Opening on neuropsychiatric effects of tick-borne illness

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And I experienced that firsthand where I realized our brains are just big balls of biochemistry. And when a pathogen gets in and it screws up that biochemistry, there is no amount of therapy and there's no amount of talking that can bring somebody out of that.

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This is Doctor Talks, real talk from real doctors on the issues that matter to you most. Hi, everybody. I'm Dr. Nancy O'Hara, and I'm very excited to welcome Nicole Bell to the podcast today.

Nicole is an author, an entrepreneur, and really an advocate for tick-borne and neurodegenerative diseases. Her memoir, which I highly recommend, What Lurks in the Woods, details her husband's harrowing experience with misdiagnosed tick-borne illness and seeks to help others navigate these chronic conditions.

She's originally from Boston, earned a bachelor's and master's of science in material science and engineering from MIT, so she's a real slacker, and master's of science in biomedical engineering from Duke.

And she's currently the CEO of Galaxy Diagnostics, where she combines her professional experience with her passion to change the tick-borne disease landscape.

And Galaxy's mission, which is a wonderful specialty lab, is to create new diagnostic standard of care for tick-borne diseases.

Nicole Bellu2019s background and family diagnosis journey

and really save millions of people from descending into chronic illness. So Nicole, welcome and thank you. Oh, I'm happy to be here. Thank you. So tell everybody a little bit about your personal journey, how you came to write this book, and how you got here.

Yeah. Like a lot of people, I went through the majority of my life blissfully unaware of tick-borne illness. I was working in entrepreneurial environments, startups.

The last half of my career has all been in medical diagnostics and devices. And despite that, when my husband started having challenges, I really kind of felt lost.

So he first presented with symptoms that were more psychiatric in nature. So he had mood swings. He was irritable. He was depressed. He was anxious. He had bouts of rage.

And then I realized we went to therapy. It didn't help. And then I realized he was starting having cognitive issues. He was forgetting basic things. He would forget the four digit code for our security system to the house.

He would forget the time to pick up our young kids from daycare. And he was a brilliant engineer. He was Georgia

Tech grad, computer science, electrical engineering, extremely creative.

And all of a sudden, he was just failing at basic tasks. I started researching, you know, doing the Dr. Google thing, and I came across Lyme disease, which made perfect sense because he was multiple tick exposures, lived all over the country, including several endemic areas.

And it just made sense. He was a hunter. He was always in the woods. And at the first doctor's visit, we went to kind of an integrative physician, got a full battery of tests done, including a Lyme disease test, and he tested negative for Lyme.

And, you know, even though I worked in diagnostics, I was like, okay, you know, you kind of believe what's in front of you on the piece of paper. And the rest of his tests showed that he was, you know, quote unquote normal.

And they referred us to a neurologist where he was eventually diagnosed with early onset Alzheimer's disease. Yeah. You know, I'm an engineer and it really just, it made zero sense, right?

Like, you know, he was otherwise healthy. He had no genetic predisposition. I had him tested with the most, you know, the most advanced genetic screen that was out there.

Right. No comorbidities. And yet he was failing fast. And we went from doctor to doctor and couldn't get answers. And to make a long story short, 15 months later, I figured out that not only did he actually have Lyme disease, but he also had Bartonella and most likely Babesia.

And so it was eye-opening for me that the medical system was so broken. like I said, as an engineer, you know, you're trained to look at root causes and to figure out, you know, I was working in robotics at the time and it's like, the example I like to give is it's like, you know, if the, if the, the robotic arm is cavitating, right?

And you're just shaking, you don't just put a weight on it to dampen the symptoms, right? You figure out what's going on. And I was just horrified that medicine was set up to do exactly the opposite and to just dampen the symptoms and not figure it out.

And so, spoiler alert on the book, I mean, my husband's journey doesn't end well. And so it's really given me a new mission and purpose to figure out how to give physicians tools to get a better diagnosis, to get to the answers and to uncover the root causes of some of these things.

Because pathogens are linked to so many chronic illnesses and they're misunderstood. And so that's kind of a short version of how I ended up where I'm at.

Yeah, and so much to unpack that. I mean, you know, although, you know, and my heart goes out to you for the journey that you and your family went through, but it is so common in the kids that we take care of and in this Pan's Pandas world.

that especially these neuropsychiatric symptoms, the depression, the irritability, the anxiety are not looked at as being a microbe driven immune intolerance disease.

And like you said, and you say it, I think in the intro of your book, root causes were a doctrine in engineering, but elusive in medicine. And I'm lucky enough that my mentor was Dr.

Sydney Baker and he calls medicine, name it, blame it, tame it. And that's what we do. And even finding the genetics is not the root cause. Genetics, as I say, may load the gun, but environment pulls the trigger, and unless we're looking for what in the environment could do it.

And then, like you said, you want to trust the doctors and the testing that they're doing, but the testing is so inaccurate. And one other quick thing I wanted to say about your book.

It was funny. I was reading parts of it. So I've read it twice now. And one of the things you said very early on was that your high school English teacher told you you had a knack for creative writing.

And you do. It's wonderfully written, though, and poignant, though. tragedy of a book, my English teacher asked me what was my problem with writing. And I went on for about five minutes talking about how I talk too much and use too many words, et cetera.

And she finally said, you mean you're verbose. And I'm like, yeah, see what I mean. So I had to have an editor when I wrote my book to sort of Bring me in, but yours is so well written.

But anyway, so talk a little bit about the systemic challenges that you see in the tick-borne illness category and diagnostics, accessibility, treatment, any of it.

Yeah, I mean, I think number one is just misconceptions of what the category is, right? So I went in and said, okay, Lyme disease is a rash and a fever.

And I had no idea that depression, anxiety, and all sorts of other neuropsychiatric symptoms were related to the disease. As I started digging in, it kind of came up, you know, leading to the second problem of diagnostics.

But before I move off of the category issue, it's not only that it's Lyme disease, but it's also so many other infections that go along. You know, ticks are nature's dirty needle.

Misdiagnosis, broken testing, and the need for root-cause medicine

And, you know, anytime I talk to a physician such as yourself, who's skilled in these pathogens, as soon as I say that my husband had bouts of rage, they're like, oh, Barnella, Exactly.

But I mean, I had zero clue. I'd never heard of Bartonella at the time. And if I had done my Dr. Google, I would have come up with cat scratch fever, which would have been a complete misfit for my husband's case.

You know, now I understand the linkage between that pathogen and some really devastating neuropsychiatric conditions, which can, at the end of the spectrum, go all the way to like completely institutionalized schizophrenia.

And, you know, I experienced that firsthand where I realized, you know, our brains are just big balls of biochemistry. And when a pathogen gets in and it screws up that biochemistry, there is no amount of therapy and there's no amount of, you know, talking that can bring somebody out of that.

And that was for somebody who, you know, hears this as an engineer, you're like, yeah, that sounds interesting. But I mean, having seen it and lived it, it is, I mean, my husband was the most logical individual in the world and he was hallucinating.

You know, he thought people were swinging from the trees in my backyard with machine guns trying to kill us. And I just, I never would have thought at the time that that could have been caused by a pathogen.

And so I think the first problem is just category, you know, category, like, okay, you have a rheumatologic condition, you've high risk of, you know, tick-borne exposure.

That could be if it's something, you know, you have a cardiac issue, neurological condition, like these are multi-systemic issues that I think The box that most people put tick-borne illness in just is not appropriate.

And so that's that to me is the biggest problem. And one comment I want to make about all of that, though, is, you know, as we have practitioners hopefully watching and listening to this podcast, as well as families, the whole should have, could have, would have, you know, I was there too.

I didn't even know what Bartonella was, and I was a doctor when my son first got diagnosed. And I think that we as

caregivers also have to give ourselves break, that we can only know what we know.

And now we can turn what we know into advocacy and to help, but going back and beating yourself up for what you didn't know and shouldn't have known at that point in time doesn't help your child or your loved one now.

Yeah, that's a fantastic point and I think anybody who's been a caregiver has gone through that journey right because you always say I should have known and it's like well how would I have known right I had multiple doctors telling me that he was fine, you know, or that he had Alzheimer's disease and to just accept the diagnosis.

You know, I think the other major problem, and this is why I'm doing what I'm doing now, is the tests and the tools, right? If you go to the doctor and you get a test result that tells you you don't have an infection, it is hard for any rational person to walk away from that and say, well, the test is wrong, right?

The doctor's wrong. No matter how skilled you are and no matter how much you study, it's a very difficult thing to just, especially as an engineer, right?

You're like, oh, well, it's the data says that he doesn't have it. And unfortunately, when you dig in, you realize that the test methods are only as good as what they're looking for.

And so providing better tools for diagnosis, giving a toolkit is what we're really focused on. And then as we talk more about Galaxy, providing testing results that don't rely upon the human immune system, but actually go after direct detection.

That's a key problem to be solved because the human immune system is hugely variable with these pathogens. These pathogens are stealthy, they evade, they confuse, they manipulate the immune system, and there's all sorts of science that shows how they do that at the cellular level.

And so relying upon an antibody response as our primary test methodology is fundamentally flawed. And that's been accepted, but it's still not fixed. And that's the other key challenge because the third challenge, I would say, which I'll stay out of because I'm not a doctor, is treatment and making sure that it's effective.

But the step before that is if you don't know what you have, you're never going to get an accurate treatment. And so the diagnostics is that first piece.

Right. And the thing that a lot of people don't understand, including many doctors, is that many of these tick-borne, vector-borne diseases actually cause or exacerbate immunodeficiency.

So as you're saying, the very method in which we look for the underlying diseases is flawed because we're missing at least 30 to 40 percent of the children or adults that may have that disease because they can't mount the antibody or immune response needed to detect the underlying problem.

Yep. And that was the case with my husband. I mean, he had probably been battling these pathogens for over a decade and his immune system was suppressed.

And so he wasn't mounting a sufficient antibody response to trigger the test. And so that's a challenge that we need to get over. And I like to say, doctors shouldn't have to treat blind, right?

These are complex pathogens where many patients have multiples of them and symptoms overlap and and the treatments depending on which modality for treatment use can be very different based upon whether it's Babesia or Bartonella or or Borrelia and so expecting doctors to guess is really just not where the environment and where our medical care needs to be.

And so that's why I'm so passionate about providing tools. Absolutely. And as you said, I mean, one of the things we're trying to get away from even is calling it Lyme disease, because that's such a misnomer in that Lyme was first found and diagnosed in Lyme, Connecticut, of course, very close to where I live.

that's Borrelia burgdorffii. But there are multiple species of Borrelia, and that's not even to scratch the surface of what we call co-infections, which are really so common.

More than 40% of ticks in our area carry Borrelia plus Bartonella and Babesia. As you said, your husband had the big three. Yep. And I have a similar hate for the cat scratch fever with Bartonella.

It's like that's one manifestation of the disease. But as we've realized with the research from Dr. Breishward at NC State and some of his collaborators, it's way more complicated than that.

And so again, it's that first piece. What's the box that you put it in? And I think that the box that tick-borne disease has been put in has been hugely limiting for the field.

And it's led to massive amounts of misdiagnosed chronic illness. Absolutely. So talk a little bit more about some of the groundbreaking, you know, advancements, especially the direct detection methods.

Yeah. So, you know, on the other end of my journey, you know, my husband passed away in 2022. And so the first step was I kind of entered the advocacy world to share the story, right?

Because to your point as a caregiver, it's like, don't beat yourself up for what you didn't know. But sure as heck, now I can go and share what I do know so that other people don't have to go through the same journey.

And that was hugely helpful and frankly, very therapeutic to tell the story and to just get it out there. And it was really, I think, what I needed to help heal from the scenario because it was really, as you read, a crazy journey.

And so on the other end of that, I was like, OK, sharing my story is a good step, but I really want to solve this problem. And I've worked in diagnostics before.

I've gotten products through the FDA. I'm an entrepreneur, an engineer. This is my calling. I've always done startups and kind of wished for something that I felt passionate about to really focus on and give everything I have and unfortunately the the passion just dropped straight in my lap and in my family and so I said okay diagnostics is where I think the biggest problem is in medicine because again if you don't know what you have then you don't you can't get accurate treatment and so I dug in and just I had taken time off to focus on the family and when I was ready to go back to work I just started researching okay what's the standard of care what are the specialty labs that are out there in the space what are the research You know that's going on in the area and what approaches are they taking and just kind of map of the landscape and galaxy and Dr Bryce words work and the work that was done at George Mason University.

And as you know, now at galaxy it just really stood out to me as the right approach, you know one. There was published science, so it was very clear what was going on.

Direct detection diagnostics and Galaxyu2019s approach

And it was published in terms of the science of how they were doing the assay, what they were doing, but also clinical utility of the assay, which is key.

What is it uncovering and what are we learning from the assay? And is it actually diagnosing people in a way that makes sense in medicine? And so that's what drew me to the company.

And I think the other thing that I really liked was the approach, which is direct detection, right? Because a lot of companies are out there and they're doing better ways of doing antibody-based testing.

And antibody testing is just looking at the host immune response. And as I said earlier, and as you said, right, immune response is complicated. Everybody's different.

Everybody has different genetics, different epigenetics. Everybody has different exposure levels. And these

pathogens are super amazing at manipulating the immune system.

And so it's an indirect marker that is often inaccurate. And that's what leads to, especially the standard of care for Lyme is 40% to 60% accurate. And that's a problem.

And so direct detection is the right problem to solve. It's just been hard because these are low abundance pathogens. They don't like to exist in certain samples that you might test as a diagnostic lab.

And that was the problem that Galaxy was trying to solve. How do we lower the limits of detection to make direct detection a a reality. And then understanding the microbiology to know that solving that problem might be different for different pathogens.

So for example, at NC State for Bartonella and Babesia and for relapsing fever Borrelia, to your point, there's different Borrelias and they have different things.

And so blood-based detection and improving the sensitivity of that is a great approach for those pathogens. Same for Ehrlichia and anaplasma and other bloodborne infections.

But for Borrelia associated with Lyme disease, it just does not like to be in the blood and it's in low abundance. The analogy I often use is you're more likely to be struck by lightning in your lifetime than you are to capture Borrelia in an aliquot that gets tested with PCR.

There, Galaxy had partnered with George Mason University, which had urine antigen testing because Again, these pathogens are good at manipulating the immune system.

And one of the ways they do that is they spit off their surface proteins. And those surface proteins are meant to basically, if you do have free antibodies, they capture on the free surface proteins rather than the pathogen itself.

It's kind of ingenious. And so by capturing and concentrating those from a urine sample, it's shown fantastic results for both acute and chronic patients.

Again, solving that direct detection challenge. How do we show who's infected? I think tick-borne exposures are huge, and antibody testing can be confusing because some people don't mount the response, some people may be having a great response, and their immune system is actually taking care of the infection.

But direct detection is a good tool and the tool that's needed in order to say, hey, are these symptoms linked to some sort of pathology that can be treated?

And that's what we're going after. Right. And the urine test is something that I've recently started using. And the other advantage of it as a pediatrician is urine.

It's a lot easier to get urine than it is to get blood in children. And So it helps not only from an accessibility standpoint and feasibility standpoint, but also, most importantly, a direct detection method that can be helpful.

in diagnosing this for physicians. Yeah. And it's great for an acute disease where antibodies take four to six weeks to develop. And research has shown that the time to get the most effective your treatment is going to be is the earliest you get infected.

And so the data has shown that at first signs of symptoms, we actually get positive results. And so we can detect early. And then for chronic disease, it's great for discerning so some people don't mount an antibody response but they might still be infected or maybe they're still sick but they actually don't have an active case of Borrelia they've maybe got Bartonella or Babesia and so for the chronic cases it's great to discern you know where might we still have a case of persistent Borrelia and where might we have other factors or immune dysregulation, co-infections, mold.

As we know, these are super complicated patients and so you need the ability to understand exactly what's impacting that particular person. Right. And which pathogens can you detect through the urine?

Yeah, so for right now it's Lyme Borrelia, although George Mason and their research has shown that it's applicable to other pathogens and co-infections.

But right now we have a urine antigen test for Lyme and then we just literally last week launched our blood-based assay for Borrelia Bartonella and Babesia.

And this assay has been driving clinical discovery over at NC State and has been essentially identifying new cases of Babesia and Bartonella in high-risk populations and in really complex chronic cases.

And now we're really excited to launch it commercially. That's great. And that's a direct detection method also? That's direct detection. So there, the technique that we use is a little bit different.

So it's a PCR-based approach that's looking for the DNA of the pathogen itself. And I think a lot of doctors are, well, PCR never gets positive. And so they've kind of written it off.

And that's true. Traditional PCR is very unlikely to capture the pathogen because they're in low abundance. And so we do a couple of things that are unique.

So one for Bartonella, we do a proprietary enrichment step, which actually helps to grow the pathogen to higher levels. But the other thing we do is we use an advanced technique called digital PCR.

And the best I can explain this is like, it's like looking for a needle in a haystack, right? So if you've got a big old haystack and there's a needle in it, traditional PCR is basically just saying, I'm going to take one measurement on that haystack and I'm going to hope that I get the result.

Exactly. And that's why PCR is not cutting it because you're very unlikely to get that. But what digital PCR does is it takes that haystack and it separates it out into 20,000 piles.

And then it interrogates each one. And so it's really great for increasing the sensitivity and actually identifying low abundance pathogens. And it's been used in other areas like cell-free DNA and other kind of approaches that require that type of sensitivity.

And at NC State, they've really pioneered the technology for use within these low abundance pathogens, specifically, you know, like they're making new discoveries in Bartonella and Babesia.

They've identified cases that, you know, before, you know, their work, only a handful of cases of Babesia had been ever identified. Like, for example, Babesia otocolli and Babesia divergens.

Most people think those don't exist in humans or don't exist in the U. S. And guess what? They're scanning patient populations and doing sequencing to confirm that it's actually in a high number of these chronic patients.

And so, like I said, we're really excited to bring that to doctors as a toolkit to help understand what patients are suffering from. And that's not yet to market.

It is. We just launched it last week. Last week. Last week. And what is it called and where do people find it? Yep. So it's called, we call it the BBB assay.

So the three B's. And you can, if you look at Galaxy's website, you can get access and we have a fantastic, you know, a salesperson that will follow up and give any providers information that they need.

And it's a it's a full blood test, not a blood spot. It's a blood. Yep. Full blood. Okay. Yeah. Got it. Got it. I'll I'll get on that next week. Yeah.

But but I think that's really important because so much of the time, even if these families do find Borrelia through antibody testing and treat that, you're really often missing, especially in the Northeast, where 41% of the ticks carry Babesia, as well as Bartonella, as well as Borrelia, you're really missing the Bartonella and the Babesia.

And as you said, with these neuropsych symptoms and many of the symptoms we see in the kids, those are often there too. Yeah. And I think what Dr. Breishwart's finding in his research is that a lot of these really complex cases, the co-infection is the norm, not the exception.

And so he was studying mostly Bartonella just because of his history, but they've recently turned their expertise to Babesia. And like I said, they're uncovering cases that were previously not understood.

And what they're finding is that the majority of those really complex cases are also suffering with babesiosis. And so that's the power of the assay, the 3Bs, is looking at it holistically.

And I think over time, we'll extend it to other top pathogens, so relicia, anaplasma, rickettsia, and really get a wide panel that can search for all the top pathogens.

Right. And, you know, as a clinician, these tests are very expensive for our families and some don't have any access to them. I mean, they're in the middle of nowhere and can't really access this.

And as a clinician, I have treated children by using a clinical diagnosis, but I always You know, I take a deep breath when I do that because one, medical legally, that's not in my best interest or in the family's best interest.

Two, it is, you know, there's a lot of clinical acumen. I've been doing this for 30 years. I get a good sense. I'm often right, but you can still miss things.

And as you said, I may not two years ago even know about Babesiotocole, let alone think about it for a child. So how else are we working to make these tests more accessible for families?

That's a great question. So, you know, one of the things that we've done is we, you know, I took over as the CEO of Galaxy in June of last year, and we kind of crystallize our mission and our mission is not to grow a specialty lab.

That's part of our plans and we want to get our assays in more hands, but our mission is different. Our mission is to change the standard of care. We want to be in the mainstream.

And so we're in the process of looking at productizing our assays so that we can sell them to the LabCorp and Quest of the world. Because if you want to be mainstream, I don't know how many people listening have ever seen a LabCorp or a Quest operation, but it is impressive.

They have the number of samples, the practices that they use, right? That is what it takes to be mainstream and to be the standard of care. And I don't have any intention of building that a galaxy, especially since it already exists and it's optimized in other places.

And so we're looking at productizing our assays and taking our innovative technology and getting it through the FDA. I've done that several times in my career and we're looking to submit and then we'll provide test kits that can go in the hands of those large labs to essentially make it more accessible.

And so that's a huge piece. The other key piece is reimbursement. Right now, I think we do have codes that people can get reimbursement for, but it might only be partial reimbursement.

And so we want to up that game and make it fully paid for. And so we're looking into that and developing our strategy and figuring out how to make it accessible.

Because a lot of the people that are out there, I mean, they're kids. They're people working outside in the environment. I mean, I know the amount of money that I spent on my husband's case was ridiculous.

And that is not the way that it should be, right? Everybody should have access to these tests. And so that's the problem long term that we're looking to solve.

Yeah. And I so love that mission.

Launching the BBB assay and expanding access

And when the mission of a company aligns with what we're trying to treat, it just It basically brings me to tears because I think that getting this to conventional labs, not only for the financial burden, but also that more physicians will see it.

Most physicians won't even consider specialty labs because you have to develop an account and you have to gain more knowledge about that lab, et cetera.

And it takes a lot of work. So for the regular pediatrician, the volume-based businesses, having this as part of LabCorp, Quest, or standard labs like that will be a game changer.

Yep, that we agree and that's what we're moving towards because that's how you really move the needle. Yeah, and you know, for those of you who know me, you know I am always looking at silver linings and as tragic and difficult as your personal journey was, the silver lining for all of us is that you've taken your incredible skills in entrepreneurship and engineering and brought that to our world.

So I can't tell you how grateful we are for that silver lining. Thank you. Thank you. Yeah. You do what you can, like you said, to prevent other people from going down the same journey.

Yeah. And let's talk a little bit about the power of community, you know, because I think that you've joined our community by hook or by crook, and the community is very strong.

So talk a little bit about that and driving change for these patients. Oh, my goodness. I can't even say That's been the silver lining for me is the amazing people that I have met because, you know, there are so many people that have been impacted in the worst possible ways, but out of it, really taking whatever gifts they have and are trying to use it to make a difference, whether it's in advocacy or the science or you know, raising funds or whatever it is, some of the, the community that I've a lot of the community that I've engaged with has just been absolutely uplifting.

Right. And some of those, and the other thing that's amazing about this community is a lot of those people are giving their gifts and they're still sick.

Right. I mean, I'm fortunate enough that I'm well and I can give it my full energies, but I have a lot of colleagues, you know, throughout the advocacy community that are giving so much and they're doing it while they're managing their own illness.

And so that is uplifting because I realized, you know, it's like the change happens when people who care, you know, step up and kind of do something to make a difference.

And I think there's a lot of turmoil in our world and there's a lot of problems to be solved. But I have confidence that this one's going to get addressed because there's a lot of really high powered people.

And I will have to say one thing that's also been awesome is that I'm an engineer. So I've spent the majority of my career working mostly with men. And in this community, I've got so many powerful women around me.

It's awesome. And most of the time I look around on my Zoom calls and they're all women and I'm like, wow, this is awesome. And so that's also been great.

But as women, we're also often caregivers. And I've also watched videos you've done on caregivers and your

advice as a caregiver. Can you talk a little bit about that?

Yeah, I mean, I'll say I've done a lot of things in my career, but being a caregiver was by far the hardest one. I mean, dealing with somebody that has psychiatric issues or dementia or just is chronically sick all the time is so challenging.

And the way that I try and explain it to somebody who's going into it or who's in the middle of it is to provide a little bit of perspective. You were once doing one job, but now you're doing three jobs, right?

Because you have everything you were doing before. That was your first job, right? Then you have everything that the person you're caregiving for was doing.

So in my case, it was my husband was doing all the stuff around the house and all the things with the kids and just a lot of the logistics of our family.

Now I had to do everything he was doing. So that's job number two. Then job number three is I'm trying to figure out how to get him well and how to arrange his medical care and doing research in this complex chronic disease state.

Not to mention getting to appointments, navigating that. Paying for it, all the things. Basically, you went from one job to three and the whole time you're beating yourself up because you're not doing any one of those jobs well and it's like, well, how how could you be expected to do three jobs?

Two of which you're just learning on the fly because I had no idea the stuff that my husband took care of at the house and all the things he was doing.

And then the medical side of it also completely untrained for. And so you're literally thrown into two new jobs and you're trying to balance it. And then we, like you said earlier, you're beating yourself up because you're not doing a good job and you didn't see something and you didn't understand.

So I really just try to encourage caregivers to give themselves some grace and to realize that you can't do it all. And the other thing that I try and encourage them to do, which I frankly was pretty bad at, was asking for help and just really leveraging the community around you to ask for help.

That's hard. It seems so simple. Just ask for help. Get your friends to help and so forth. But disease and especially in the neuropsychiatric space and in the dementia space, there's a stigma that goes wrong with it.

My husband was embarrassed. He was a brilliant engineer. And he was ashamed to tell people that he was losing his mind. And he imparted that shame on me because it was like, well, I don't want people to know.

And I don't want to be a burden on other people. And so you don't ask for help because you have the pressure to kind of do it yourself or to figure it out.

And I almost imploded because of it. And I'm pretty strong and stubborn. And I mean, it nearly broke me. And so I try and… I've learned from that and I've watched other people do it differently and how much easier, not that it's ever easy, but how much more sane, I will say, that their journeys were because they leveraged the community around them and asked for help.

And if you are part of the community, I have a couple of words of advice too. One of the things is, as a caregiver, if you just say to the caregiver, what can I do to help?

As a caregiver, you're so overwhelmed. Like, now I have to think about something else, how you can help me. I did have grace when my my former husband, who my mother would call her husband, which I always liked.

But but anyway, when he was very sick with cancer, I had a day where I could just sit down and because

everybody what can I do? What can I do? And I just sat down and I said, OK, what are other people's strengths?

And for example, my dad was really a dog on the bone when it came to insurance companies. And our insurance had dropped us because I had treated my husband for Lyme disease because nobody else would.

But I hadn't documented it. And so they had dropped us. And so I put my father on getting our insurance back. And one of our friends was an amazing cook, and I stunk at cooking.

And I put her on cooking us meals once a week. But as somebody in the community, thinking about what your strengths are that that caregiver, that family may need, and just giving that, or at least offering that.

And as the caregiver, just taking a breath and thinking specifically about the people in your life and what their strengths may be that they could give you.

They love to go for walks on the beach. They can walk with you and just listen and let you cry and bitch and everything else or cook or make calls for you.

But I think the specificity of it is really helpful as a caregiver. Yeah. And I mean, some of the best help that I got along the way was just a neighbor offering to come over and sit with Russ for a few hours so I could get out of the house or do something with the kids, you know, bringing over some dinner, like basic things.

You know, I think my mom really helped me one time kind of flip asking for help on its head by saying, you know, look, if you had a friend and they were going through something really tragic and really difficult and they wouldn't allow you to help.

Wouldn't you be kind of upset about that? Wouldn't you want to give your, you know, to help in some way and to make them feel better? And it's like, well, yeah.

So basically by not allowing your friends to do that, it's almost being selfish because you would want to help them and they want to help you. So let them do it.

And to your point, which is a fantastic one, is figure out how you can leverage other people's strengths because every people, people are good at different things and sometimes it literally can be as simple as just letting somebody get a break by, you know, just sitting with the person and having a conversation and it can make all the difference.

Yeah. And the other thing I'd add to that is when the child or your spouse or any family member is going through this, when they can, also have them weigh in.

Because for example, when my husband now was going through a lung removal, we had to figure out other people to help him. And the ones that I had in my mind that could come and just sit with him or be with him, he's like, no.

I can't be vulnerable with that person.

Community, caregiving, and practical coping strategies

And even when it's a child, giving them some choices, because they don't want to be put upon. You may think Aunt Sarah is great to come and sit with Johnny, but Johnny thinks Aunt Sarah is a, you know.

And so giving when possible the person that is going through this some choices is also really important. Yeah, it is. I think there's a lot of, again, confusion, shame, things that go along.

It's just part that comes with the disease state, right? And so that was absolutely something. My husband felt like he was losing his dignity. And so giving him some sort of say in the matter, even if it was something small, really mattered.

And oftentimes, I was so caught up in doing the right thing that I would forget that piece. You know, like I would be talking to a doctor in front of him, in front of Russ, about all of his symptoms.

And it would cause Russ to spiral downward, because he's like, he would disagree. And he just didn't want to hear how bad things have gotten. And so figuring out ways that you can do that in a way that allows people to keep their dignity is really important.

Yeah. And to the practitioners out there, one of the things that I often do is I will talk to parents alone. We have another place where kids can go. It's a great time to let them have their iPads or their phones.

But talking about the things from a year ago or five years ago or even currently that the child is going through, it can trigger the worsening of the symptoms, the anxiety, the depression, the OCD, the mood instability.

So making sure even if it's a child with autism that you think may not be hearing, they're hearing everything. So being clear on that. And the other thing I've heard you say, Nicole, is about being active rather than reactive in your care and trusting your gut.

Yeah. Yeah, absolutely. I mean, I think I'm a project manager by knitting, right? And so one of the things that I tried to do was organize and communicate.

And so it's really hard. I really sympathize with doctors because you're basically even in a functional medicine environment where you're sitting with somebody for two hours, right?

Which seems like a really long time in the context of medicine. but you're trying to understand a month's worth of living in two hours. Or years worth of living.

Right. It's just really, it's challenging. And once I kind of put my project management hat on and said, wow, that's a really hard thing to dissect complex chronic illness in a quick session with patients who are sometimes not in their right mind and caregivers who are definitely not in their right mind.

And, um, and so I started just writing things down and, you know, and taking a log every day. And, um, and then before my appointments, I would, I would sort through it and look for trends and come up with questions.

And so every time I would show up to a provider presentation, it would be here. What, who were my observations? Here's where the things that we worked on and here's what I noticed.

And then here are my questions and. And I found that it made it way more efficient of a conversation because it helped that person get up to speed. My provider was great about reading it beforehand, so every dollar that I spent was well done because it was efficient.

And it really just helped me feel like we were tackling the problem in the best way that we could. I like to encourage people and it's hard because that's my skill set.

I'm a project manager and I like to run things and other people don't take that necessarily as naturally. But to your point, maybe somebody else in your network does and they can help with certain things and just writing things down because that's the other thing is I've always been able to keep things in my head and just kind of manage and But in the chaos, there's no way you can.

And I realized that because as I wrote things down, and then I would go back and look at it and be like, oh, yeah, I forgot that. Exactly. Oh, I would have never noticed a trend if I hadn't written it down.

And so journaling and coming up with systems that patients can use and help communicate to doctors, I think, is something that needs more work. And if you do it well, it can be powerful.

Yeah, and to the practitioners out there, you know, those of us who have been doing this for a while have have

very long questionnaires and lots of information that people fill out beforehand.

And most of my patients find it very helpful because those that haven't on that timeline haven't on that project management of the whole thing now are sitting down and have to reflect.

And they pick up things that they never thought of before. Oh, yeah, this did happen after we went to grandma's after she had the water leak. Maybe it is mold, or this did happen when we went to the Poconos, you know, etc, etc.

Yeah, they have that symptom. For those of you going to practitioners that may not do that, for the parents and the families out there, do what Nicole is saying and do write down that timeline, do journal, do bring it to your doctor.

When they see that book of notes, sometimes they take you more seriously. Great advice. Yeah, and I had a simple symptom tractor on my phone. And so I would basically, at the end of every day, I would kind of write down.

I'd had certain symptoms. I would rate them on a scale of 1 to 10. And I would put some notes. And that was enough. It would take me five minutes every day.

And that was enough for me to see trends. And it's hard to see the forest through the trees, especially when you're primarily in chaos management. Again, back to the three jobs, right?

Yeah, exactly. You got to figure out a way to make it easy to help yourself in that endeavor. Right, right. And the chaos management is also important because of the PTSD of this disease.

And that tracker helps you to see when you're, you know, I always tell the story, you know, my son was in college and we were together for four days and he had been doing really well and he said to me, Mom, I'm just, I don't feel good.

Something's off. And I am up for four nights back in the rabbit hole of, is it Borrelia? Is it Bartonella? Is it strap? Is it mold? You know, on and on and on.

After four days, he goes, you know, mom, it's about a girl. And in that moment, I realized that my PTSD was also keeping me from healing and keeping him in a role that he didn't deserve or need at that time.

And even when you're in the midst of it, when you have that symptom tracker, you can say, OK, this was a 10. Now that we're treating, we're at a 7. It's still awful, but it is better.

And all of that can help. Yeah, that resonates so much. I think it's It's a journey, and it takes time to unpack it and to deal with it. And I still deal with it with my kids and myself.

But the best you can do is learn. And again, I want to provide science that helps people figure things out. And I'm very encouraged by the work that's being done that there's going to be better solutions out there.

Absolutely. So tell people first how they can find Galaxy. Yeah, so you can find us on our website, so galaxydx.com, so that we have information on there and all of the testing.

We have the direct detection options. We still believe in antibody testing. It's useful for certain things. We have best-in-class antibody testing for Bartonella and soon others.

And you can find all the information. You can also reach out. We've got a great customer care team, and they're happy to help you with any questions that you may have.

Finding Galaxy, the book, and closing encouragement

That's great. And then how can they find you and your book? Yeah. So the book is What Lurks in the Woods. It's

on Amazon. I do have a website. It hasn't been updated in a while.

It's NicoleDanielleBelle.com, but it has some information. And I think the thing that's useful on that platform is just some videos that we have that explain the challenges in diagnostics, explain some of the uh, the technologies that can help, help that.

And we're, we're doing that now at Galaxy Two more. I think one of our, because that first problem that I talked about is awareness in the box, one of our ways of achieving the mission is to educate.

And that includes educating providers and also educating patients and, and really educating our government and all the things. And so there'll be more kind of videos and resources and, um, things that are related to just general tick-borne illness and also the science-related tick-borne illness that you'll see coming up as we progress through the year.

That's fabulous. And any last words of encouragement, hope, or anything that you'd like to leave our listeners and viewers with? Yeah, I mean, like I said, I really do feel that there are a lot of really passionate people trying to solve this problem.

And I also spend a lot of time steeped in the science and I think the sciences is out there and the science is coming and solutions. will be provided.

It may not be tomorrow, and it may not be readily available to everybody just yet, but we're going to get there. And I think the more people get involved, I mean, one of the messages that I've used on my personal advocacy work is demand better.

Don't just settle for a doctor that's telling you you have some random symptom-based diagnosis who wants to give you immune suppressants and steroids.

Right? Don't. Demand better. You deserve an answer. There's a reason why your symptoms are causing. Symptoms are your body telling you something's wrong, so listen to it.

And so I think if we all demand better, then it's going to happen. And the more that we can raise our voices, the more that we can talk to people that have influence, the better off we're all going to be and the faster that we'll get to that reality where we have better solutions.

Absolutely. Well, Nicole, thank you for your grace, for your advocacy, for your brain, for everything you're doing in this community, and for joining us today.

And thanks to everybody for listening and watching, and we'll see you again soon. Thank you so much. Thank you for tuning into Doctor Talks. We hope today's episode has enlightened and inspired you on your path to optimal health.

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