're talking don't believe that that was the trigger like the initiating event.

But it's like always interesting because people are looking for that acute trigger and they're like, whoa, I didn't have they didn't have a cute onset.

I'm like, you know, something is like, well, you know, I talked to a patient the other day. It's like, yeah, there wasn't really an acute onset. I mean, I don't know.

There's like, you know, for a month or two, I just had some ticks that I never had before. And then like and then I had this and like, well, didn't the ticks start out of the blue?

They're like, Yeah. I'm like, Well, that's acute, you know? So it's kind of funny. Yeah. It's one of those things, you know, that when, when you talk about the immune modulatory.

So this is one of the things that I think is really interesting to some of the research. Try to look at like IVIG like right up front or a single dose and then there's a bunch of Provi IT practitioners are doing six 1224 doses.

I mean, have you seen any trends in our immune modulatory treatments, you know, in their efficacy? Because I know there are some studies that show a variety of efficacy.

Does the timing of when the kid gets treatment make a difference? Yeah, I wish that I had, you know, as you know, clinical data can be so complicated because each patient is kind of coming coming in with their own story and they often from a tick borne illness standpoint, you know, people are often co-infected.

Also, typically, I don't just see someone coming in with a history of Lyme disease. It's often Lyme disease and Bartonella were Lyme and would be easier.

So it's very hard for me to know as a clinician sort of what exactly triggering what and what are we dealing with kind of in the moment. So that one's a kind of a hard, hard one for me to answer.

Yeah, I mean, and this is fun for me because I love having real conversations, not the one where you talked to the person. Everybody needs IVIG. They need 12 to 24 doses and they need three antibiotics for four years.

And they'll be like, That's bullshit. Like so everyone we're having like the real conversation that people should be having with you. And I know in some other interviews we've talked about things like informed consent.

These are the conversations you should be really having with your practitioner. Anybody who tells you they've got plans figured out, got Lyme figured out, they're full of crap.

Now, a lot of us have a very structured approach, and I think that's really important to understand. It's not like we're flying by the seat of our pants or we're just making crap up, but we're really trying to be honest with you that the stuff that you're unsure of in your own symptoms are is the same stuff that we're unsure of now.

We have a lot of data to support what we're doing and a lot of experience. But we're, you know, we're really in the summit here trying to have like real conversations about the challenges.

And this is also I mean, because I don't want to discuss all of our colleagues, a lot of them, we are raised in a system where if we don't know, that's kind of like not acceptable.

And so to me, I love not knowing because that means we can learn more and we can help you even more than we could yesterday. If I'm open to that. So and I guess, Shannon, one of the questions too is do these kids with pens and pandas?

I mean, are they so like, let's say the you know, because I don't I've never heard or seen you withhold psychiatric therapies and treatments just because you're like, oh, you just have bartonella just treat it with azithromycin or rifampin.

It's like it's kind of that combination treatment of everything that whole person needs.

Treatment Approaches and Medication Sensitivities

But if you were looking specifically at a child with pads, are they and this is kind of, I think the thought I lost a minute ago when I was getting all riled up.

The one thing that really strikes me is I guess I'll ask you the question first before I finish the thought. Do these kids respond the same way to typical psycho psychiatric medications if you have patterns, their patterns versus sort of the general population?

Yeah, I think that's an important question. So I it's sort of again, depends on the patient, but the classic patterns patient that I that comes to me often is one who has been down the psychiatric road and maybe has been admitted to the psychiatric hospital a couple of times because of the severity of their symptoms.

They've often been tried on psychiatric medications, sometimes from every single class and numerous psychiatric meds from every class. And oftentimes their illness is just intractable.

It's not as if the psychiatric medications are helping. They often make the situation a lot worse. So when I approach a patient, it kind of depends. If they've tried every single SSRI and every single antipsychotic medication and other things to help treat their OCD and just nothing has worked and they're presenting with a history of infections, then I think I would be a lot more leery to trying another psychiatric medication for the 14th time if they haven't really worked before.

That being said, if someone is coming to me and they have a history of Lyme disease and like significant OCD, will I try a psychiatric medication at a very, very low dose and go up very slowly?

I probably will. So it sort of depends on the history. But in general, these patients, especially the Sarah Tanner object, medications in the Lyme disease population and also kind of the patterns pan this population, they can be extra sensitive to those types of medications.

So for that reason, I usually rarely will prescribe and SSRI for a kid who has a strong history of Lyme disease and pans because I've tried it numerous times, even at very tiny doses, and sometimes within 24 hours, it can induce suicidal ideation or make these kids very agitated or more anxious.

It does not have a calming effect on these kids. So I typically like to go to medications that are more calming and kind of mood stabilizing. Thank you.

Have you shared a few patients before in the past? So you know that I really like the medication, the motor gene, and I still start that at low doses and go up slowly.

But it's a medication that is generally well tolerated in this population. And I don't see the extreme like emotional dysregulation that I can sometimes see with the SSRI medications.

So it is important to consider psychiatric medications in this population. I think you just have to be somewhat thoughtful about it. And sometimes, interestingly, the medications that aren't typically deemed psychiatric like for example, the beta blockers for propranolol and other medications such as that can actually help some of the psychiatric symptoms, even though it's not something that we would typically think to prescribe as a psychiatrist.

Yeah, I think that's one of the things that's always struck me about this population, is when the typical meds don't work, why do we keep saying it's, you know, because like, if even if I have someone with a conversion disorder, I can pretty much squash their mood pretty easily.

There's a lot of drugs that they can give them, but it's like I feel like even like a lot of the benzodiazepines, people respond very if they have a very weird response to them.

And, you know, and that's what I was kind of thinking about this particular person that I, I mentioned earlier, it's been several months and they still can't control hallucinations where we were able to control them quite easily with a little bit of medication and transition their herbals.

And it was like, so I'm not saying like I feel the same way, like don't not offer it, but when you have a response that's unexpected, they did. Maybe you should look a little deeper and go, Oh, because I, you know, because when I look at the diagnostic criteria pans, there's no lab work that says, yep, like that. There's just nothing there. It's all clinical.

But I know that there is some work on these autoimmune, you know, these antenna ronel antibodies, but maybe it's like the NMDA receptor encephalitis that may be.

And when we have a little better technology or we think about it a little differently in five, ten, 20 years, we'll actually have a diagnostic lab test and we'll be able to go back to all this blood, you know, I know we talk a lot about Borrelia immediately because like I published for the first 24 cases in the country, which are among the first 73 human infections published in the world.

And it was like crazy within the year or, you know, after that they went back and looked at stored blood from 2014 back to 1992. And they found like hundred and 20 other cases where they presented with Lyme like symptoms.

But it wasn't Lyme and we just told them they were crazy and it was in their head. Yet when we learned more later on, when we became more curious, we went back to become curious. It's kind of funny.

We found out, Oh, you know, you actually had Borrelia near Moto, and then we all published these papers like, Oh, we found Beryllium in water. I'm like, But you're the same exact doctors who diagnosed these people with being crazy.

Mm hmm. So it's anyway. I mean, I just think it's important to think that way, you know? Yeah, it's an interesting intersection for me because I went into psychiatry because, you know, to me there is such a world ahead in terms of an entire frontier that we just don't know about and exploring the brain and how it works and how it causes psychiatric problems and influences behavior and things like that.

To me, that's just completely fascinating. And psychiatry is like in its infancy because we know very little about what causes psychiatric conditions.

But it's an interesting confluence of also working in the realm of tick borne illness, because it's it's another area in which I feel like doctors and the medical profession is just like we know so very little about this problem that is truly an epidemic at this point.

And also fascinating that we're still discovering new tick borne illnesses since you mentioned Pirelli Miyamoto, that was human cases. I think in the Northeast were identified in 2013, just a few years.

It's pretty wild. So I just think that it's so fascinating and I really appreciate your willingness to come and have a real conversation. I think if we could have more real conversations because I heard nothing, but I just, you know, I was a little frustrated because weren't open to the possibilities for the child, not, you know, and it's I love the folks who have come together for this summit because none of us are going, hey, by the way, like I was right and they were wrong.

It was like I wanted to work together with the other practitioners to make sure that we were doing the right thing for the kiddo. And I really think that it's been an honor to be able to work with you on these cases because we've been able to make progress where other people haven't.

And it's not that I did it by myself, but in partnership we've been able to unlock the Rubik's Cube. It's funny. It's like my buddy just came for. We went out skiing for a couple of days.

When he came out for a little retreat, we did. And he brought his kidneys. Kids doing this Rubik's Cube thing like a million miles an hour. Right. And I'm like, I've never solved the Rubik's Cube because I kind of like when I was younger, I gave up, right?

I'm like, too complicated. And then he says, Oh, just watch this guy's building. I pegged the type of guy who's doing that every night. Yeah, right. Yeah.

But it's like. But when you learn. But what was interesting was this Ford is he's now 17. I've known him for a few years, but he just goes, here, you do this, this and this and this.

And I'm like, Yeah, now he's like, I learned it from this one video. Just go look. And I followed the, the thing.

Collaboration, Curiosity, and Closing Thoughts

And even though I followed the instructions, I still made mistakes, even though I was just pausing it. But what was really cool was when I started to see it unfold, I got more excited and more curious.

And then you can see the people who dove down that rabbit hole doing it, learning how to put things together. But if you make one wrong turn, you have to start all over.

And so I think together as a community, this village that is working on patients like this, we can minimize the wrong turns. And that's why I like when I see it, when I send patients, like I want to line literate cardiologists online literate neurologists, a Lyme letter dentists and a Lyme literate librarian.

Well, you don't need that. What you need is someone to make sure we're not missing something. And I haven't put on the tunnel vision, you know, and I just think it's, you know, I'm open to other diagnoses as I know you are.

But when I see a patient who's been treated by everybody and nothing's working and you're telling me I'm wrong, but you have nothing else to offer, I'm like, That's kind of a little blasé, you know?

You're like, So I appreciate this opportunity, you know, today to have this conversation, because I think a lot of people need to know that you're not.

I mean, I don't none of Shannon and I don't want you guys to be out there experiencing this medical gaslighting and this invalidation and all the trauma that comes along with them not believing you.

But, you know, and it's different for us than you. But we're still fighting that fight, too, where, you know, there's so much closed mindedness and we should really be open to curiosity.

So I just really appreciate the opportunity to have this conversation that's like real and raw rather than fluff and BS, because this is what moves the needle forward for our patients.

Thank you. Yeah, I totally feel the same. It's like sometimes as a as a doctor in this field, it sometimes feels like we have so many more questions than we have answers.

And it's nice to have have close colleagues who are all working together. And, you know, we're trying to to solve this for our patients as well. Yeah. Well, again, thank you.

It's an honor to chat. I always love talking and, you know, I love being able to work on patients together because it opens my eyes to things that I might have been missing.

And I just hope that everyone listening I know there's so many practitioners listening, keep your eyes open. It doesn't mean throw out your differential diagnosis and throw out regular medicine.

It's just like look at the all the possibilities and then figure out what's best for that unique individual in front of you. And I hope that really, you know, Dr.

Delaney's experience and, you know, my little bit of crazy commentary can help you kind of remember to bring that together, right? We want the best of everything.

And it's just like be open possibility. And as a patient, you know, advocate, you know, there are plans, guidelines. I'll make sure that we get those into our show notes like you know, our summit resource page for you, because those guidelines that Dr.

Delaney mentioned are just so critical because I feel like we can it's really nice to talk about the emotional side of things and be human about this.

And there's also a lot of science behind what we're doing. And I actually I just you know, I always it's I'm the worst at closing an interview because I always think of something new.

But I was talking to Jim Lachman at one of these Connecticut panels, Panda's Advisory Councils, way back in the day. And we talked about a paper that showed that IVIG really didn't help that much in pairs, and they're trying to figure out why.

And then within 12 months, another much more study that involved more people and had more data points that allowed us to pull out who it's good for not came out.

And next time we're talking, it's like, oh, we have more information. And to me that's exciting. You know, the next day, you know, what I knew last week may be different.

You know, the truth is ever evolving. So thanks for reminding us of that. Yeah, thanks for having me. Yeah. So everyone, thanks so much for joining us for another episode of The Healing from Lyme Disease Summit, I'm Dr.

Tom Moorcroft and I hope you found a lot of value in this and inspiration. Definitely. Look, Dr. Delaney up. She's amazing and love working with her. And I know you will, too.

And until next time, we'll see in the next episode.