Introduction to Lyme diagnostics

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As an engineer, like to solve problems. And I was like, this is the problem that needs to be solved. A healthy point of view podcast, your top rated show, where we bring experts from all over the world to talk about health, wellness, beauty, and mindset.

We have Nicole Bell. Nicole is the CEO of Galaxy Diagnostics, an MIT engineer, researcher, and author of What Lurks in the Woods. After her husband's battle with Lyme disease, she dedicated her work to advancing research, improving diagnostics and driving change in Lymedisease policy.

And actually, Lime was one of the first things that I thought of. So he was not just irritable, but he also was doing things like hallucinating. He came in and was terrified because he thought that there was a man swinging from the trees in our woods with the machine gun trying to kill him.

What should be the standard when it comes to testing for Lyme? So for Lime, we actually use an antigen test. And because Lyne doesn't like to be in the blood, We actually don't use blood for a matrix.

We use urine. Yes. So I would love for Welcome to another episode of a Healthy Point of View podcast, your top rated show, where we bring experts from all over the world to talk about health, wellness, beauty, and mindset.

I'm your host, Sam Tahata. And today's guest, we're going to be talking about diagnostics. These diagnosticks are a little bit different than what we typically talk in the functional medicine space.

We're gonna go deep into Lyme disease. Yes, this is part of our Line DCs series. This episode, we have the pleasure of speaking with someone who's helping lead research, someone whose helping on the policy making side.

We have Nicole Bell. Nicole. All right. Nicole, welcome. Great. How was that? That was fantastic. Yeah, I feel special. I know you're saying that you haven't really been going on actual in-person, you know, podcast.

So I wanted to make sure you get a nice warm welcome while I appreciate that. But I don't know if you got to get them on the other ones that she go on.

So we'll do awesome. So Nicole, you know, we have our line disease series where we're bringing experts from all over the world to talk about this topic.

This topic is, obviously, getting a lot of hits online because of things that are happening and policymaking and committees that have been put together.

Nicole Bellu2019s background and family story

And it's a topic that hasn't really gotten the attention that it should, right? You yourself, you're the chief executive officer for Galaxy Diagnostics.

You guys have certain testing methodologies that are a bit different than other labs that which I'm really excited to really kind of hear your story to begin with and dive deeper into, you know, what is it that you guys are doing and why is important for physicians or even patients to understand this throughout their treatment regiments that they're doing, et cetera.

But before we get into the meat and potatoes of any of this, I want the viewers and listeners to really get to know you on a personal level first. And I wanna go way back from your upbringing of how you grew up here in the United States or out of the U. S.

and what brought you to where you're at today. Yeah, well, so I'm originally from Boston, Boston girl and grew up, I've got great family, older brother.

I was a athlete, a three sport athlete growing up and always really gravitated towards math and science. So I went to MIT for my undergraduate and studied engineering.

so material science and engineering and a master's degree in that. And from there, actually, my MIT professor started a company and asked me to join. And, from, there I kind of caught the entrepreneurial bug and really fell in love with being in a startup and bringing new technologies to market.

So, pretty much my entire career, I've been in entrepreneurial, small company environments. I did two years in big company, and I realized it wasn't a fit for me.

My professional journey brought me from Boston to California and now in Raleigh-Durham. And the last half of my career, kind of mid-career, I went back to school.

I got a biomedical engineering degree from Duke, and since then I've been in medical devices and diagnostics. and taken lots of products to market through the FDA.

And I got interested in tick-borne diseases, the reason that a lot of people do, when it hits your family. It was my husband in this case, and he started first with mood disorders, he was depressed and anxious and eventually irritable.

And we went to therapy and nothing helped. And then I started realizing that he was also having cognitive issues. He was a brilliant engineer, electrical engineer computer scientist, but all of a sudden he couldn't remember the four digit code to our house alarm.

How many years in did you started started noticing this from the first symptoms of like the mood changes and stuff where all the sudden you start to see more of the cognitive change?

So I would say probably maybe two years or so where I'd say he was starting to have more mood-based issues. And then it was about 2016 when I realized he also was having these cognitive issues and at the time I just started Googling brain fog and confusion.

And actually, Lyme was one of the first things that I thought of when I kind of did the Google search. Well, he was a big outdoorsman. He was the hunter.

he did all the landscaping in our yard. It was always outside, multiple tick exposures in multiple endemic areas. We had lived all over the country. And so I had him tested at our first doctor's appointment and he tested negative.

What kind of tests did they utilize? The standard of care test. At that point, he was given a Western blot, which looks for antibodies. And as we dive in, I can talk about all the reasons that that's an interesting test with a lot of limitations.

But he tested negative. You have to have five bands on the Western Blot in order to test positive. He only had one. So he wasn't even close to a positive, and they referred us to neurologists because all of his symptoms had to do

with the brain.

And at that point, after a series of brain scans, he was given a diagnosis of early onset Alzheimer's disease. And it was like a baseball bat to the face, really.

I mean, I was frankly still trying to convince him that something was wrong. He didn't believe me. There's nothing wrong with me, it's you or you're being ridiculous or whatever.

He was given that diagnosis of Alzheimer's early onset. And they also said that his PET scan showed that not only did he have Alzheimer, but he was in the late stages.

I want to highlight that because I know where the conversation is going to go because obviously I've interviewed a lot of people on the line so far. And the Alzheimer's, I want to highlight that because that's something that is important to kind of really pay attention to when we talk about Lyme disease.

And I'll let you get into that a bit later. Yeah, no, it is. There's a lot of neurological effects for some of these pathogens. But again, you go to the doctor, You respect their opinion.

But it didn't make sense to me. Again, I'm an engineer and I like root causes, right? That's how you're trained as an engineering. And it did make since because he had no genetic disposition for Alzheimer's disease.

He was still young. So he was older than I was, but he in his late 50s, early 60s at the time we were going through this. and he, was declining so quickly.

It just didn' make cents. I kept going from neurologist to neurologists, Asking for the why's like why is this happening? What is going on? I don't understand and It was about 15 months after our first doctors visit where we returned to the possibility of vector-borne or tick-Borne illness and it was because another family member had been diagnosed and realized my brother his wife at the time had multiple tick-borne infections.

My brother's a doctor, so he started researching, and he encouraged me to get breast retested, at which point I figured out he was not only positive for Lyme, but also to common co-infections, which I hadn't even considered at that original appointment.

Specifically, he had Bartonella and Babesia, which are, unfortunately, all too common. And both of them have the capability of crossing the blood-brain barrier and causing a lot of the neurological effects that he was seeing.

But, again, 15 months after, we got a diagnosis of late-stage Alzheimer's. You know, we proceeded with treatment, had a roller coaster of a ride, but to make the long story short, he ended up going into memory care in 2019, and then he passed away in 2022. Sorry to hear that.

Now, you know, it seems like right from the beginning, You were there to really kind of be his advocate, right? And help spearhead, a lot of this process that you were doing.

Someone with Lyme, like how your husband had, how difficult is it for an individual who doesn't have someone like yourself to help spare had some of these things that that You're doing?

How difficult does it become for that individual? Oh, it can be completely overwhelming, right? Because a lot of times, these pathogens are associated with brain fog and confusion and memory loss.

I mean, even basic word finding, I remember talking to him and he would be talking about his car and would say, plain. And so, like, basic functions of communication become difficult.

to take a medical issue and try and research it and figure it out and advocate for yourself and then engage with doctors. It's really challenging. Even as a caregiver, it was challenging and so doing that while you're feeling miserable, while do you have chronic fatigue or brain fog or other disorders can sometimes be an unrealistic task.

Nearly too impossible. And I like to put emphasis on that specifically because You know, I've never had a illness at that level, right?

Lyme, co-infections, and neurological symptoms

But I could tell you that when, and my wife will tell, you like, if I just have the common cold or the flu, i'm useless. So I can only imagine someone who's really chronically ill at the at How do they you know get the right help?

How did they do the research if you just can't function? Yeah, but Your husband Well, you said he was an outdoors person all the time Was he someone who that you of that would say?

Oh, I got a tick. I had to pull the tick off of me Is that something that was known? Yeah. No, he had had multiple tick bites over the course of the years, even some while we were together.

And that was one of reasons why it was on my mind when I started researching. He had lived in New Jersey, New Hampshire, North Carolina, California, lots of areas that are either considered edemic or emerging endemic.

You know, so it was something that we were aware of, but he never had any outward signs. He never have the rash and the fever. Never had an official diagnosis of Lyme.

And then when I did get him tested, he tested negative. So there was nothing to indicate that that was. Something that causing all of his issues. At what point in time did you know that he did have Lyne?

Well, it was when my brother called me and my sister-in-law had just been diagnosed with Lyme, Babesia and Bartonella, ironically, the same pathogens that my husband ended up having.

And he encouraged me to get him retested. At that point, we decided to go to a tick-borne specialist and really understand and try and figure out what was going on with him.

We figured out that he was positive and started putting all the pieces together. So, you know, when someone gets diagnosed with Lyme, going through that process that you guys went through, treatments start to begin.

And there's a variety of different types of treatments, especially when you go into the functional medicine world. What type of treatment were you going to?

He went through a little bit of everything. So the doctor that we ended up going to was pretty big on antibiotics, so he was on broad spectrum antibiotics for a significant period of time.

He was also on herbal therapies to support and kind of immune support to really bolster his immune response and promote his gut health and his detox and other types of things.

We also, towards the end of his journey, tried more experimental things like stem cell treatments and he also had heavy metal issues and so he was on chelation therapy.

He was he on a lot just because we were diagnosed late or he diagnosed and it felt like we're trying to do as much as we can as quickly as In hindsight, maybe it was a little too aggressive, but at the time, it the best that we could do.

Yeah, you have to really hit it from every angle at that point. Now, what do you feel that was probably the most effective course of treatment through what he went through?

I mean, one of the things that I really had my eyes opened up to through the whole process was the power of herbal medicines and therapies. He responded really strongly to some herbal medications and treatments.

And one the other things it had opened my eye up was other pathogens. So everybody talks about Lyme disease,

but in his case, Bartonella, which was a pathogen I hadn't even heard of, was huge actor.

When he went on herbal therapies for Bartronella once starting the tinctures within 24 hours of starting these tinkers, he started having massive reactions.

He was having urinary incontinence, irritability and agitation, and then he would go off the herbals and those symptoms would subside. And I was, at the time, as an engineer, thinking, wow, how is just a little bit of some of these herbils having such a massive impact?

And I really came to appreciate that medicine is a lot broader than what you get exposed to in traditional medicines, but then also the things like Bartonella, which is associated with neurological conditions and neuropsychiatric conditions.

So he was… Not just irritable, but he was also doing things like hallucinating, you know, one of the reasons that our story and the book what lurks in the woods is is named that is because obviously ticks lurk in The woods, But he also thought that people were living in my woods trying to kill us And they were very real for him.

And this is, again, an electrical engineer, computer scientist. One day he came in and was terrified because he thought that there was a man swinging from the trees in our woods with the machine gun trying to kill him And as I've researched and as i've learned more about these pathogens, I absolutely attribute that to Bartonella because the researchers that we work with have shown that there's a correlation with key neuropsychiatric illnesses like schizophrenia and psychosis.

And having lived it firsthand, sometimes you have to see it to believe it. know that that pathogen causes some some really serious, you know I'm happy you brought that up in conversation because you Know my 12 years working in the fire department as a firefighter paramedic I've transported a lot of patients that have been you, know in a position where they're hallucinating and I remember my first few years I I felt like they were crazy, right?

Until I really started understanding that whatever they see, they actually see it in their head. You know, it's a real thing. It's the chemical imbalance that's happening in the brain.

So, you know when people have a family member or a friend that is going through that stage, like people will have to understand that, hey, They see that.

And it is a very scary thing if not handled properly in that scene, if you will. Absolutely. So you're talking about Bartonella. Can you explain a little bit more for the listeners and viewers to really understand where that comes from and, you know, what is it, because a lot of people are hearing now about Lyme, but there's other pathogens that we have to worry about, correct?

Yes. So if you Google Bartonella, you'll see cat scratch fever, right? And a lot of people are aware of that, of course, because of the song. And that's the acute form of a disease.

You get scratched by a cat. Oh man, I got the neighborhood cat coming to the house all the time. Yeah, well, and cats are actual natural reservoirs for Bartonella.

And so especially outdoor cats, lots of them have really high levels of Bartinella in their bloodstream. But they're not meant to be in humans. A lot of us get exposed and a lot times people can get expose and not have any issues.

Your immune system can keep it at bay. But in some people and also when some of these pathogens combine with other pathogens, right? So maybe you have Bartonella and your immune system is keeping it in check, but then you get Lyme disease or then the collaboration that's going on between these pathogens, right?

And you get sick. And Bartonella can lead to joint issues and arthritis. It can led to neuropsychiatric conditions. Actually, our founder at Galaxy did a study that showed 65% of schizophrenia patients were PCR positive.

65% so there's a huge correlation as it turns out like the crazy cat ladies actually really a thing, right? there there is a correlation in a biology that that can be linking these things and And so, you know and definitely my husband like one of the telltale signs of Bartonella that happens is you get these striate, they're like they almost look like stretch marks and and they often can be on your torso or they can happen sometimes like after you take a hot shower or you have like an allergic reaction or something, you see these striae.

And absolutely, my husband, I remember seeing them after he would get out of the shower, but at the time I didn't know what they were. Wow. and like I said, it's really can linked to a lot of irritability.

The Bartonella rage is kind of a term that you might hear when you start talking about vector-borne illness. I attribute that to lot his neuropsychiatric behavior.

Wow, wow. Nicole, nearly 476,000 Americans are diagnosed and treated for Lyme disease each year. When did you realize that the biggest challenge wasn't treating Lyma, but providing, sorry, proving that it actually exists?

Well, after the journey with my husband, I couldn't go back to my regular programming. I had a lot of people that were interested in having me come to work for their company or run.

I kept going back to that first doctor's appointment where Russ was diagnosed negative. Like it was the first thing I thought of. I talked about it with the doctor and he got a negative test result.

And I was like, what if at that visit we got an accurate result? And what, if they had tested us for some of these common co-infections, where would that be?

How many years was that before he actually passed? Well, it was 15 months before we figured that out, and then it another several years before he passed in 2022. So, you know, time matters with these pathogens.

And so I kept coming back to that point and I realized as an engineer, I like to solve problems. I was like, this is the problem that needs to be solved, right?

Because if you don't know what you're fighting, how are you ever going to win? And if you don't have an accurate diagnostic, how are you ever going to develop better therapies?

Because you do not know who actually has the pathogen and then whether the pathogens been cleared after treatment. And so that to me seemed like the place to lean in and having worked in diagnostics before, it also just happened to align with my skill set.

Right, right. Now, with your husband's illness that he had, at what point in time did you say, you know what, I want to go this direction with my career and this is going to be my mission?

Why standard Lyme testing falls short

It was after he was in resident care, right? Because before then, it was all consuming. I had two young children. My children were five and eight when he went into resident.

Care I was still working at a medical device startup and running all new product development there. And so when he went into resident care, I made the decision to step away from my job and really focus on the family.

And I did. Then it happened to be the COVID year. He went in to resident in 2019, and then COVID hit. So it kind of extended my time. Around 2021, when I really started thinking about where I wanted to lean in, that was when started focusing on diagnostics and researching.

There has to be better solutions out there, right? The current testing methodology is based on technology that's decades old, and it provides such an incomplete picture about what's going on in the human and in host.

And so I started looking at different specialty laboratories, what was going in in university, you know, I came across the work at Galaxy and really fell in love with their approach and their technology.

And that was kind of how I got involved. I literally just called up the founders and said, Hey, my name's Nicole. Love what you're doing. They had over 450 peer reviewed publications on their.

Technology. Wow. Now, did you have your engineering background before that or did he get your engineer background after that? No, engineering before. That right.

So, yeah, material science and then biomedical engineering was kind of when I started working in medical devices and diagnostics. So if I were to ask you, your engineering background, how do you think, if you could break it down in a few sentences, of how your engineer background really has helped fight that challenge when it comes to Lyme disease diagnostics?

I think that the key with engineering is that everything you're taught in engineering, is to look at root causes, right? If you have a problem, what's causing it, if you are looking at a robot, for example, Is it a software problem?

Is that a hardware problem is it? A mechanical issue? But then when I started dealing with my husband's illness, I realized in medicine, that's not how things are handled, right?

They're treating symptoms, not actually getting at the root causes. And it was a challenge for me. Then I just started, kept digging and trying to figure out, well, why is my 60-year-old husband, Why is his brain systematically destroying itself?

There has to be a why. And that was when, you know, I started looking and seeing that pathogens can cause these issues. Toxins can caused these issue and start digging deeper.

So I would say it's all about root causes, which that's why I love the functional medicine community so much because it is a focus. And, when we talk about traditional medicine, our allopathic world, It really isn't about root cause.

And that's something that I saw over so many years in emergency medicine as a firefighter paramedic, taking the same people back and back to the hospital and just seeing more medications be prescribed.

No one's addressing lifestyle. So, you know, when it comes to the Lyme disease community, or should I say Lyne disease in general, there's a lot of conspiracy talk out there.

And that conspiracy can become a loud of noise into what you're trying to work on. But at the same time, I'll give you an example. You know, we hear about a lot of the things that are happening now, the toxic chemicals in the foods, you know.

We know that there's certain things to enhance your detox pathways to get a lotta these toxins out of our body. But at the same time, you know, I think it's important to address, why are these chemicals in our food, right?

Is it the big pharmaceutical system that's working with the food companies to keep us sick? Because people will always have those questions. One thing I want to talk about is you know one thing that you mentioned to me is that The science speaks louder than the conspiracy theories and that we have to focus on the science I Want you to kind of just comment a bit I don't want spend too much time on this topic here but I wanted you To comment on why the Science is so much more important than a conspiracy side of what's happening with Lyme disease.

I Well, because I think we need to find solutions, right? The problem is here. How it got here is an important question. But for the people that are suffering, the real answer is how do I get a better diagnostic and how I do get better treatment, and so helping those people today is really getting those solutions in the hands of clinicians as soon as possible.

Like I said, the diagnostics was the piece where I think is the number one problem to solve. And because I've always been in science and engineering, it's like on the wall of the FDA when you walk in, and it says, in God we trust, all others bring data, right?

And that's always something that resonated with me. Science will provide the answers. If you're asking the right questions and if you are looking in the areas, then you will figure it out.

But sometimes that's a long journey and it takes longer than we like. The good news is that people are keyed in, it's starting to happen, the government is taking notice and this is really getting the attention it deserves because it really is linked to complex chronic illnesses in a way that…

people need to understand. Absolutely. Let's talk a little bit about the world of data when it comes to Lyme. Research supported by the Global Lyma Alliance suggests that 10 to 20 percent of Lyne patients continue to experience persistent symptoms after standard treatment.

So my question to you is, has medicine done enough to listen to those patients? I would say no. There are a lot of people, even with early diagnosis and early treatment, you're correct, 10 to 20. The study that I often cite says 14% of patients still have complex chronic symptoms that impact their daily quality of life, right?

That's a huge number. And so the question is, why? And this is why testing is so important, because there's lot of reasons why. One could be that the treatment didn't actually kill off the pathogens.

So Lyme is caused by a bacteria called Borrelia, and there has been evidence in the research that's shown that. doxycycline, the standard course of treatment, or any antibiotic in single, you know, any single antibiotic doesn't actually kill off the pathogen.

And so that could be a potential root cause. It could also be root causes that maybe that person had a common, another co-infection, like my husband. Babesia is on the rise and a huge issue these days.

That's a parasite. that's not even a bacteria. So antibiotics aren't going to touch it. If you had that co transmitted with a tick bite or maybe another tick then that's going to be a different course of treatment.

That might be reason. Or, you know, these pathogens can cause immune dysregulation. Sometimes the antibiotics can causes issues. And so why is the person still feeling sick?

And is pathogen still present? What's the right course action for the next phase of treatments? That's important thing to really understand. Nicole, I want you to kind of get into the details about what has been the standard when it comes to testing for Lyme, right?

And then us utilizing that as a segue to talk about, what should be the standards for testing? And there's big labs out there that everyone knows about, Quest Diagnostics, LabCorp.

What are these big lab utilizing as a standard diagnostic tool for Lyme? Yeah, so the first thing before talking about the testing is really starting with the pathogen and why they're different.

So Borrelia, the bacteria causing Lyme disease and some of these others, Bartonella, Babesia. They're a class of pathogens known as stealth pathogens, right?

It's because when they enter the body, they replicate really slowly, They actively evade the immune system and they hide in tissues, Right? So they are really difficult to detect as opposed to say a pathogenic like COVID, You know, you get it, right?

Once it's in your body, it amplifies pretty quickly and you can test with standard PCR or antigen testing, and know whether or not you have the pathogen.

But with Borrelia and some of these other pathogens, that's not the case. And so if you use a standard pcr test, It's Not Sensitive Enough. One thing I like to say to put it in perspective is, you have a better chance in your lifetime of getting struck by lightning than you do capturing Borrelia in a test tube with a blood sample, right?

It's just, it's in low abundance and it hides in tissues. And so if you take a sample you're going to get a negative. So as a result, going back to the standard of care, what they use to diagnose is antibody-based testing.

So has the person been exposed to the pathogen? And that is, if you go to your traditional doctor and you get a test, it's going to be an antibody-based test.

But that's an approach that flawed for a lot of reasons. One, early diagnosis and treatment is the best. There's research out there that shows even a 30-day delay of treatment over doubles your risk of developing complex chronic symptoms.

And antibodies, right, the way that our immune system works is it takes a while for you to amount to an immune response. An IgG response can take four to six weeks to peak, and so you're missing that early window.

Then, even in the later stages of disease, you have a person like my husband, Russ, who probably had had the pathogen on board for years, and his immune system had been keeping it at bay, but it was fatigued.

And so his overall antibody titers were low. I think that's one of the reasons why he tested negative on the antibody test, because his system was fatigue, so he test negative.

And then yet another issue why antibodies are challenging is it because it indicates exposure, not active infection. So just think about, again, COVID.

I have COVID antibodies, but I don't have covered right now. And so if you've ever had a Lyme diagnosis at any point in your life, antibody testing really doesn't tell you.

Do you have the pathogen on board right now? Which is the answer that you need to know. And so across infectious disease, the preferred approach is direct detection, right?

Think of COVID again, PCR testing, antigen testing. These are methods that are directly telling you is pathogenic present right But because there's stealth pathogens, that hasn't been available, right?

And you need to develop the technologies and lower the limits of detection in order to get those accurate results.

Galaxy Diagnostics and direct-detection methods

And that, when I started researching all of the different techniques out there, That's what I found was the core problem that Galaxy was solving and what drew me to the founders and to company.

So the test that's done at Galaxy, it's a PCR test? So we have different types of tests for different type of pathogens. So for Lyme, we actually use an antigen test.

And because Lyne doesn't like to be in the blood, again, think of the lightning example, We actually don't use blood for a matrix. We use urine. And that's really why the microbiology of these pathogens matter, right?

So, Lyme likes to hide in tissues, but one of the things that it does when it's in your body is it actively sheds surface proteins and molecules, either as part of its immune evasion or as its replication cycle.

And those key proteins or biomarkers get filtered by the kidneys and excreted in urine. And so researchers at George Mason University and then later Virginia Tech and now Northwestern show that you can use those for a diagnostic.

Which is great because urine is such an easy sample, right? You can collect it at home. It's great for kids. And it's highly accurate. Because it is a direct test, you don't have to wait for that immune response.

So patients that are you know, in the early stages of the infection, or maybe immune compromised later in infection. It really doesn't matter because it's looking at the direct detection and evidence.

But then for other co-infections, we do use PCR for pathogens that are in blood. We use enrichment techniques to diagnose things like Bartonella and Babesia, relapsing fever, Borrelia which is kind of another part of the Borrelia class, which is more blood-borne.

So we use a mix of technologies based upon what's the right approach for the pathogen. Okay. This is a random question that just kind of popped into my head.

It's like I had no plan of asking this question until now. You're talking about in the urine because of what is happening internally where it sits in And just curious, wouldn't sweat be a way to be able to collect a sample as well?

So I mean, that'd be kind of nearly impossible to get the right, hey, you gotta get in a sauna or something to it. But what do you think, what's your professional opinion on testing from sweat?

Because you know, like, a lot of your toxins and all that stuff, they come out through your sweat, right? Yeah. I'd have to, you know, again, these proteins, they get cleared by your kidneys.

I don't know about sweat excretion. Have never seen any studies on that. So that's something I have take back to my scientists to see if there's any indication that that would be a useful mechanism.

But always open to new approaches. Yeah, I just found that kind of like interesting. What have patients with chronic Lyme taught you when it comes to traditional medicine, what they're really overlooking?

Oh, I mean, the average Lyme patient is seeing many, many doctors. Like, you know, and I've personally met lots of patients that have been to dozens of doctors without getting answers.

And again, it goes back to our earlier conversation of traditional medicine isn't really looking for root causes. I think the other thing that's important is we hear a lot of incorrect data, right?

Like there's no Lyme in insert state here, like Florida, for example, where we are right now, a lot of people we've heard, they go to the doctor and it's like, well, there is no Lime in Florida.

And that's just frankly not true. I think one, endemic areas are emerging. and growing, and then also people travel, you know, that these pathogens are spreading.

And so there's a lot of misinformation that's out there that leads people to bounce around and they finally don't get the answers they deserve often until they end up with a tick-borne specialist or with the functional medicine provider who's really open to, okay, maybe we need to look a little bit deeper and start exploring alternates.

Nicole, you've put a lot of emphasis on the importance of doing the correct type of testing. Now, someone like yourself who's had a personal experience with someone very close to you, your husband, I want to talk about when someone goes through years of inconclusive testing, what that does to that person's self-confidence, what does that do to them in their mind?

What does it do? It's so disheartening. The doctors are the experts in your mind for health. And it really takes a mindset shift to realize, well, they might be the expert in their field of medicine, but you're the export in you.

To go from doctor to doctor and not get answers is so demoralizing and painful. And we regularly get stories from providers and patients where they're in tears when they finally get their positive test result from us, and they get the

answers that they've been searching for for so long.

It's an emotional experience because they feel validated, right? They feel like… For so many years, I've been telling people there's something wrong with me, that it's not in my head, it is a real thing.

And to finally have a piece of paper and a test that tells me that is so validating. It's a joy to do that kind of work and to give people those answers.

What can you say to the people that are out there, that listening, going through this, right? That are being labeled as crazy. That they've become psychotic.

And even some of these individuals, they start getting treated differently. Where they're putting them on a lot of psych beds. you never were crazy to begin with, and now you've been labeled as a psychotic crazy person, right?

And you're being put on all of these medications that can potentially make you suicidal and cause even further issues, a further chemical imbalance where now, you have, your experiencing things, insomnia, experiencing hallucination, You're starting to see things that you potentially might have to be admitted to, a psych ward, you know, I want you to comment on that, because that's something that I've seen people go through certain journeys with their health, where maybe it wasn't something related to a tick-borne illness, but it was something as simple as hormones, right?

Where they're seeing a medical provider that just doesn't care to address the hormone deficiencies that that person has, and they've become very moody, now they are being labeled as someone who's crazy.

And now they're being put on a whole magnitude of other medications that cause you, you know, after a few years to be on even more medications. Basically their health circles down the drain.

Well, the first thing that I would say is that, especially in the vector-borne and the tick-born space, is these pathogens actually can cause mood disorders and psychiatric issues.

And it's the pathogen that's doing that. If you think about it, it makes complete sense. Because if these pathogens can cross the blood-brain barrier, they get in your brain, drive up inflammation, cause cytokines and all sorts of expressions.

you're going to have brain fog. You're gonna have mood issues. And like I said, with Bartonella and some of these other pathogens, you can have clinical diagnoses of serious things like schizophrenia, suicidal ideations, depression, anxiety.

It comes along with the infection. When you go to and you tell somebody you have anxiety, The first thing they're going to say to you is not going be, oh, maybe you have a tick-borne infection.

But the reality is that we see this quite commonly. And then on top of that, you send them from doctor to doctor and tell them there's nothing wrong with them.

It's a tragedy that patients are seeing in this medical environment. There's real science there. You know, one case that we saw with our research partners and our founders was a young boy who experienced sudden onset psychosis.

Again, this is, they adopted a cat, right? Going back to cat scratch fever and having different forms. And he was 14 years old, he had sudden-onset psychoses, He was homicidal, suicidal.

His parents had to put him in psychiatric care and spent over $400,000 trying to get him well and putting him on that medication soup, none of which, happened and helped him.

And fortunately, an astute practitioner, actually the nurse, noticed, remember the striae that I was talking about, the

stretch marks on his torso, and referred him to our founder.

They tested him for Bartonella using Galaxy's techniques. He was diagnosed. With a few months of antibiotics, he got his life back. Wow. he went back to high school, graduated valedictorian of his class, went on to study at Ohio State University.

The emotional journey, the neuropsychiatric symptoms, The mood disorders can have a real root in biology and in pathogens and infections. And so that's an important thing that people need to understand.

Chronic illness, validation, and mental health

It really shouldn't, and I see, what I'm seeing out of this is the mood swings and avoid that person's feeling and maybe the, should be utilized more as part of the diagnosis, right?

Instead of just treating those and putting a bandaid on it, let's take a further deep dive to figure out, well, why? Yeah. And there's signs, too. So there is a study that will be coming out, hopefully shortly, looking at case studies of a series of suicide patients, which is tragedy, right?

And each one of their six cases, and in five of the six case, they were able to confirm either Bartonella or Babesia in these patients. And if you also look at their medical history, they all had neuropsychiatric issues, but they also had other issues.

You know, joint pain, nerve issues chronic fatigue. And so anytime there's kind of multi-system issues right. I have brain fog and joint, pain. You know, mood swings.

Anytime you kind of have multi-system issues, I would start thinking, you know maybe this is a vector borne issue. Or when you have people that are not responding to therapies, traditional therapy.

You're on hormone therapies. We see a lot of patients that were diagnosed where they go into the doctor because they have para-menopause. They go in, they're saying I'm tired.

I have issues, and fortunately, a lot of the doctors we work with are keened in. They see that this patient had a Lyme diagnosis, sometimes decades, like in their 20s.

And they test them with our urine antigen test, And sure enough, it's positive. Well, It's not just hormone shifts. You actually have an infection. That's another thing, is that these infections can be on board, but as you go through a hormonal transition, their behavior can change.

Now all of a sudden, your immune system can't keep them at bay. Again, if you're doing a hormone therapy and you are not responding to therapy, and your having a lot of issues, especially if your living in an endemic area, you might want to start thinking about vector borne infections.

Nicole, do you feel that advancements in diagnostics is the next breakthrough for modern medicine? I absolutely, I mean, again, if you don't know what you're fighting, how are you ever going to get better, right?

Some of these treatments, If you look at Bartonella, Borrelia, Babesia which are the three top vector borne infections in North America, they all have different treatment protocols.

They'd have, you know, Borelia and Bartonella are both bacteria, but they have different antibiotics that are frontline for recommendation. Babesia is a parasitic infection, so the treatment is more like malaria than it is like Lyme disease.

And so if you have babesias that you got from the tick and your provider doesn't test for it and you don't know, how are you ever going to get better?

It's like in the diagnostic space, it's always rare if don t test it. Yeah, right. That's the truth. Listen, I'm a huge proponent of tests don't guess.

Exactly. And if we're guessing, that means we are guessing on the treatment as well. So now when it comes to the testing of it, when is the appropriate time to test?

And the reason why I ask this is that a lot of the specialty testing that's out there, we wait until the patient is symptomatic to then test. And on the back of these cups, I have prevention, early detection, and treatment intervention.

So, earlier detection is key, right? And how you said, even with your husband, if you would have had the right test early enough, who knows what the actual outcome would've been doing early treatment and intervention?

So would it be appropriate to do this type of test as part of your yearly wellness pattern? That's a dream of mine really is to, because I think my husband was a perfect example of doing everything right on the longevity side, right?

He ate a Mediterranean diet, he was very physically fit, He exercised, had no comorbidities, but he had these pathogens on board that ended up causing an early pretty dramatic death.

And if, as part of one of his annual fitness tests, he had gotten tested for Lyme with an appropriate test and knew that it was on board, we could have put him on herbal therapies, immune support, and all sorts of things to reverse any of that decline long before it showed up.

and the way that it did. And so, absolutely, I would love to get there. The earlier, the better. So, and that's one of the reasons I love antigen testing, because you can get it, you know, within days of a tick bite, instead of waiting weeks, which, for antibody testing.

But even for people that have been exposed and really want to know is this what's causing, maybe I'm a little bit more tired than usual, right? Get tested, see if it's on board and see, if you, can deal with it early before it becomes a hot mess.

So in a few simple steps, if you had the ability today to redesign the care for Lyme, how would you actually create those steps? I would have everybody, especially in endemic areas, getting screened on a regular annual basis, right?

That would be, again, because if don't know what you have, always be thinking about co-infections. You know, everybody thinks about Lyme. They think it's in a very narrow box, which it is actually not.

And so, but co infections are often not really considered and Babesia is on the rise, Ehrlichia's on rise. These are conditions that are treatable if caught and tested and treated early.

So that would be number one is just making it part of a a regular screening so that people understood what they've been exposed to. And I would say, this is prime tick season, and so one of the first things people always say is, oh, I got bit by a tick.

Well, what did you do with the tick? Oh, flush it down the toilet. Please do not flush the ticks down. The toilet, save the test, the tech figure out what you've.

Been exposed. To it doesn't mean that you have that pathogen, but it's an exposure that. You need to be aware of. Then if you. Have weird symptoms, you know what might potentially be causing.

you know, what's going on in your body. And so I think awareness is key, but also early screening and testing is the number one thing that I would want to change.

Absolutely. How do you test for the tick? Do you guys do that? We don't, there are other testing companies, you can send it to Bay Area Lyme has a recommendation of a couple of top testing agencies or companies that you send them out to and they'll tell you what pathogens are on board.

Okay, what excites you the most in the next five years about diagnostics? I think looking at the links between complex chronic illness and infection is key.

So if you look at Alzheimer's, for example, a lot of people have had a lots of discussions about the metabolic issues and, you know, the hormone issues, and the things that can lead to cognitive decline.

But I thing infection as the key missing piece. And what I would like to see is infection panels. Not just tick-borne, right? Vector-born pathogens like Borrelia, Bartonella, and Babesia need to be on the list.

But also, there's respiratory infections like chlamydia pneumoniae. There's oral infections. there are viruses like HSV and others that you need be screening for.

So I would love for, I think it's coming, You know, for when I go to a neurologist with my husband in his early days and have this atypical presentation of Alzheimer's disease where they say, let me run a pathogen panel and see what could be contributing to your symptoms and looking across all different infection types to give better answers so that they can have customized treatment to get them better and to avoid that continued cognitive decline.

Absolutely. Now, Nicole, I know you're involved in research and then also involved policy. Can we talk about that? Yeah, sure. So before I actually joined Galaxy, I joined up with the Center for Lyme Action.

The founder of CLA read my book and she called me and said, you're a very nice writer and I have another project for you. I was like, okay, what's that?

And she said they wanted to write the state of Lyne disease research, really summarize a lot of the funding in Lyme disease, and a lot of the research from Lyne disease has been funded by private organizations and private philanthropy.

And they wanted to summarize that research and show all of their learning and the science that was linking these pathogen Lymes to complex chronic illnesses.

They wanted it to write it in an accessible way. And use that to lobby with Congress to have more NIH funding for research and to really start thinking about ways to improve the situation for patients.

And so I worked in that project with them. We wrote the state of Lyme disease research, which is on the CLA website. educate Congress and show them the devastation, show how it's linked to complex chronic illnesses.

And now, of course, HHS and the Department of Health and Human Services is very much on board and supporting that this is an issue that's impacting Americans' health, and so we've been engaging.

We're part of Galaxy as part the Limex Diagnostic Prize, which is the H. H. S.

Policy, research, and the future of diagnostics

and Stephen and Alexandra Cohen Foundation to accelerate new innovations through the FDA to get it in the hands of patients, and we're really honored to be a part of that program.

That's amazing. Yeah. So, you know, right now there's a big movement that's happening, the MAHA movement, Make America Healthy Again. What are your thoughts about this movement?

I think we need to take it seriously, right? For so long, we haven't been taking our diet and, you know, toxins and exposures and so forth. I thing it's something that we all need take seriously.

And I love that Lyme is a focus in that discussion. Because, again, somebody like Russ, You can do everything right and still have a really complex, horrible disease if you have these infections on board.

I think that that is an initiative that we're proud to be a part of, right, and that's desperately needed. Right, right. And, you know, R. F. K. Jr., he's definitely an outdoors person.

So I know that the whole topic of Lyme is something that has been close to him. You know. Obviously, he is, um, big into the functional medicine world and wants more diagnostics for everyone, for the our guys in the military that are also out there.

Um, so so great to hear about that. So I want to talk about the book. Yeah. So, you know, You got the Book here. What looks in the wood. At what point in time did you decide, hey, I'm going to put a book together to get the word out?

So I've always liked to write, but I have mostly done science and engineering kind of writing. And actually the first chapter of the book is really when I started journaling.

It was a pretty interesting moment in my family. At this point, we didn't know that my husband had Lyme and tick-borne infections. We just knew that he had Alzheimer's disease.

But my kids were very young, and they didn' understand what was going on. And so… And again, he was irritable and kind of nasty. So one night he… We were getting ready for dinner, And my husbands stormed out and he left.

My son, as we were having dinner he looked at me and said, I know why Dad's mad at, you know, why he's left, that was very… Oh, what do you think? What's going on in this little six-year-old boy's head, right?

And he said, it's because he's very disappointed in us. And I was crushed, like, here's my little boy who thought that what was going with his dad was his fault and that he was the cause of his issues and his his problems.

And I looked at him and I explained for the first time, I tried to as much as I could, what was going on with his dad and that it wasn't his fault and then his Dad was sick and he needed help and it was our job to help him support him.

The next day I went into work and couldn't get it out of my mind. It was a very emotional moment and just kept circling in my head and could not focus and work.

I just sat there for the first hour of the workday and I started typing and just getting it and pouring it out on the page. And that ended up being pretty much what ended being the chapter of book and started journaling to help me through the chaos.

I'm an engineer and like to solve problems, so problems ruminate in my head and think about them over and over again. But as a caregiver, in this situation, I couldn't solve the problem.

I could not figure it out. And so it was just ruminating. and I found that journaling gave me an avenue to get it on the page and it made it feel better.

Then when he was finally diagnosed with tick-borne illness, that was the moment where I said I'm going to take my journal entries and turn them into a book, because people need to know that Alzheimer's and tick borne illness belong in the same sentence sometimes.

And at the time I was like, it's going to be a story about how my husband got better, right? And unfortunately that was not the story that ended up living.

We ended living, but if anything, that just solidified my resolve to tell the stories because the stakes are that high, so it literally can be life or death.

And people need to know that. When I was off work for 2020 for COVID, that was the year that I wrote the book. And I decided to take my journal entries and turn them into a memoir to really spread the word about how devastating these diseases can be.

It's really a raw and honest look at life in complex chronic illness and in tick-borne illness, because it was chaos. and the amount of other people that are living right now in your shoes, the shoes that you were in at that point in time, this can really help them navigate that process a bit better.

I can't tell you how many people have reached out and shared, oh my gosh, this is exactly what's happening to me or what happening my loved one, or it's so validating to know that we're not alone.

And that was so heartwarming because, you know, when you're going through something that is that challenging, it is easy to think, well, is just happening me.

This is unique to. But the more I started sharing our story, the I realized that it was happening everywhere. And that's something that makes it even more important to tell the story because people need to know what questions to ask and what helped and What can you know help if you ask the right questions at the time?

Nicole, you know, I've heard you mention multiple times about, mixing Lyme with Alzheimer's disease, right? Out of curiosity, if you were to take a guess out of the people that are living today with diagnosed Alzheimer disease what percentage would you say could potentially be people who have Lyne?

That's an interesting question, and I think the research needs to sort that out. But I the numbers are in the double digits, would be my guess. And that's really just a guess, because I that research isn't out there.

It can always be a contributor, right? And it doesn't have to just be Lyme. Like I said, there's other pathogens that can cause chlamydia pneumonia, which is a respiratory pathogen, HSV, herpes simplex virus, inflammation and cognitive decline.

And so it really needs to be a multi, like a pathobiome based approach. I mean, my husband, and this is also another paper that's being worked on for publication because I'm stubborn.

So after he passed away, I donated his brain to science. and to researchers that are looking at the linkages between pathogens and Alzheimer's disease.

And they found evidence of Borrelia in his brain. They found Evidence of Chlamydia pneumoniae in His brain, which wasn't even on my radar screen when he was alive.

and they also found evidences of Babesia otocolliae, Which is a Babezia species that until recently wasn' t even thought to be in humans. And so it was thought to be just a deer species.

But this is important because it's in a high percentage of ticks in Pennsylvania and other areas. And that's where my husband used to deer hunt, was in Pencilvania.

These pathogens can cross the blood-brain barrier and wreak havoc and really lead to cognitive decline and inflammation. I think the numbers are higher than you think.

obviously there's other issues, metabolic issues hormone issues. But as we know in functional medicine, these things are often intertwined. And so I think for anyone that is experiencing atypical Alzheimer's, early stage, really development, genetic issues or correlations, that's when you should start thinking pathogens.

I mean, we've got people reaching out, and it's like I was just diagnosed with early onset Alzheimer's, I'm in my 40s. They don't have any genetic predisposition to Alzheimer.

Those are the perfect people that I would start testing for. Vector-borne infections. Nicole, obviously we're talking

about health, wellness. What are top three things that you do for your health and wellness?

I mean, diet is always one and really I think through my husband's journey, I really learned about eating anti-inflammatory and kind of keeping as healthy and whole foods as possible.

Strength training is another one that is a core tenant, especially I'm in that So trying to build as much muscle as I can to keep me healthy and longer.

And then I think the other thing that I really started to appreciate as i was going through such a stressful period is meditation. Editation and having quiet.

So I actually got a sauna for my husband as he was going through his treatments to kind of help him with detox and other things. And he didn't like it and I couldn't get him to sit in it.

But it became my safe haven to meditate in the sauna. Yes, for quiet and calm. Because now I'm a single mom with two kids. I am the CEO of a company. You need that quiet time to get your brain to reset and to breathe.

And I find when I don't do it, I can feel the energy building.

Personal wellness, rapid-fire questions, and closing advice

That's become a core thing for me to Listen, meditation has more of a powerful effect on your body than a lot of the treatments that we do in the functional medicine space.

It's very important. You do self-meditation or do you do guided meditation? Both. Both, yeah. I'm an active user of The Brain Top. Okay, I haven't used that Yeah, especially if you buy the headset, you know, it's dr.

Patrick Porter has really developed something with that so I Want to have a little fun here to kind of get to know you a bit better. We have these Conversation cards by Stephen Barlet from the diary of a CEO.

So you'll grab that. Okay. Take that sleeve off of it and And then you can mix up the cards if you want, but just grab two random cards. You'll read the card and then answer.

OK. All right. Fortunately, they're in large text because I don't have my reading glasses on. So the first one is, what is my proudest moment? That's a good one.

I think that the thing that I'm the most proud of is my children. I don't know if that's a moment, but it's definitely when I thing of being proud, it is with my kids.

We've been through a lot as a family and my kid's had to endure a while and they've had grow up without a dad and really navigate life in a whole different way than a lot of families do.

And I think they've emerged. My son's now 16, my daughter's 12. They're good kids. Because I was a single mom, I had to make them self-sufficient and really help around the house.

and they're working hard and I'm doing pretty well despite all the circumstances. So they are my biggest pride and joy. That is a proud moment for sure.

That's that. And then the second one, what is my selfish dream? Oh, talk about bookends on the different questions. I would say my selfish dream is to live on a beach and have serenity and quiet and listen to the ocean every night and really just be a little bit more.

I think, you know, as, again, CEO, mom, running the house, I'm always doing things. And so when I was going through a lot of the journey, i started painting and little sayings that I have in my closet.

One of ones I had is, when you do, don't forget to be. And the ocean is where I feel like I get to be more. And so I would love to just retire by the oceans and chill for a little bit.

I mean, you are in Florida right now. Yes. Yeah. A couple of real estate agents. But I don't think we're ready for retirement yet. We got a lot of work.

Awesome. Nicole, as we wrap up the podcast here, if there's someone listening to this show and truly resonates with today's message, what is that last thing that you can leave them off with?

Don't stop digging and don't start advocating for yourself. It's really easy to go to a doctor and get minimized or put off the path. And you know that something is wrong with you and keep digging for those answers.

If you think that it might be a tick-borne infection, then Galaxy is here to help. Absolutely. So if people want to find you, where can they find So galaxydx.com is our website, and there's a lot of information for providers.

We, you know, really take education really seriously because so much is emerging and we're learning every day. Even at the research level, things are changing in an accurate, in a really rapid pace.

And so we have a whole lot information out there for the providers, they're also good for patients to self-educate and figure out how you can learn about these pathogens and how they can manifest in complex ways.

We're also on Instagram, you know, Galaxy Diagnostics. You can find me on instagram and Facebook at NicoleDanielleBelle.com, or Nicole Danielle Bell, and then I also have a website, NicoleDanielBell.

com. The book is on Amazon. And if you are a person that's suffering with complex chronic illness or Or if you're suffering and you want people around you to understand, that's one of the things I tell patients is, you know, maybe my story might not help you because the story is not good, right?

It's not this uplifting story that he gets better, and if your sick you might want to hear the ending of book, But it is something that you can give to your loved ones and your friends so that they understand what it's like to live in complex chronic illness and to deal with these pathogens and go from doctor to doctor and not get answers.

And it might help give them a little bit of empathy and understanding for what you're going through. Absolutely. Nicole, it was a pleasure having you on a Healthy Point of View podcast.

It was great being here. I appreciate it. Guys, you heard Nicole, don't stop digging. This is the importance of having the right diagnostics. You can literally have the answer right in front of you.

you just have to have right guidance, right coach. How I always say, every great athlete has a coach, so there's a lot that's happening in the world of functional medicine.

If you have any friends or family that you think will resonate with today's message that are potentially challenging, going through challenging moments with their health, make sure you share this podcast with them.

Make sure like, subscribe, and we'll see you for the next one.