Grief, caregiving, and healing

Looking back, you must have so many lessons about resilience and the process of grief and healing. And what would you share with people who are on that journey now?

Ooh, I mean, the grief journey is hard. I remember there were many, many times when I was sitting on the floor of my closet just crying, feeling completely at a loss for what to do and how to move forward.

We had two young children. My husband was declining. His care, my navigating two young children and being a mom and then my job, it was awful. And I think one thing that helped me was journaling and studying.

That's what led to my book where I I did that primarily as a mechanism to heal and to understand the lessons from the chaos, because I think it would have been easy.

Well, actually, I don't know if it wouldn't have easy, but it it, would've been one path to just kind of say, well, that's over and I'm going to move on and do something different.

I'm the type of person that likes to learn from things and likes figure out how to help others and how learn form the journey. And that made it a lot easier for me to process and to talk about what's happening.

But for anybody that thinks that there's a magic secret sauce to getting through it, it's just through. That's it. You just have to survive sometimes and then live for and that's extremely messy and devastating, honestly.

Welcome back to the Think Well, Age Well podcast. I am your host, Dr. Heather Sandison. Today's guest is bringing together the mind of an engineer, the heart of a caregiver, and the determination of true advocate.

Nicole Bell is an author, entrepreneur, CEO of Galaxy Diagnostics, a company dedicated to improving the diagnosis of Lyme disease and other tick-borne infections.

Her path to this work was not one that she actively chose. It was born from tragedy. After years of searching for answers, Nicole's husband was ultimately found to be suffering from a severe tick-borne illness that had been misdiagnosed, at times even raising concern about early onset Alzheimer's disease.

Rather than allowing this experience to end in loss, Nicole has transformed it into a mission. Through her memoir, What Lurks in the Woods, and her leadership at Galaxy Diagnostics, she is working to change how we think about chronic illness, stealth infections, the gaps that unfortunately still exist in modern medicine.

Nicole Bellu2019s background and husbandu2019s diagnosis

Nicole holds degrees from MIT and Duke University in engineering and biomedical engineering. Her greatest expertise comes from walking alongside someone she loved through a devastating medical journey and refusing to stop asking questions.

Nicole, I'm delighted to have you here. Welcome to the ThinkWell H-Well podcast. Thank you so much. Your story begins with this deeply personal health crisis.

Can you take us back to the beginning of that journey and what kind of time when you first realized that something more than stress aging, typical aging was happening with your husband?

Yeah, I mean, his first presentation was all mood-based. You know, he was depressed. He was anxious. He was irritable, sometimes kind of nasty. And so we were going to therapy.

We were trying to work it out. But that moment when I realized it was something deeper was really when he started forgetting things, right? He started for getting the time to pick up our kids from daycare.

the code to our house security system. And this was a brilliant engineer who was electrical engineering, computer science, and all of a sudden he was struggling with some basic tasks.

He was 59 when we first realized and started going to the doctor and then he age 60 when he diagnosed with early onset Alzheimer's disease. That was his official diagnosis.

Wow, so this forgetfulness, this cognitive changes in his 50s and early, early 60s, right at 60. Why did that experience kind of teach you about the overlap between neurodegenerative conditions and hidden infections?

Yeah. I mean, honestly, the whole experience changed my view of our healthcare system and of how we should look at symptoms and how should we look a chronic illnesses because, you know, and I actually thought about Lyme disease very early on.

We went to the doctor and they tested him for Lyne and he tested negative with the current standard of care. And I didn't even know enough to test for common co-infections.

You know, that led us to be misdiagnosed for an extra 15 months, right? He had probably already had these pathogens on board for years slowly doing damage because, you know outwardly, he was extremely healthy.

He was, a hiker, biker. he would do all sorts of outdoor activities, but there was kind of this smoldering problem that eventually came to a head. Now I realize that pathogens can manifest in a lot of different ways, right?

And neurological, these especially tick-borne pathogens or vector-born pathogens, they have a lots of neurological components. And I never would have thought his anxiety and his mood disorders were an infection when they first happened.

But now doing this on a daily basis, I realized that's actually quite common. So tell me about, you mentioned that this changed your entire perspective of medicine, of modern medicine.

Can you just walk us through that? What did you think before, and what do you believe now? Yeah.

Why Lyme and tick-borne illness are often missed

I mean, the first thing that I think anybody who's dealing with complex chronic symptoms is when we went into that first doctor's visit, I really asked her to dig deep.

And this was an integrative medicine physician. It wasn't just kind of a standard primary care physician that would see us in 15 minutes. And she ran a pretty comprehensive workup and I remember getting pages and pages of results of his lab work being.

And so I think the thing that, that I learned is really, you need to dig deep and you to figure out if you know that something is going on with yourself, your loved one, don't accept that.

you know, your labs are normal, and then move to some sort of symptomatic-based diagnosis. Because a lot of what people in complex symptoms end up with is these diagnoses, which really aren't root causes.

I mean, even Alzheimer's disease is not a root cause. It's a manifestation of the neurodegeneration that's going on. But we see people every day with chronic fatigue syndrome, fibromyalgia, idiopathic arthritis, you really digging a layer deeper and then also advocating for yourself.

It was really quite disheartening. You know, when I would go into the neurologist and I'd ask questions, they almost chastised me for asking questions in the first place, right?

And that is what disillusioned me about our current care system is They're really just designed to get you in and out of the office, give you a prescription that may or may not be helpful.

And the lack of root cause analysis was something that was really frustrating to me. So you mentioned that you had actually done Lyme testing and it came back negative.

Talk us through how that could happen. Yeah, so a lot of people don't realize the current standard of care for testing is actually often incorrect, especially for early stage disease.

There's been multiple publications by Bay Area Lyme and others that show that in the earliest stages of disease, it's, you know, over 70% inaccurate. So it misses over seventy percent of cases.

And a lot of the dogma in the literature would say, well, that's just early stage disease. And the reason that that happens is because it's an antibody-based test, right?

So it is looking for the host's immune response to the pathogen. But antibodies can take four to six weeks to peak, and so you're going to miss the early stages of infection.

The problem is that is when the pathogens is the most treatable. Once it disseminates into tissues, it becomes a little more difficult. But the dogma would say that for late stage disease, antibodies is actually pretty effective.

But what we saw with my husband and what see with a lot of other patients is, actually, that's not the case. Because if you have somebody who has been sick for a while and their immune system is dysregulated, they may not be producing any antibodies, or they maybe producing such low quantities of antibodies that it doesn't trigger the results.

then we have other patients that are hypersensitive and they're literally producing antibodies to everything because their immune system is triggered by something.

But the antibody that you're testing for may or may not be what's actually causing that immune dysregulation. And then it's been shown in what was that?

Is that because of like cross reactivity where one will mimic another? And so you have, you might not have that infection present, but you are getting this essentially the signal that there's an immune response to it.

Yes, there's often cross-reactivity in antibodies. And then also, you know, if your immune system is hyperreactive, it's just going to take anything you've been exposed to, those memory cells, and they're going up-regulate.

It's going cause issues. Then even in some scenarios in animal models and humans, It has been shown that some people just don't have an immune response.

These pathogens are stealthy for reasons that we're still beginning to understand. You know it has shown in monkeys, for example, that even a set of monkeys that are established or infected by the exact same strain of bacteria, some may have a very strong immune response and others may not have any immune responses.

So using antibodies as a basis of diagnosis is really complicated. It can miss early-stage disease, it can mislate stage disease or it doesn't help you if you know you've been infected previously, just like I have COVID antibodies, but I don't have covered right now is challenge when you have somebody who lives and knows that they've had exposure to Lyme or other tick-borne pathogens.

And so it's really quite common for patients to be misdiagnosed. My understanding is also that these tick borne infections often are actively suppressing immune function.

Is that true? Yes. So they're actively suppressing and evading. And there's multiple studies that have shown kind of the microbiology of this. It changes the cytokine expression, it changes T-cell reactivity, and actually just physically

evades.

You know, Borrelia, the bacteria causing Lyme, swims faster than any of your immune cells. and it hides in immune-privileged sites like the brain, the joints, and places where the immune system doesn't have full access.

And so, again, you have a pathogen with a whole bag of tricks to evade and suppress the system, then what are you using to measure it? A measure of immune response.

That is one of the challenges in why the testing can be misleading in many cases, including my husband's. And you also mentioned when your husband was being tested, you didn't understand that there were co-infections.

So you mentioned Borrelia, Borrella burgdorferi, which is the Lyme Spirochete, often what people are referring to when they say LyME disease. But there are these other tick-borne infections that often come together.

Would you help us kind of take us to the journey of you understanding that? Like, okay, there's more to it than just LyMe. Yeah, I mean, that's one thing is Lyme rarely comes on its own.

There's usually some sort of immune dysregulation or other infections that go along with it. And so in the case of my husband, he had a common tick-borne co-infection of Babesia.

Co-infections, geography, and direct detection testing

But actually, It wasn't so common. I'm still uncovering the nature of his disease. So he tested antibody positive for a strain of Babesia or a species of babesias that's typically on the West Coast where we had lived.

It was not out of the realm of possibility. But his symptoms really didn't reflect what was known about that pathogen, and so I always kind of questioned that diagnosis because, again, it was antibody-based.

And, you know, spoiler alert, my husband's story didn' t end well, so when he passed away, I donated his brain to science and to people that are studying the role of microbes in Alzheimer's disease and the pathobiome.

As it turns out, they found a whole new species of Babesia called Babiesia otocolliae. And that Babésia is a sequestering Babísia and acts differently.

It's also in a lot of the ticks up in Pennsylvania where my husband was always in the woods, hunting and shooting and doing all sorts of other outdoor recreation activities.

So that was one. And then another vector-borne infection is Bartonella, and they call him the three B's, Borrelia, Bartinella and Babesia. And they often come together in these really complex cases.

Unfortunately, in his case, he had all three. I'm so sorry for your loss, Nicole. Thank you. It's a profound journey. And I am so impressed by your transformation of this tragedy into advocacy and support of others.

So thank you for the work that you're doing. Thank you. You mentioned that he had spent time in Pennsylvania, so I want to talk about geography, but also remind people or inform people that it's interesting, I think, that we don't all realize, you know, Lyme is a spirochete with persister forms and cystic forms that is bacteria.

Babesia is a blood-borne protozoa. It's a parasite, it's blood parasite similar to malaria. And then Bartonella is another very different type of bacteria.

So I think a lot of people don't realize that you can't just take doxycycline, you just can take antibiotics real quick and be done with this. It is really much more complex than that.

So maybe if you want to talk about that, and then we'll talk the geography and what people need to know about where they've lived, where, they could potentially be exposed to these.

I want take a moment to share something really exciting with you. This is something that's been a long time coming for us. At Solcery, our mission has always been to make dementia rare and optional.

To give people real tools, real answers, and real hope when it comes to brain health. But one of the biggest barriers we've seen over the years is access.

So many people need this care. They're motivated, they're ready to do the work, but they simply haven't been able to afford it. And this is why I'm incredibly excited and proud to share that we are now participating in Medicare's Guide Program.

This means that for the first time, eligible patients can receive ongoing support for cognitive decline, Alzheimer's and dementia through Medicare, with significantly reduced out-of-pocket costs and support from caregivers.

We are not just opening the door, we are expanding our team to meet this need. We now have two new nurse practitioners trained in our functional root cause approach to brain health.

They're working alongside us with our teams to deliver this care in a way that's personalized, comprehensive, and deeply supportive. This is about reaching more people earlier and staying with them longer on their journey.

It's about supporting caregivers who have been carrying too much for too long. And it's about making sure that the cost is no longer a reason that someone doesn't get the care that they deserve.

If you or someone you love is experiencing memory loss or cognitive decline or has been diagnosed with Alzheimer's or dementia, I want you to know that there are options and that now there's more access than ever before.

You can learn more and see if you qualify by visiting solserre.com or calling 760-385-8683. This is just the beginning and I'm so honored and excited to be able to bring this announcement to you today.

Yeah, so it's a great point. I mean, all of these pathogens are very different and they have different treatment modalities. So even though Bartonella is another bacteria, it will not be impacted significantly by doxycycline.

And so generally, its got a different type of like either rifampin or rifibutin, or other combination antibiotics. As you mentioned, Babesia is a parasitic infection and that treatment is very similar to what you would see for malaria.

And I think these pathogens, in terms of the regional distribution, particularly for Lyme disease, there's always been a thought that, oh, it's just the Northeast or the upper Midwest.

But I as we test more and more places, we realize that's not true. I mean, California has been demonstrated to have significant levels of Borrelia burgdorferi in ticks.

Even in my now home state of North Carolina, which is thought to not really be an endemic area, they just did a study out in the western part of Carolina and found that 33% of the ticks, the black-legged ticks had Lyme disease or had Borrelia in them.

So it's definitely spreading. These ticks populations are on the rise. They can travel on birds along migration routes. It's pretty much an everywhere problem at this point.

And for pathogens like Babesia and Bartonella, those are even more widespread than I think people realize. You know, I Think our Galaxy's founder, Dr.

Breishwert, always said, you know that Bartonella is more prevalent because it has more vectors, because household cats are actually a reservoir for Bartonnella.

And so he has always said that he thinks it's way more prevalent than Lyme disease. And the more that I do this, I

realized that… I believe that that is true.

I think a lot more people are exposed. It's just that their immune systems can keep it under control. But then if you do get another pathogen like Lymedisease or Borrelia or Babesia, then all of a sudden, your body kind of reaches this tipping point and you start descending into illness.

Some people, listeners might have heard of Bartonella, also called cat scratch fever. And fleas, spiders, other vectors, and other insects can transmit this, not just the deer ticks.

So there's other ways that we can get it. It often comes with like the stray or it looks like stretch marks in a place that you wouldn't expect them or if there hasn't been a lot of weight gain, weight loss.

An interesting one to be aware of. Now you mentioned that there are people who, many many people have been exposed and I've certainly seen this in my clinical practice where people are testing positive but have no symptoms and then someone else testing negative has a wild amount of symptoms, and maybe even had a bull's-eye rash at one point, has clear exposure to this and they're debilitated but testing negatives.

Maybe even using your engineering background and your scientific training, I wonder if you can help us understand how does this happen that we have people with what looks like a region infection on a test with maybe known exposure but no symptom, and then somebody else with a tests that looks negative but debilitating symptoms.

What is going on and how do we use a better test? It's a challenge. And I think in my husband's case, I believe he had these pathogens on board for years before they became to a head where he was clinically exhibiting symptoms.

Our immune systems are very complex. Right? So they can, we know that we have a whole host of pathogens that are on board and, and sometimes your immune system can keep them at bay.

And then at some point you might reach a tipping point or the bucket overflows, whatever analogy you want to use, where now all of a sudden you tip into a state of unwellness.

And we see this all the time where somebody maybe had some minor symptoms, but things that we just chalk off to daily life. Maybe I have some migraines, I'm tired.

I've got some mood swings, like things it seems like in our society everybody's dealing with. But then something happens. Maybe you've got COVID, maybe you went to a surgery, or maybe had a trauma or a stressful period in your life, and now all of a sudden things become debilitating.

And we see this quite commonly. The immune response is very variable from person to person. And that's those factors we still don't fully understand. But I think my husband had probably been keeping these pathogens at bay for a while.

By the time I clinically tested him, his immune system, if you look at his overall antibody titers, they were very low. His immune was fatigued. So it is a complex environment.

That's one of the reasons why at Galaxy we focus on direct detection. right? We don't use the immune system and antibodies. It's a useful tool, but it's one and, you know, if you think about other infectious disease areas like COVID, for example, If you want to know if we have COVID you don t get an antibody test, right, that would almost be laughable from doctors because I have covered antibodies but I don' t have coded right now at least and And so you're going to use a PCR test or an antigen test to determine whether or not the pathogen is present.

But with these stealth pathogens, like you said, they actively evade the immune system. They're in low numbers.

Treatment complexity and the limits of standard care

That's really been challenging because conventional approaches haven't been sensitive enough. And that's the key problem that we're trying to solve at Galaxy is how do you make the direct detection tools sensitive, enough that it's useful to And can you describe direct detection?

What does that mean? It means you're looking for something specific that's related to the pathogen and shows that the patogen is present. So an antigen-based test could be looking a protein or some other molecule that is shed by the pathogens, for example.

For example, with Lyme disease, we use a urine antigent test. So as part of its immune evasion, as a part its life cycle, Borrelia actually sheds a lot of proteins and sugar molecules kind of into this environment.

And a lots of those molecules or biomarkers get filtered out of the body by the kidneys and then they aggregate in the urine and they're excreted. You can use that as a diagnostic tool to determine whether or not the pathogen is present.

In other cases, you can look at looking for either the DNA or the RNA of the pathogens itself and show that that's present, and that is what we use for common co-infections like Bartonella and Babesia.

There, we're looking for, and again, they're low abundance pathogens, so you have to use enrichment techniques and you to have use high sensitivity methodologies to detect because if you just run a traditional PCR, it's likely going to be missed.

I mean, you guys are really focused on improving this detection. Part of the reason why, if I understand rightly or correctly, is that an accurate diagnosis matters a lot.

Do you think the trajectory of your husband's treatment would have affected the outcome? Do think he might still be here today if you had an accurately diagnosis and then could have started treatment?

Absolutely. I think the earlier and the more accurate that you can diagnose, the better chance that have. Now, that being said, there are some limitations of existing treatments.

The later that the therapies are to fail patients. And so, but in my husband's case, that's what drew me into this diagnostics field is I kept thinking back at that first appointment.

If we had tested positive, how would his trajectory be different? If I had understood that he had this species of Babesia that is different from the one that was actually diagnosed off, you know, with that behaves differently, then, because we didn't really adequately treat the Babessia because that kind of a question diagnosis for him.

And, so if we have treated that, earlier and more completely would his case have been any different. And so, as you mentioned, right, those three pathogens alone all take different therapies.

So if you don't know which one you have, it's going to really be difficult to get well because they're all different and the symptoms overlap immensely.

And, you know, one of my favorite things is talking to the lab, people at the Lab companies about treatment because you guys are seeing all these labs come through from all over the country, probably all of the world, and so are there particular strategies of treatment you see are getting better outcomes?

I think that's one thing that seems to be universal, because it's really difficult to say anything universal in this space, right? Because everybody's so individualized.

But I thing one that is universal is that it is not just enough, especially for complex, you know, later stage disease. It's not enough just to kill the pathogen.

You really need to support the immune system and think holistically about the person. And I the providers and the

patients that are getting well are the ones where they're looking holistically.

I think we see herbal therapies as very effective within this space. And when you're thinking about immune support and all of the integrated parts of our body, gut health, you know, detox and we see the most progress.

But again, if you're not fully aware of which pathogens are on board, you might be missing something. And we do see a lot of patients that have been under treatment for years for Lyme disease or years, for Bartonella and not getting better.

Then we run testing and we're like, well, Or, you know, we don't pick up any evidence of Lyme, but we are still seeing Bartonella. Has that been treated effectively?

And so those are the types of things that we really hone in on is making sure that the doctor knows exactly what they're fighting. Yeah, okay. And, you know, there are these pretty aggressive treatments.

I was talking to Dr. Rich Horowitz recently about his Dapsome protocol. We've had patients go to Germany for hyperthermia. There's kind of some far out treatments that happened in Tennessee that sound a little more homeopathic, but people have claimed to get benefit from.

You know if you were kind evaluating some of those more aggressive treatment for your husband, how would you think about that? How would navigate that Yeah, I mean, my husband was on some pretty intense antibiotic therapies, you know, very broad-spective.

I think that there were a lot of benefits that he saw, and a lots of his symptoms did go away. The neurocognitive piece never quite improved. And the reasons for that I still don't know.

As I said, he donated his brain to really help uncover what was going on. And to me, the presence, that the DNA of Babesia oticuliae in his brain shows that there were still live pathogen in brain tissues at the time of his death.

So if I had to pinpoint one thing, I would probably pick that, but as I said earlier, it's never just one thing. It's always many things. He also had, when his immune system got suppressed, you get elevated viral titers.

toxin exposures. And so I think unraveling these really complex cases is something where we need more evidence and more science to really determine what is effective and what's not, but it's going to require a personalized medicine approach, not a one size fits all, you know, type clinical trial.

One of the most frustrating experiences patients can have is being told that their symptoms are all in their head. Get that referral to psych. What advice would you give someone who knows something is wrong but they're not getting clear answers?

We, this happens to so many patients and I really feel for them because it is such a challenge when you're looking at a doctor who, I mean, we perceive them as experts in their field, right?

They have the education, they have. The degrees and the pedigree, and when they tell you something's wrong or is not wrong, you know, when it's all in your head, that is a devastating moment.

And what I've said to people in those conditions is like, look, you might not be an expert in tick-borne disease or whatever the issue is, but you are an expertise in you and you're an experts in the person that you care for.

And so if you don't like the answers that your getting, keep digging. I think unfortunately this is where we've talked to many patients that have been to over a dozen doctors trying to find somebody who would listen to them and hopefully that that convergence upon somebody who will help you and go on the journey with you will get better.

I think as more doctors get trained and as a lot of education materials and content get out there in this space, it will better, but in the meantime, You're not crazy.

There's so many documented cases of how this, I mean, my husband was hallucinating, right? Like it is in your head, meaning the pathogen is your in head.

And so, and that really changes everything. I, mean he was the most logical, the, most straightforward engineer that you would ever meet. In the height of his illness, he told me that there was a man in my woods swinging from the trees carrying a machine gun.

And you're like, wait a second, I don't even know how to reconcile this in our brain. So it would be really easy to give him a psych diagnosis, right?

But that's not addressing the whys. You know, that's like a frontotemporal or a little more Lewy body, probably, right? And as you mentioned, Alzheimer's, Lewye body.

Frontotemporal dementia, Parkinsonianism, all of these things. That's not, it's an ICD-10 diagnosis code, but it is not an answer to why. Why is there a neurodegenerative process happening?

And I think these tape-borne infections can be part of the why.

Advocating for patients and trusting your instincts

Often, as you mentioned, it's multifactorial, right? So it is toxins on top of major stressors, on the top nutrient deficiencies, sleep deprivation, all these things that can affect the immune system and then make it so that the infections are winning, right?

And your immune system is losing the battle. That is so challenging. I'm so sorry. You went through this process and you've lived this journey as a wife, a caregiver, now a widow, an author, and a CEO.

Looking back, you must have so many lessons about resilience and the process of grief and healing. What would you share with people who are on that journey now?

I mean, the grief journey is hard. I remember there were many, many times when I was sitting on the floor of my closet, just crying, right? Feeling completely at a loss for what to do and how to move forward.

And, you know, we had two young children. My husband was declining. his care, my navigating two young children and being a mom and then my job, it was awful.

And I think one thing that helped me was journaling and studying. That's what led to my book where I did that primarily as a mechanism to heal and to understand the lessons from the chaos because I It would have been easy.

Well, actually, I don't know if it would've been easier, but it, it wouldn't have one path to just kind of say, well, that's over and I'm going to move on and do something different.

But I am the type of person that likes to learn from things and likes figure out how to help others and, and how learn form the journey. That made it a lot easier for me to process and to talk about what's happening.

But for anybody that thinks that there is a magic secret sauce to getting through it, it's just through. That's it. You just have to survive sometimes and then live for another was extremely messy and devastating, honestly.

How old are your children now? So my son will be 16 in a couple of weeks and my daughter is 12 and a half. Wow, I mean they're still quite young. Yeah, when my husband went into memory care they were five and eight.

They were really young and And that was part of the challenge is like, I knew I had to be there for them and I couldn't because I was a full-time caregiver to somebody with some pretty severe dementia.

And there's no good form of dementia, but there is, you know, my husband was very combative and very difficult and he was fully mobile so he could get into a lot of trouble.

So it was really challenging. Yeah, unbelievably. And then you went on to become the CEO of a company. I mean, I think most people kind of, that could end things, right?

Like you could never recover potentially from going through raising small children and having your husband with severe combative dementia. I actually have a patient who the family calls it the best dementia because every time, you know, there's so many forms of this, right?

And I think for anyone listening, I there is this horrifying, scary version, which is what you unfortunately had to experience. And then there are these forms of dementia, like this patient, when he eats soup, he's like, this is the best soup ever.

This is best walk we've ever been on. It this the most beautiful day. And so he is always saying, This the the everything. So they call it the Best Dementia.

There are different manifestations. things that with, I don't know if it's because of the Lyme or the tick-borne illness or if the part of brain that's affected, because certainly we see that, with frontotemporal dementia, but also with Lewy body, like the type of pathophysiology seems to have a role in how this manifests and you can't predict it.

You also, it is dynamic, right? You can predict a day to day. I'm sure your husband had relatively good days and then you want to attach on to that and maybe he can have this time with the kids.

And then the next day, maybe, he's traumatizing the kid. only imagine, Nicole, what you have been through. Yeah, you go back to the question of how did my view of medicine change?

And that was really one where I realized that the biochemistry is really what's driving the bus, right? It's not anything that you can get I mean, therapy is very useful and very helpful, but there are things that are outside of that realm that you need to look deeper into why the chemistry is happening.

And, you know, for example, with patients with Bartonella, irritability and rage is quite common with bartonell infections and hallucinations and schizophrenia diagnoses.

So I think a lot of the manifestation that he saw was was potentially the pathogens that he had on board. And then over time through some of his treatment with functional medicine, there really were things that would make him better.

So for example, exogenous ketones were something that I could give him a drink of ketone and he would be screaming at me about how I basically was the worst human in the face of the earth.

I was keeping him captive and I took away his truck keys and stole all his money and all the things. He would drink these exogenous ketones and within 15 minutes, he was like, I love you.

You're the best thing that ever happened to me. And like the first time you see something like this happen, you're like wait a second, right? Like again, biochemistry driving the bus, within a short period, his entire behavior changed.

It was eye-opening on so many levels, really. We're big fans of the ketogenic diet and exogenous ketones in the neurodegenerative world. We see big shifts like that, not for everyone, but often.

And reproducibly, I think probably like what you saw, right? Consistently, there was a shift in mood and behavior and function. when someone has ketones to burn his fuel in the brain.

I mean, you're an engineer, and you experience this firsthand. Can you describe, like, how did you use that tool?

And did try to get him into ketosis, a carb restriction, or how do you navigate that?

Yeah. So absolutely. And we, and I used to have to hide all of the, you know, the we didn't have any treats in the house, but even things like I'd have apples on the counter and he would eat like six apples.

But once I figured out with the ketone, it's like literally his brain was starving for fuel. And so once we figured that key with ketones, he was on a regular regimen.

You know, every few hours, I would give him like a half a scoop of exogenous ketons, and it kept his mood extremely stable.

Resilience, journaling, and lessons from grief

There were days when I'd forget, get wrapped up with kids, miss a dose, see it coming, right? Like he would start pacing and you could see the agitation in his face.

And then I had to figure out, okay, how can I get this in him as quickly as possible? And it was unbelievable. It was something that you would never believe until you actually saw it firsthand, but it he was able to really be cared for.

So up until that point, I don't think I would have successfully been able put him into a resident care community if we hadn't kind of cracked the code with the ketones because he so combative and so difficult that they probably would've had to put them in a psychiatric institution.

And it makes me want to take more ketones, right? I mean, do you take exogenous ketone and get into ketosis? Because whenever I see patients have this dramatic experience or like hearing your story with your husband, it's like, gosh, if it does that for someone who has that severe disease, I could probably be optimized by a little bit of that too and have more stable blood sugar, better fuel for my brain, all of these things.

So do you take it? Do you give ketones to your kids now? Seeing the magic. I don't get ketone to the kids, but I do use it periodically. And I definitely try and eat low carb and keep as close to ketosis as possible.

Do fasting to kind of stay metabolically fit. But yeah, like I said, it was really eye-opening as to how important some of these pathways and fuel sources are.

I think specifically as a caregiver, do you have any advice for, or just insights, experience shares from being a care partner for a spouse? It is one of the hardest things that you can do.

How, and many people tell me that they wouldn't have given it up for anything either, right? There's so much gratitude, especially after the fact. Is there anything that you maybe wish you had done differently or appreciated more?

Is anything on the other end of it you would suggest to other people who are in it right now? I wish I had asked for help more. I think as someone who, again, I'm an engineer, an entrepreneur, and I like to solve problems, so there's this tendency to just throw it in the backpack and carry it.

Like I can do this, but I don't want to burden anyone. As I went through my journey, frankly I watched others with similar journeys. I realized it's not think of it as a burden.

If any of my friends came to me and asked for help in a similar situation, I would almost be angry with them if they didn't ask for health. But I didn' really leverage that.

I have fantastic friends and I had fantastic family. particularly with dementia, there comes a lot of shame. My husband was ashamed that he was losing his mind.

He was a shamed that, he couldn't do the things that you used to do. You see a lots of patients with Dementia, they

withdraw, and then sometimes they bring their caregivers with them.

That certainly happened in my case where he didn't want to talk about it, so I just withdrew with him. And that meant I didn't ask for help. It means I did not get help for myself, not just help with him, but help from me.

And fortunately, I had a really fantastic functional medicine doctor that we approached as part of the journey. I asked him to take on Russ's case and he was like, yes, i will take the case under one condition.

Well, my attention, what is that? And he said, well, you have to become a patient too. And that was a turning point to realize that I can't care for anybody else if I'm not at my best.

There's always this tendency to put everybody else first. And there was moment where my engineering brain was like, look, if i'm running on 30%, If I'm giving 100% to everybody else, that's not serving anybody.

Like I need to get myself to 90% and then there's more of me to give. So it's actually practical, not selfish, to take care of yourself first. And that was the moment I needed as my engineering brain to be like, oh, this is actually logical, right?

I needs to care for myself. But I made that connection way too late. It was like the point where I was run down and I could feel it. Unfortunately, you know, a lot of dementia caregivers are their spouses, they're older, right?

They're in their 60s, or in the 70s. And it's, I mean, it was in my 40s and so it is really easy to get yourself run down to a condition where you're impacting your own health.

Yeah, I've had almost a similar conversation with some of the care partners for my patients where I say the condition is you have to take eight hours to yourself each week.

It can be four hours on Tuesday and four on Thursday or it can all day Friday, but you need to have time to your self where you are not caregiving. And you're not talking about dementia.

And I think for a lot of people there is hopefully there's that shift of like, all right, if I'm going to, I can't serve from an empty vessel, right? I cannot, have to put my own oxygen mask on first, whatever the analogy you want to use.

but you have to have something to give if you want to be a care partner, a caregiver. And also having that, I mean, for you, you had kids and work, but having an identity outside of caregiving I think is also really important because it's not going to last forever.

There will be an endpoint to it, and then who are you on the other side? Yep, no, all fantastic points and things that you struggle with, right? And I struggled with and there's definitely things I would do differently.

But again, that was one of the reasons why I wrote the book was to try and learn those lessons, solidify those lessens.

Ketones, caregiving, and self-care

It doesn't mean I still don't make mistakes and have to remind myself, but That's the key is trying to keep that front and center. And I, at the end of our journey, I kind of wrote out, what are my values?

Like, What do I care about? And health is number one, because it came to me and I realized that if you don't have your health, you can't serve your family.

You can serve God, You Can't Serve Your Job. you Can do anything. Really. Yeah. So then that has to be the number 1. Otherwise, like you said, we can you cancer from an empty vessel.

Wow, what a journey. I want people to understand where they can get your book. So will you share that? Yeah. It's

What Lurks in the Woods, and it's on Amazon and Barnes & Noble and other places.

You know, it really is a memoir. Some people have gone in, but it is not a how to learn everything with tick-borne illness. Its just one family's experience and how devastating it can be.

But I wrote it from my journal entries. And so it's, I think, a pretty accurate depiction of how chaotic life can be within this sector. It's all out there.

When you think about the next decade of research, of treatments, testing into Lyme, Bartonella, Babesia, and neurodegenerative illness, what developments, things are on the horizon that give you the most hope?

Yeah, I mean, so obviously at Galaxy, we're working every day to give better tools and to provide that direct detection. So patients and providers can understand which pathogens are on board.

Because as we said, there are different treatments. And even the most experienced providers struggle with the clinical diagnosis because the symptoms overlap so much.

That is beginning to take hold. I think we are seeing a lot of uptake in functional medicine, which is great. But in terms of what I'd like to happen in the next 10 years is for it to become mainstream, right?

So our mission at Galaxy is not to be the best specialty lab for functional medicine. We're certainly working on that, and that's part of who we are. But we want to change the standard of care, we wanna get it in hands of everybody.

So we're taking our novel assays and putting them through the FDA, getting reimbursement so that it can be with your primary care provider. So when you go to the doctor because you suspect you might have tick-borne illness or you have been by tick and you some acute symptoms or if you want to know if got exposed, then we want have accurate tools so the doctors can assess whether or not you've been exposed or infected.

And then even longer term, I would love to pathogen-specific panels for different disease states, right? Alzheimer's is something that has been shown can be linked to infections.

But it's not just tick-borne infections, there's fungal infections there, respiratory pathogens, oral pathogens. There's elevated viruses, like everything.

I think over time, I would love it so that somebody like my husband shows up at a neurologist and it's like, hey, he has no genetic predisposition to Alzheimer's.

He's declining extremely rapidly at young age, which doesn't make any sense. Let's run this infection associated panel that's linked to common, you know, dementias and other things.

And similarly for aphritis and carditis and mental health. Like, we should be screening for pathogens because even if it's a percentage, say it is 10% of patients, right?

That's huge number when you think about chronic illness and you thing about conditions like dementia and schizophrenia and even, you know, arthritis, that can be a debilitating diagnosis that impacts people's lives and their ability to thrive.

And so that's where I would like to see this go and we're working every day to make the technology more mainstream and accepted. We would certainly run that panel.

I mean, we kind of put together a panel that is like that, looking at herpes and even toxoplasmosis and P. gingivalis, some of the things you mentioned, screening for Borrelia and COVID, you know, a lot of these things that have an impact on cognition.

We, would love to have a channel that puts that together and helps us understand if those particular pathogens are

present. You know, it's so interesting because you put, and in the PubMed, you've put H.

pylori in Alzheimer's and you got stuff that comes up, right? You put Yersinia in Alzheimer's, then you get things that come up. So it looks like you can almost put any pathogen in there and it really, I think it is about immune burden and there are some that have a bigger impact on the inflammatory cascade in But I also think that it's about that immune system balance.

How good is it at keeping that infectious burden down? And part of that equation is the toxic burden. The higher the topic burden, the lower the immune function.

And so all these things work together. It really does, I think, require that individualized and very thorough workup to address what's driving all of this for anyone.

So fascinating, so interesting and very hopeful. Thank you, Nicole, for all of the work that you're doing. I'm curious, after all that, you've been through professionally and personally, and you still are on the ride raising children.

What brings you the most joy at this stage? I mean, obviously my kids, that's the family and my friends and that network is, I think, what continues to fuel me as a person, right?

That grounds me and keeps me going on a regular basis. I think professionally, it's really, a lot has shifted in the last few years. Like when I first started researching my husband's case, the position from the CDC and other government organizations was that chronic Lyme didn't exist.

The future of diagnostics and mainstream access

Right? And we've moved beyond that. And I think that there's an awareness and there is even the term, IACI, of an infection-associated chronic illness is becoming something that is mainstream.

I that's key because it's that root cause, right? As an engineer entering into medicine, and I was appalled. Nobody's asking why. Why? It was insane to me.

And that is something that I realized that there are people that are asking why they're just in a different sector. That's what drew me to functional medicine is like, okay, here's a you know, a group of folks that really are looking at the right answers.

And I think hopefully that mentality will spread across more of medicine, right? It's not like diagnoses like chronic fatigue syndrome are just ridiculous, that's just a naming of symptoms.

And I think those are the things that need to change and at least we're starting to ask the right questions, right? And so that brings me a lot of hope.

I that there's still a long way to go until it gets into mainstream and it pains me sometimes because the access to care is just not there, you know, for people that can't pay out of pocket, but it's coming and that makes me hopeful.

It is coming. We are really excited because at our clinic at Solcery in California, in San Diego here, we are now taking Medicare. Through nurse practitioners who can bill Medicare, I'm an atropath.

I won't be able to bill medicare. But using both the guide program and our nurse practitioner to support those who have dementia and Alzheimer's as well as their caregivers, We can take Medicare which is super exciting and expands that access.

to more people. And a lot of the functional medicine labs are taking original Medicare, not the Advantage plans, but the original medicare plans. I mean, there's a glimmer of hope.

There's like a path, at least, I hope right now. It's all very new to us. But I think like you, my hope is that more and

more people have access. It's not just going to be for people with discretionary income, especially in the over 65 retired community.

So many people are on a fixed income. I'm excited and hopeful that people will get access to good quality medicine that's asking why. Yes, 100% agree.

Thank you so much for sharing both your expertise and your story today. This is one of those themes that stands out to me. It's the importance of staying really curious when the answers aren't coming easily.

it takes work and dedication, devotion. And your journey is just this powerful reminder that symptoms have causes. and that persistence and asking those hard questions, even when the neurologist is rolling their eyes at you, that's sometimes where the most important breakthroughs happen.

And you have been someone willing to question the status quo and not give up and then transform this tragedy in your family to answers for others, to hope for other through this path at Galaxy.

Thank you for being an incredible caregiver, supporting a loved one, being a practitioner, a CEO, trying to connect the dots. And I hope that today's conversation with you really inspires others to keep asking these questions, to remain open to possibilities that might not yet fully be understood, but that there's a lot emerging out there.

Thank you, thank you. Thank, you Nicole for doing the work that you're doing to improve diagnostics and advance the research and to share this really, You know vulnerable story to other so other families who are navigating this don't feel so alone Thank You It's a lot it's heavy and I think that that's true in this space right it can it feel heavy It can, but as we said, there's hope.

There's better tools that are on the horizon. I think what brought me to Galaxy was the science. And I really, truly believe that science will solve all of these problems.

We just have to continue to be curious and to ask the right questions and help educate others on that fact that there are other solutions out there. So that's what we're doing.

Thank you for being here to help us with that and thank you to all of our listeners for joining us on another episode of Think Well, Age Well. Until next time, keep thinking well so you can age well.

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