The Lyme Disease Connection Medicine Can’t Afford to Ignore | Nikki Schultek | Ep. 165 Transcript

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Lyme Disease and Brain Infections

Lime disease bacteria are like a corkscrew. They can literally burrow into tissues and they can burro into the central nervous system and brain. If you treat these things promptly, they are more treatable.

When it comes to Lyme disease, 476,000 Americans are diagnosed with Lyne each year. You know, it was a healthy point of view podcast, your top rated show.

We're bringing experts from all over the world to talk about health, wellness, beauty, and mindset. Today we have Nikki Schulteck. She went from being a patient who was told she might have MS to leading a global research movement.

Nikki Schultek is the founding director of the Pathobium Research Center at PCOM, and executive director at the Alzheimer's Pathobiome Initiative. I just had this air hunger.

So I kept saying, this feels different, doc. Like, it just doesn't feel like my asthma. Had asthma since I was a kid. He said, let's put you on some prednisone.

The prednizone didn't help whatsoever at all. In fact, I got worse, got a rattle in my lung. I just started to lose weight. Just was getting more and more sickly.

Why is it that we're so focused on treating end stage versus actually going through the root cause? A lot of reasons. The plaques in the brain and the tangles.

These are the villains. We have these things that show up in brain. They must be bad. Let's get rid of them. Well, the field's been trying to do that for 30 years.

And when you get of those things, patients don't get better. You know, with what you're doing, are you ever scared? All kinds of things scare me. Welcome to another episode of a Healthy Point of View podcast, your top rated show.

We're bringing experts from all over the world to talk about health, wellness, beauty, and mindset. I'm your host, Sam Tahata. And today's guest, what we're gonna be talking about today.

This is part of our Lyme Disease series. So our expert today, we gonna to be talkin' about the power behind collaboration. not just any type of collaboration.

We're talking about in the field of research, how we bring experts together from all different areas of medicine to really get to the root cause of what's happening with Lyme disease.

She's a researcher, she's collaboration architect. Today we have Nikki Shotek, Nikki. Nikki, welcome on the show, How are you? Hi, Sam. I'm wonderful.

And thank you for having me. So grateful. Absolutely. Collaboration architect. That's the first time I hear a title like that. But I love it. Yeah, I had to figure out a way to describe what it is that I do.

I work in science. But the reason I worked in sciences, was a patient that was incredibly ill with Lyme disease and other infectious infections that were basically driving these different autoimmune processes in my body.

And it was realizing how siloed the medical system was, right? The specialists were each caring for one part of my body. I had a lot of different things going wrong and they weren't really communicating with other each other or cross pollinating in a way that would sort of see the bigger picture in my case.

Um, in case I. Had an infection that was causing, you know, bladder pain, joint pain neurological and psychiatric symptoms. It was devastating. You know, um, my doctors thought I might have MS and all through this journey, I called myself the human hockey puck because I would go to a specialist and say, Hey, My lungs aren't working properly.

My oxygen is low. And they would say Wow. Okay. It must be your asthma flaring up. Let's give you steroids. And so during the journey with having, you know, gotten a tick bite, contracting Lyme disease, instead of being treated properly, I was effectively immunosuppressed.

What I suffered with was a string of different misdiagnoses. And so what I have, thankfully I get to be here with you today, I'm well, and that's a blessing and a gift.

Over the last decade, what i've done to contribute is bring researchers together with physicians, with innovators, understood and fully formed approach to how we tackle this problem, which is that chronic infections like Lyme disease bacteria.

can drive chronic diseases that are extremely devastating. And we have tons of evidence that infections get involved in Alzheimer's, in Parkinson's in MS, and pediatric disorders called pandas and pans, but yet we really haven't done anything to harness this yet.

It means that there are unused therapeutics and untreated patients. So by bringing different groups together, it really also raises the volume And through creating a consortium called the Alzheimer's Pathobiome Initiative a number of years ago, we have really basically been intentionally collaborating, bringing together research teams that would never otherwise talk to each other from different universities and coming up with better research plans.

And it also helps us to really maximize precious things. Like if someone passes away with Alzheimer and that family decides to donate a brain, We want to make sure that that brain is as exhaustively analyzed as possible, right?

You don't want just one narrow approach to look at what those issues could have been for that patient. Our team is sharing specimens and sharing data, which means we are not just, you know, in one silo looking at one, narrow thing.

We're looking a multitude of things like, for example, what infections are there? what immune responses are there and what other things may have been going on that were important.

And so this is the way that I have chosen to leverage what my skill set is, which is to bring people together. I'm a uniter and I love science. So I've always been deeply curious and very broadly curious, tangential even.

Nikki Schultecku2019s Misdiagnosis and Health Crisis

But I think it's so important for us to remain curious and to put aside assumptions because we still don't have solutions for a lot of chronic diseases, but we have clues that we can potentially be leveraging.

Well, that is one great way to explain and define what a collaboration architect is. But, you know, one thing I do know is that there's a lot more behind it that we're going to get into.

Before we get in to any of that, I want the viewers and listeners get to know a little bit more of your story, because to do what you're doing as a Collaboration Architect, That's not something that anyone just goes to school for or just picks and choose to do that.

There's a level of passion and purpose to what you're doing. Because I can assure you, just knowing what I know about business, you probably stay up a lot of nights trying to get things and crack the code and working overtime.

What was your story that got you where you're at today working as a collaboration architect? Because you had your own experience where. You were diagnosed with falsely diagnosed, right?

Incorrectly misdiagnosed with MS. Is that correct? They thought I could have MS, so I was never formally diagnosed, but I also was told that I can develop it at any point.

I had all of the symptoms of MS. But at that time, my neurologist said in Connecticut, where Lyme disease is named, the town of Lyne, Connecticut. He said, I will never forget this, looking at my brain images kind of very coldly.

Well, you can't tell you don't have it. A lot of people I see like you will smolder for years. They use the term smoulder. like your symptoms will be there and then boom, lesions will show up.

So it's sort of like not an answer, right? I left that appointment particularly devastated. But that was just one of many different things that happened to me over the course of a year.

I basically developed body wide autoimmunity. Like if you name a system of the body, it was impacted and how old were you when that happened? 34 years old.

And I actually, so to answer your question about like, how does someone become a collaboration architect? So I started out my career. I studied business first of all, um, always loved science though.

Even thought about becoming a physician, but then decided I'm a real empath. It was concerned, you know, even as like a 16, 17 year old kid, I may not be able to, you know, handle the patients passing away portion of health care directly.

So a distant relative recommended considering the pharma industry. You know you can maybe help get involved from another angle, but still help people.

And so I did just that. I studied business and then I started right out of college working for Pfizer in sales and very serendipitously. Um, and I believe this is all meant to be.

Honestly, I worked in the neuroscience division of Pfizer. Those things were paired together, which is deeply ironic because of what I do today. So I worked with microbiologists, infectious disease doctors and hospitals and learned all about resistance.

You know how antibiotics are basically not working as well. Bacteria are learning ways around them. and attended a ton of basically physician lectures called Grand Rounds and just learned like a sponge.

Like I always just loved to learn. And during that time of my life, I then transitioned to a role of clinical specialist for Genentech, which is an incredible biotechnology company.

I learned so much there as well, continued onward in neuroscience. This time though, working with 50 different hospitals in the state of Maryland and a little bit of Virginia.

and figuring out how to get these hospitals communicating with one another. So again, this sort of collaboration building aspect of, you know, uh, me that I realized was a strength.

And then I became a full-time mom for eight years. It was during that time when I stepped into my role as a mom and put pause on the career that. I got sick and my kids were three and five and it was truly It changed the rest of my life in every way possible.

It started out with this horrible breathing thing. I'd had asthma, but this was different. This was like someone had a belt around my rib cage and I couldn't get a full breath of air.

So of course I went into my asthma specialist, allergist, and he was, well, you're probably having an asthma exacerbation. Had been doing a ton of running and training for half marathon and was in amazing shape.

Never smoked, never abused my body, always ate healthy. And, um, I just had this air hunger. And so I kept saying, this feels different doc. Like, it just doesn't feel like my asthma.

I had asthma since I was a kid. This feels like something else. He said, let's put you on some prednisone. That's where things really got worse. So I.

Was all the way up to 80 milligrams of prednizone to make a long story short. Neither of them knew what the heck to do with me. And finally, they said, based on some chest x-rays, looks like you might have a little pneumonia going on.

Maybe it's an atypical pneumonia. Let's put you on a Z-Pak. This was the first clue that I had an infectious process happening. So a z-pak stays in your body 10 days, right?

Is a thermicin antibiotic. As soon as I got on it, within about a day or so, The lung thing was lifted and I was like, Oh, thank God. You know, I'm, um, going to be okay.

This is great. Remember celebrating with neighbors that were getting really worried about me and, uh, you know. As soon as day 10 hit and that antibiotic got out of my system, I relapsed with the breathing trouble.

Dependence on didn't help whatsoever at all. No. In fact, it got worse. I got a rattle in my lung. Wow. And I just started to lose weight, which is sort of a paradox.

People usually gain weight on prednisone. It just was getting more and more sickly. So I ended up getting a longer course of azithromycin that that antibiotics.

One of the pulmonologists said I have no idea what's going on. But let's do 30 days, please stay on the prednisone, which I could feel in my gut was a bad idea.

And but I did. Uh, and then after that on, the heels of this terrible breathing thing, Which never really got fully under control. But I got it to like a serviceable level where I was, okay, I'm existing.

and I had this chronic cough I developed. I Got a bladder pain disorder. It was Halloween. I remember my kids were dressed in their adorable little costumes.

My younger son was in this cute little skeleton outfit and they're unwrapping candy bars. And I said to my husband, I feel like I have a urinary tract infection.

Like it hurts so bad, my bladder. Right. Ended up being diagnosed with one of the most painful disorders a person can be diagnosed. Interstitial cystitis, which is where you Once again, an idiopathic disorder, I hate that word by the way, idiopathy means we don't know what's going on.

That bladder pain disorder is unknown. It basically leaves people where they may go to the bathroom 60 times a day, chronic pain. And so that was a devastating diagnosis.

And I remember thinking, what the heck is going on? You know, my lungs, now my bladder. I also had joint pain during this time I had developed terrible fatigue, like to the point where I could fall asleep, feel like I can fall sleep driving.

Um, I was just getting worse and worse, but I kept trying to like also exercise through it, by the way, use exercise

as, you know a means to understand or to, to at least wrap my arms around coping with what I was dealing with.

I remember at one of my lowest points I literally would drive to church and sit in the parking lot. Like this bladder pain thing was so bad that I couldn't put normal pants on.

And I had this one pair of sweatpants that now just like the thought of them, I despise them because I'd wash them and put them back on again. and sit outside of church and pray and cry because I felt like I was too much of an emotional wreck to go in the doors and present myself and set down in a pew.

And it was at this point in time that I became incredibly desperate and I started to do my own research. And I decided that if I didn't figure out why all of these different things were happening to me, cause by the way, I also had a cardiac arrhythmia and I had gastroenterologist cause I stopped digesting my food, you know, neurological symptoms.

Um, it was literally like I was a mess and spiraling, but none of my different physicians in their different silos was talking to one another. And remember saying to the bladder expert, You know?

Would you consider having a conversation with the people that are helping me with a pulmonary situation? and GI and these other specialists, because I feel like something systemic is happening here, right?

So I did a Google search that changed the rest of my life. I looked up the bladder pain disorder, interstitial cystitis, and I look up atypical pneumonia, cause I started to do all these different pairings of searches with my diagnosis.

Came up with a paper out of Vanderbilt, a guy named Charles W. Stratton. He was, I could see from his research profile, And I knew how to read research from being in pharma and biotech.

Thank goodness I could see that he was a global expert and he had a paper where he identified with the urology colleague this stealthy bacteria in the urine and in lining of women's bladders that had my bladder pain disorder.

But this bacteria was so interesting because you wouldn't find it if you did a routine urine test that they do at the doctor cultures because it lives inside your building blocks, your cells.

And this organism called Chlamydia pneumoniae is not chlamydia, the sexually transmitted disease. It's something that you would get from coughing. And so when I read this paper that this bacteria was there in the women's bladders that had this disorder and it was a small study.

So they were very clear that more research needed to be done. When they looked at women that didn't have the disorder, it was largely absent. This bacteria.

And their conclusion was this bacteria is known to drive chronic inflammation and it should be studied because it could be treatable. Now I decided I go, a respiratory bacteria.

I've had asthma my whole life, I'm having this weird breathing thing. So then I look up that bacteria and asthma and thousands of papers came up. And it blew my mind, and I started reading.

As you said, you know, went down the wormhole late into the night, but for the first time felt like I was seeing something that made some sense, some semblance of sense after everything I had been through.

You could connect to it. Yes, I connected to it in the sense that I was like, this feels like me. It feels this is what's happening to me, an infectious process turning on my immune system and driving problems all over my body.

So I decided to email that doctor on the paper. And I'm like he's going to probably not answer me he is like a world's expert. But when you read medical literature, you always see the corresponding author's email is there.

Right. you know, like a whole year of information. I'm like, now I've just put my whole medical history in an email

and I felt desperate, quite honestly, and he wrote me in five minutes.

And he said, he wasn't a man of many words, in email anyway. He said there's a test for it. Go to your doctor and ask for chlamydia pneumoniae blood test, IGG, big I, little G, Big G.

IGM and that will tell you if you have some antibodies to the bacteria and then tell me what the test result is and and so it began my journey with him.

He passed away four years ago he went by Chuck he became not only my physician he came my mentor. My friend, and by the time he left this earth a member of my family.

He helped co found my organization together. he treated me for multiple chronic infections I did indeed have that chlamydia bacteria that has likely been driving my asthma since I was a small child.

He had my blood sent to a specialty lab up at UMass to be screened for the organism directly. Instead of looking for antibodies, we can miss antibodies.

When you look for someone's immune response that's had a chronic infection for many years, it may not be positive. And so these things can hide. We call them stealth infections.

I also tested positive, he suggested obviously based on where I lived, We look I tested positive for Lyme, although not CDC positive initially. The CDC criteria are such that you have to have a certain number of bands on a test called a Western blot.

And that is really arbitrary criteria and in doubt dated. So when, you know, the current administration and RFK Jr. announced that the gaslighting of Lyme disease patients was over on December 15th when I sat in Washington, D. C.

with my colleagues, it literally gave me goosebumps to hear those words because when I was going through my diagnosis, I remember going back to some of the specialists and saying, hey, you know, figured out what was wrong.

I wanted them to know that they could help other patients potentially because Dr. Stratton began treating me with antibiotics. He put me on two. Now these chronic infections, they're not something you can just give someone seven days of a single antibiotic and they get better.

And we know in medicine there's precedent for this. There are infectious diseases that require multiple antimicrobial drugs in order to get the infection, you know, fully eradicated.

And these neuroinvasive infections, especially in patients like me that have been given prednisone and immunosuppressed, Lyme disease bacteria are like a corkscrew.

Sam, they can literally burrow into tissues, and they burrows into the central nervous system and brain. And so if you treat these things promptly. they are more treatable.

But if you tell a patient, oh, you know, let's say the practitioner in all fairness, doesn't know they haven't been trained, right? They went through med school, they got almost no education on chronic infections.

They don't anything about chlamydia pneumonia, even though 50 to 80% of the population has it by middle age. Well, They Don't Know That Chronic Infections Can Cause Chrotic Disease.

And this is literally what my life's mission is all about is to shed light on this underappreciated area that where we really need a tremendous investment from the biggest funder in the entire world, that's the United States government.

We have a $50 billion budget every year for research funding and more of it needs to go toward root causes. And one very plausible one that has been completely ignored, it's not the only one, are infectious diseases and how they interplay with our immune systems and they are impacting us as we age.

The treatment that you did with the antibiotic, how long were you on that treatment? So I was cycled on and off multiple antimicrobial drugs. And this is sort of like art and science combined.

This is where we don't have the clinical trials. We need to understand what a patient like me really needs, quite frankly. You know, the gold standard for medical research is a randomized controlled trial, RCT.

those cost millions of dollars. If there isn't a drug where a company can profit from that, very unlikely to see RCTs of old antibiotics that are off patent, for example, like the ones I was treated with.

But I took medications for anyone listening that might be a healthcare provider or work in the field. Some of the treatment that I received or that Lyme disease patients receive can be similar to what someone would get if they had tuberculous meningitis like TB and you end up with like a central nervous system infection.

So at times I was on three antibiotics, two antibiotics.

From Patient to Collaboration Architect

You do experience terrible symptoms when you're treating a Lyme infection and some of these other co-infections like Bartonella that I also have by the way.

they actually create inflammation as they die. And because some of these infections were living inside your cells, particularly your immune cells you can actually drop yourimmune cell counts.

So I have labs from during the time my treatment was initiated where it was startling how many immune cell I had lost. My immune counts were low. I spent six weeks in bed at one point during treatment.

I wouldn't wish how sick I was. That's called a Herxheimer reaction. I would not wish that on anyone. It's brutal. You almost can't tolerate it. What happens is physicians that know how to treat Lyme and these chronic infections will take breaks.

They will pulse the treatment, give the patient's body a moment to recover. There are toxins being released massive cell death cytokines, which is a word we all became familiar with during COVID.

Basically a toxic soup in your body. So I underwent this treatment. And today, really only just a year ago, I learned I had another co infection that the prior testing had missed.

Which one was that? But be ziosis. so it's a red blood cell parasite that is frequently being transmitted with tick bites, but underappreciated and under tested.

and Sam, honestly, it put the last puzzle piece together for me, maybe not the one, but there was always this thing with my case, like the air hunger.

We never really understood that. Well, I started working more closely with the ILADS, the International Lyme and Associated Diseases Society of Practitioners.

I sit on the Ilads Education Foundation Board. And I began soaking in all of their clinical experience like a sponge and listening to case reports about babesiosis and the symptoms.

And one of them was air hunger. It was something I said, oh, my goodness. So I'm actually a part of a research study at North Carolina State University where my blood is collected.

Thanks to Dr. Ed Breichwert, who's an incredible pioneer in this field for decades. Found out that I have this infection and it was in my blood in 2021 and then when they looked at it again in 25 So I still am undergoing treatment today.

So what kind of treatment is usually done for that? So those are usually anti-malarial drugs actually So some of the drugs for malaria like a drug called malarone is what I'm actually taking right now But babesiosis can cause this sort of relapsing fatigue dizziness I had these enlarged lymph nodes that would come and go and And by and large, though, my initial treatment got me back to what I would say 95% of what it was before.

But I do live very carefully. I take really good care of myself. And make sure I sleep. Eat healthy. If I don't, you know, I can't burn the candle at both ends because I'll be sick.

And I believe that if I were diagnosed sooner and if people are caught early, it can prevent the chronicity aspect, which is these lingering issues and even chronic infection, because in some cases, these organisms, they hide and they can get inside biofilms.

and be incredibly difficult to eradicate. So in the future, what I really hope and pray for and what we work toward, my research consortium, is better solutions.

Antimicrobial drugs that we have today, we had drugs to treat patients. Stimulating the immune system may be a better long-term strategy. And people are working on these sort of things.

Nicky, there's Three type of individuals, right? There's a person who has a diagnosis, who's sick, and they just go to the doctor and do whatever the doctors tells them to do.

Regardless how they end up feeling, they go with whatever course of treatment is. Then you have another individual that's fed up with the current system or with a current doctor and further dig digs deeper, right?

Goes further into it, starts researching things, kind of like how you started doing, because they want to feel better. You know, they wanna figure out the solution.

But then there's the third individual that does exactly what that second person does, but then they also take all of that information throughout that journey and they bring it to the next level to help other people.

Why are you that third person? So I remember saying to Chuck, my doctor, when I started to feel better and I saw the clouds breaking, you know, because at one point I was crying in bed next to my husband, talking to God, thinking, I'm not making plans that I wouldn't get to see the boys grow up, and really wondering if I would survive.

And it's those dark moments and The thought that some other mom or dad or someone right now, as we speak, is looking at their life and making plans and they're not ready to be gone yet.

You know, they still have a beautiful and wonderful life to live. I remember going to Chuck and saying, what can I do to help? And I remembered him saying hold your horses.

They're. Not all the way better yet, we got to get you better. But I. Remember saying you know what are we doing about this? Do you have. A do you. Have a mentee?

You know, do you have somebody else that you're training? to treat people in this capacity because he worked also on infection and MS, multiple sclerosis.

He treated patients, Sam, that got out of a wheelchair. Like he would give them combination antimicrobial drugs if they had this chlamydia pneumoniae infection.

And he believed at that time that this was one of the drivers and he published on it. We also know that Borrelia Lyme disease can mimic MS. It can cause lesions on the MRIs and that those lesion can actually go away with

treatment.

So, you know, because he had all these other patients that he treated, I said, did anyone else ever say, hey, let's get involved. Let's start a nonprofit.

What are we going to do about this? And I say don't you just want to stand on the top of the mountain and scream that we have like completely misunderstood autoimmunity?

You know that there could be infections. It's not the immune system attacking the body, it's the system, attacking an invader we haven't seen or appreciated.

And he said maybe it is you. I'm not a doctor. Can't take care of patients. And so I think that's when I started thinking, well, the crew that studies infections, this particular bacteria, these chlamydia respiratory bacteria that is linked with asthma, MS, heart disease, arthritis, a bladder pain disorder.

I thought, have these folks been talking to each other that study these different diseases? And that's how this consortium approach began, very grassroots.

Literally just me saying, you know, one day I'm a stay-at-home mom, my youngest son goes off to kindergarten, and I say, Chuck, it's time. I am going to start something called intracel research group.

interest cell owing to the fact that we're studying bacteria, viruses and things that invade human cells and drive inflammation. I want to start getting you all together and figure out what is the plan?

What do we need to do to advance this? And that's how it started was. And it's not funny in a lot of rooms to say you got a bunch of chlamydia people together, but it is funny a room of scientists.

But that is how all began. Then we realized, oh boy, this idea that infections can become chronic isn't just about one infection. It's about a bunch of things.

And then I came to learn there were all these other communities out there, people studying HHV6, which is a herpes virus and its relationship to chronic disease and a foundation that had done incredible work.

People studying chronic bacteria in the gut linked to Crohn's, People's studying, you know, fungal infections and how they can drive asthma and sinusitis.

and then all of these people beginning to think about the brain because the Brain is connected to the rest of the body. And the brain has traditionally been thought of as it's hidden away, it is protected by something called the blood-brain barrier, inaccessible, totally safe.

Well, that's not really true. The brain is accessible and the body is interacting constantly with the brain, including microorganisms, bacteria, viruses, fungi, parasites, things that can get into our immune cells or that could get in to the bodies through olfaction or through our sense of smell.

Because right where the nose meets the brains, it's deficient in blood brain barrier. So it sort of like an open gateway. And that's where a lot of viruses enter and infect us in the first place.

And one of the things that we think is incredibly compelling, linking together neurodegenerative diseases like Alzheimer's, MS, Parkinson's and psychiatric illnesses like schizophrenia and others, is the patients will lose their sense of smell.

It's a unifying characteristic of a lot of these diseases. Well, what causes people to lose their sense of smell, among other things, infections, because it affects the nerves actually at the top of the nose in an area called olfactory bulb.

So we believe these are incredibly compelling things and clues that we need to pay attention to. And our team has

been really passionate, not only about studying diseases in a silo, like we're called the Alzheimer's Pathobiome Initiative, but we've recently, thanks to a philanthropy grant, expanded out to five diseases.

So one of our brilliant scientists trained at MIT, has team at Hebrew University and in Pittsburgh. And these folks are able to expand human brain tissue and see things that would normally only be able be seen under the world's most expensive and sophisticated microscopes.

It's pretty incredible, actually. We are comparing these brain diseases because they've all been linked with infections. So we're doing comparison between Alzheimer's brain specimens from people we lost, Parkinson's, ALS, the pediatric disorders, pans and pandas, and epilepsy.

Wow. You know, Nikki, you make that collaboration of what you've done with a lot of these researchers and scientists sound so easy. But what I want to know is when you started doing this, I'm the kind of person who's just thinking over here, you're knocking on people's doors, calling them, sending them emails.

And being in the medical field myself, not too many people are responsive. I know how busy a lot of these individuals are. How many nos did you get? You know, it's funny, when I started to reach out to people in this field, I had like no credentials, right?

So I have a bachelor's degree in business. I Had no publication history as yet. But I reached out on the basis of, you know being a patient wanting to contribute.

You this idea of starting to bring people together and converge and have meeting one Sunday a month. where we would hop on a zoom call and talk to one another, and I think the idea of these folks having a community.

You know, because research can be especially research that's on the cutting edge or hasn't been accepted yet, perhaps by the mainstream is one of the most difficult places to be as a researcher or even as researcher physician and.

Having a sense of community, being able to talk to one another, I think was one of the ways that it moved past and no, it wasn't an immediate rejection of like, Oh, who's this random person?

She has no credentials. You know, what has she been like? You worked in pharmaceutical industry, worked and biotech, but like what are we doing? The idea of them getting together was appealing and then it sort of like it snowballed and grew and I honestly didn't even know what I was going to do at first.

I had no idea what the model was or exactly how I would contribute other than by just starting. Like I remember my husband saying just put one foot in front of the other and begin.

And that was the best advice ever. And it turned into something incredibly beautiful. It really grew. I learned that not only was I really loving doing the work, but that there were very meaningful benefits for the researchers and the clinicians and innovators by coming together.

In some of those things are, you know, it amplifies opportunities to apply to grants together. So we were doing collaborative grant proposals, both into the government and also to foundations that fund research.

You know people are sharing specimens, they're sharing ideas. I mean, the most beautiful thing is our global team convenes for 30 minutes every single Wednesday for years, but some us a decade.

Uh, we, you know, We're sharing in so many different ways. We are sharing disappointments. You know times where you take a shot on goal with a 10 million dollar grant that is 378 pages long, that you, blood, sweat and tears, weekends, too many cups of coffee, missed vacations, uh, but didn't get, get a, shot, right?

But then you keep coming back for more. Another thing we're united by is that we all really have a reason that we're in this particular field of infection associated brain disease.

Many of us have very interesting origin stories of how we came into the space. And so I think it's mission driven for a lot of the scientists. That's it there.

Absolutely. Yeah. It's the heart. Right. Because you can't it. Not just about it, not a transaction. What we do together in Al's PI is not. A transaction we genuinely care about one another.

We have built a team that has a culture. We also have a junior scientists group called the LSPI next gen, because it shouldn't just end with you know the top experts, it needs to be how are we cultivating that next generation of young innovators young scientists young clinicians.

And other patient advocates, people like me that have the ability to learn and maybe lead teams and get people together. We want it to be copied. You know, everyone.

It would be a dream of mine to start to see these consortia crop up that has patients woven in and business people. What are the areas of medicine do you see benefiting from what you're doing in those other areas?

Literally all of them. Yeah, I don't think there's an area that wouldn't be informed by educated patients that have multidisciplinary expertise, patients, that might be attorneys, patience, uh, patients from industry, you know, and then also by pulling together people that might have ideas that some of the mainstream people think are a little fringy, but there's good evidence to support it.

Cause this is the thing that we battle against Sam. One of most powerful things is human nature. You know? There's, there sort of a knee jerk response, especially in medicine, that when something flies in the face of convention is a, uh.

Danger, you know, we that's not how we do things. This is how. We've always done things, right? Right. But you. Know, science is made to be questioned.

Absolutely. It's the only way that you can actually become innovative and bring new things to the table to improve what was the new science that has become the old sciences by questioning and digging deeper and bringing that collaboration.

You know. And that. Our job, our generation to figure out how to make things better. So you're right, you know, with what you are doing, are you ever scared?

Oh, yeah, I mean, all kinds of things scare me. You know I. Been doing this for more than 10 years. I started the LLC interest cell research group, which now really just represents the consulting arm of my work, where I can work with life sciences companies or go in on projects as a consulting expert on building collaborations.

Building Research Consortia Across Diseases

And now with this big consortium and a research center at PCOM, you know, my fears along the way have really evolved, right? In the beginning, it's like fearing for my life.

And then it like, fearring like oh, wow, I'm stepping out of my realm. You know I studied business, here I am, in a pond, little tiny fish in big pond.

Trying to make a difference in the space that's not even something I've trained in formally. but reading and constantly devouring the literature and trying to catch up.

And now that the stage that we're at now, which is we are on the runway, We've built a plane. It's taxiing and it's amazing. I'm like, oh gosh, we built this plane, it here.

We did it. we wrote a research plan to tackle these chronic diseases, published it in the world's leading Alzheimer's journal in 2023, effectively open sourcing the whole plan and calling for collaborators from around the.

And now we're trying to get the big project funded and off the ground. and that's going to have to be with the government. So we'll do it, I know we will.

I have faith that we're going to continue to work and refine the plan until it's worthy of that. And the thing that I always fear is with scientists, they live grant to grant.

So like their jobs are not secure. Most scientists even at the most prestigious places. In fact, They have to bring in their salary. and then pay for the people that are in their lab with grant money.

So one of my biggest concerns always is having built this beautiful team that has this research plan ready to go, locked and loaded, could be applied to any infection associated brain disease, and it's looking at all infections, not just tick-borne infections like Lyme.

is that if it doesn't get funded, the research team has to work on something, right? So they'll work other things and then they won't be available when the time comes.

But this is how this, I've become a researcher, and I live and breathe in their world now. I realize it's a whole different set of concerns and problems, but I like to leverage experience from my business side to remain pragmatic and to be agile.

And to think of it as a startup, truly, because that's exactly what it is. And a lot of the lessons of entrepreneurship are applicable to what we're trying to do.

What I've really learned is that just showing up and continuing to remain positive, which if there's one thing that I can count on is I'm an eternal optimist.

But I am driven by something that is sort of infinite. And it's self-renews. And I want to leave my kids in a better place. I wanna leave them with solutions to the problems that I know they may face in the future based on genetics, based the prevalence of the diseases that we're studying, and based things that have already happened to my family.

So when I look at Owen and Ian, I think we got work to do. Even when scared, even when burnt out or a little bummed, because something didn't go our way, because as you and I both know, a lot doesn't your way for a long, long time.

Anyone that's built anything has been rejected. Absolutely. I mean, that definitely gives you the fuel that you need to feed that fire that got going on in you.

So who out there doesn' like what you're doing? You know, we haven't had a lot of like overt opposition. I will say I expected it. OK. Expected more in your face.

Yeah. Y'all are wild. Get out of town. Where's your Ph. D.? You. Know, this is wild, you know. This is not the way things are done. You use the Alzheimer's example.

The field's been trying to target amyloid and tau, right? The plaques in the brain and the tangles. These are the villains, we have these things that show up in brain, they must be bad, let's get rid of them.

Well, the field has been tryin' to do that for 30 years. And when you get of those things, those patients don't get better. We have drugs to market that have marginal efficacy at best, it can be dangerous, or really expensive, and they're not accessible to a whole lot of people.

I expected us to have more opposition to what we were proposing, but we are finding that people, once you explain it and, you know, they read the research, it's compelling.

You know there isn't a real way to refute it because you can go all the way back to 1907 when Dr. Alzheimer

himself discovered these plaques and tangles in the brains of a patient that passed away.

And another scientist was competing him with him at the same time named Oscar Fisher. And the two of these guys were neck and neck. In fact, it could have been called Fisher's disease, because Fisher just showed up like six months later with a paper that may have even been better done than Alzheimer's paper.

Well, they were living during a time of syphilis. People don't talk a lot about syophilus, but it's the type of bacteria as Lyme disease. Aspiraki. Syphillus causes a dementia.

Dementia is the broad category that Alzheimer's sits under. Alzheimer is is most common form of dementia. All the way back in 1907, these early scientists were saying, ah, this plaques in the brain kind of look like bacterial colonies.

And they knew that dementia could be triggered by this infection. They just didn't have any treatments yet because penicillin didn' t come out until the mid-1940s.

So people, when they think about it, we were just, our team was presenting at the American Society for Microbiology in DC in June. and we gave a mini symposium and the room Sam stayed well into lunch at the conference.

Like people's bellies are grumbling, but we had four of our teammates, you know, myself and three others. And when you explain the data and when walk them through the logic that different infectious diseases can cause things like dementia that we already know they can, like HIV can a dementia if it's not treated.

it's no longer a question of is this legitimate? It's legitimate and who is it affecting? And what are we gonna do about it? Right, right. So, Nikki, you know, the data shows that seven million, over seven millions Americans have Alzheimer's disease and 13 million expected by 2050. Why is that we're so focused on treating end stage of this disease versus actually going to the root cause?

A lot of reasons. I mean, I recently made a video because I'm trying to create a lot educational content that inspires people to think differently and also educates patient and raise patients and raises awareness.

I think that if the discovery of Alzheimer's disease, you know, when Dr. Fisher and Dr Alzheimer were looking at the brains of patients, I. Think if. The discovery that Fleming made of like accidentally leaving a petri dish on a window cell and discovering penicillin antibiotic to treat these infections happened before the.

Discovery of the disease. We would have seen treatments that were upstream. You know. They would. Have thought, huh? You. Know, without all of. that they have today where we can really scrutinize pathology and all these different biological pathways.

They might have said, well, the most logical thing is without all of these sophisticated tools at that point, they may have thought about infections. Why is pathologist being targeted?

Well, that's kind of the way the industry has moved in general. The most profitable drugs are Oftentimes monoclonal antibodies infusions that people take for various diseases targeting a pathway, many of them autoimmune or inflammatory pathways that the patient has to take forever.

They're very profitable. And so it's economic in my opinion, but the economics can potentially work in the favor of actually addressing the problem. You know, for example, chronic infections that have gotten into the central nervous system are going to require a prolonged therapeutic approach.

And so companies that has safer, let's say narrow antimicrobial drugs that don't harm the whole gut microbiome, but that target things very selectively, these things could potentially be very profitable.

So I think there's a tremendous amount of hope You know that if people become aware that this is a problem,

innovators will come to the forefront, right?

If you build it, they will. So, you know, I had the pleasure to interview Dr. Horowitz. Are you familiar with him? Yes, yes, so, uh, he talks very, very closely on the Alzheimer's topic.

Yes. And he believes he has the cure to that. He believes that a high percentage of people that are diagnosed with Alzheimer is actually lying. So are these things that you've been diving deep into as well?

Yeah, we had Dr. Horowitz come and present that case report to our OSPI team that every Wednesday. OK, I always want the team to hear about cases. So in twenty twenty three, when I told you we published our research plan and put it out to the world, one part of the paper that I worked on extensively was digging through the literature to find cases of dementia that were caused by infections and that we're treated and the patient got better.

And we found 86 cases in literature. The infections were pretty diverse Sam. They were like some of them had Lyme really infections Some of him had more than one infection at the same time.

Oh some had viruses There was a fungal infection that was found called cryptococcus over and over again and then parasites depending on where in the world you lived some people had parasitic infections and the people that got treated and got better and These physicians were so moved that they wrote a case report and the conclusion in nearly all of the cases where the patient had drastic improvements in their memory scores was we need to be thinking about infections when patients first develop symptoms of neurocognitive decline.

In other words, right when that, you know, I put my keys in the fridge. I forgot the code to get back into the house that I've used a thousand times. When they first have subjective memory complaints or even sooner, like the concept of doing mammograms or having a colonoscopy, we should be screening for things that we know that can harm the brain.

And so in. The sense that, you know, these case reports really showed us and inspired me that. We need precision. even earlier, ideally, than the disease would begin.

But research studies that way are incredibly difficult and hard to fund. If you took people that had, let's say, mild cognitive impairment, the beginning, very first early stages of what could become Alzheimer's disease or another dementia, and you started testing them, I suspect you would find a lot of them have evidence of these infections on board, including Lyme disease.

And I agree with Dr Horowitz. But my one concern is that a one size fits all approach is not how you treat infectious diseases. Infectious diseases demand tailoring.

It was never underscored more than my early years just out of college working for Pfizer. sitting in the infectious disease grand rounds at the hospital, listening to them talk about targeting anti-microbial drugs to kill the pathogen.

You need to know what they're susceptible to. you can't just go in and think you're going to give everybody minocycline. That trial was done with Alzheimer's disease.

They did a trial in England. they gave everyone minocicline to see what would happen and it didn't work out. Well, if a person has, let's say, multiple infections, what say they have active viruses on board or a fungal infection or they.

Have Lyme, which typically needs more than one antimicrobial drug onboard to get after it. It's going to be, you know, a fool's errand. And the bad thing about clinical trials that aren't well designed is they can lead to false conclusions that something is not important and it can cause people to abandon a whole research field.

and there have been examples of that in history. That's a lot to take in and understand, and I'm happy that we have people like yourself that really have gotten a good grip on this and moving things forward.

Nikki, when it comes to Lyme disease, 476,000 Americans are diagnosed with Lyne each year, in up to 20%

developed persistent chronic conditions. So right now there are certain treatments for Lyme and there's certain ways to diagnose Lyne disease, which from what I've heard on different episodes on this podcast, they're not the best way to test for lyme.

Yes. So why is all of this, these processes in the medical industry right, now in allopathic traditional medicine industry, why's it so misunderstood?

Boy, you know, the physicians haven't been educated on it properly, like coming through medical school, whether it's osteopathic or allopathics, it needs to be into the curriculum.

What is an infection associated chronic illness patient look like when they come in, when the present to the clinic? What systems of the body could be affected?

What tests would you order? what tests will look normal and fool you into thinking that patient's OK? My my CBC while I was sick was unremarkable. Complete blood count.

You know, it was kind of my white count was like at the high end of normal, but nothing was screaming at anyone. So, you know the testing that we have had available and covered by, insurance companies, tests like what LabCorp and Quest have or Lyme.

Recently, the Bay Area Lyne Foundation funded a study with Dr. Liz Horne where they determined the traditional testing can miss Up to it's about 76 or 78% of cases early.

So that's like the majority three quarters can be missed, meaning a false negative because those tests are relying on a response from the body. And so not looking directly for the pathogen itself.

And that timeframe when the person gets a tick bite, let's say, and they're exposed for the first time to these, you know, it's like a dirty needle. They don't just have one infection.

they've been out biting other critters. And oftentimes they can have multiple infections inside the tick. So it bites you. The best time. To address that is immediately.

Right. I actually am a proponent for prophylaxis. you should be treating people that get tick bites, because what we know happens to someone if you delay treatment, far outweighs the risk of subjecting them to a course of antimicrobial drugs.

You know, people will talk about resistance, you know. Oh, well, if we use them, that's irresponsible. Well, there's also you have to weigh the other side of the coin.

Like if there are a significant proportion of patients that go on to become like me, where you're literally losing your quality of life and fearing that you are going to lose your life.

You're so chronically sick that don't even function, you have to weigh that against using an antimicrobial drug. It's an example going all the way back to history of the scientist that demonstrated that ulcers were caused by bacteria.

His name is Dr. Barry Marshall and his colleague Dr William Warren, the late Dr Williams Warren. What they, when they were trying to show that bacteria could cause ulcers, everyone was saying, these are mad men.

That's a direct quote from people in high places in the infectious disease world. And they just kept persisting, saying no, we're finding these bacteria in ulcer's helical bacteria and we can make animals sick with it.

You know, and Dr. Marshall even drank it himself and made himself sick.

Alzheimeru2019s, Infections, and Root-Cause Science

He was so tired of being doubted. Kind of a wild maneuver. Fast forward, they end up winning the Nobel Prize, but one of the gastrointestinal conferences that happened during this time, somebody got up in defense of these scientists and said, you know, because someone was saying, oh, well, if everybody is going to start with an ulcer using antibiotics, this is gonna be terrible for antimicrobial stewardship, meaning The antibiotics will be overused on these patients.

Someone stood up and said, well, would you not treat someone with a urinary tract infection because you're worried about overusing the antibiotics? How do you decide what condition is severe enough?

Like if someone has a bleeding ulcer and they're literally losing pints of blood, that's pretty serious. And so I draw the same parallel over to Lyme because if we know it's a neuroinvasive pathogen, right?

A corkscrew that can get into your brain. make you chronically ill, be incredibly difficult to get rid of if you wait to treat it. Why are we gambling?

We shouldn't be gambling. To me, it's crazy to think that, you know, We vaccinate our kids and family members with all these different vaccines without them even being exposed to anything.

And now you have someone who's actually gotten a tick bite. That's an exposure on its own. You don't necessarily know if they have that infection, but there's that potential.

So in my opinion, Let's do something about it so it doesn't get worse. When I worked at the fire department, if you got a needle stick, they still ran you through a series of medications, regardless if actually got exposed to whatever.

Because you don't know what's going to come up down the line. And I'd be the first one, yeah, give me the medication. I don' want to try to figure this out a year or two years down line when it's taken over my body.

Yeah, it's been one of the greatest challenges, but this testing problem is one the biggest issues, right? So if your test is giving a lot of false negatives that everyone is leaning on, the impression is that it is not as widespread of a problem as it it.

It's likely far more widespread than anyone can possibly appreciate because we haven't detected all the infections. And you have people too that are probably walking around only mildly sick.

So that's the thing too, not everyone gets to the level of severity like I was. Some people get worse than me. Other people might just be having panic attacks.

You know, there are symptoms that can come and, you know be transient with this kind of infection, right? You can have like moving joint pain. A knee might hurt, a hip might heart.

And these patients end up being, pushed from one specialist to next on a lot of drugs to mask the pain, You know, taking a lot of SSRIs or like one physician offered me Xanax when I was really sick and I stormed out, I.

Was extremely angry because it seemed really inappropriate, right? To offer me a drug just to, you know. He was it felt like he was insinuating I, was hysterical or that my symptoms weren't real.

You were sedating you. That's what dating my brain. Right. I couldn't think any longer. So so we have to really approach these things as an emergency because that's.

What it is. Because I can tell you that it's a robber. It robs people of their quality of life. It rubs family members of having a loved one. For anyone that's out there listening and they're starting to hear all these different symptoms and this could be me or one of my family member, what would be some of the top most appropriate tests for them to actually go get done?

So the thing that I always dissuade people from is going down a rabbit hole of having a clinician that's not an expert

in this area start ordering them tests because that'll be an uphill battle even to get them to order the tests more than likely because the clinician will think, well, how will I interpret these tests, right?

If it's like, let's say a specialty lab like Galaxy Diagnostics and the patient comes back that they have Babesia, Bartonella and Borrelia. You know, the three B's that frequently get transmitted.

Well, that doctor in that moment is thinking, what am I going to do if that's positive? I can't put this patient on long-term therapy. That scares me.

I've been told Lyme, chronic Lyma isn't real. They start swirling, right? Because this has been an area that has gray, which is so weird because it's so clear cut.

What I would suggest before thinking about testing is getting the right practitioner on your team. So I typically tell people to visit the ILADS website, the International Lyman Associated Diseases Society, These are a global group of practitioners and on the website there's a provider search and you can even look at people's level of training.

iLADS offers training that teaches these practitioners how to handle difficult cases. And they're not just gonna look for infections. They will also look immune function, they'll look hormones, look toxins, are you being exposed to mycotoxins for example in your home.

You need a root cause practitioner on your team. and then they can start ordering the better tests and more than likely they'll use labs like Galaxy Diagnostics, a lab called Igenix has much better Lyme and infection testing.

There is a company called Mosaic Diagonostix that'll do gut microbiota testing, look for mycotoxins, and there are all different companies that can assess for things that could be driving chronic inflammation or driving.

Chronic issues. But one of the biggest challenges, Sam, is that a lot of these things aren't covered. And so it's out of pocket pay. It is. That's the thing also in the functional medicine space.

Obviously, you know, I have multiple longevity clinics. Yes. All the different testing that we do, it is out-of-pocket. Is so difficult for people to be able to afford it because it could cost you thousands of dollars to just, run the test.

So that doesn't even include the doctor's time. Absolutely, and take Pan's Pandas. So for kiddos that have this disorder, the Molecular Biosciences Brain Autoimmune Panel, formerly known as the Cunningham Panel after the brilliant Madeleine Cunningham who found these five different markers for neuroinflammation, this test is $1,000. A lot of the families whose kids are suffering from like abrupt onset OCD, bedwetting, handwriting decompensating, It's terribly tragic, but the way that they die is by suicide.

A lot of them have as a literal symptom of the disease, suicidal ideation. And it's like the part of brain that is controlling all of these different functions is hijacked completely.

The way the that disease has been understood is that you get like an infection in the body and then you auto antibodies produced and it starts hitting that one area of that brain, the basal ganglia.

Well, one of the things our team wants to rule out with our study that we're doing is that infections aren't directly invading that area of. The brain and we are partnering with a very special and very sad brain bank called Pond at Georgetown, where there are cases of children that.

We lost to this horrible disease and were going to be studying with. Our teammates looking to see if infections were in those areas of those children's brains because I don't want to make the assumption that we understand something that really hasn't been studied enough.

And the treatment for these kids and some of their symptoms is curiously similar to some. Of these other disorders that are more common in older persons, you know, like Alzheimer's, Parkinson's.

These kids experience memory issues. They experience personality change and rage, which you do see with Alzheimer disease sleep disruption. You also see that in the brains of these.

Kids, what we do know about it, they have inflammation. and they have markers that are similar to cases. you know, of Alzheimer's in terms of pathologies that are there.

We need to pay attention to these things because kids that develop these disorders, they may later in life be at greater risk for neurodegenerative or other psychiatric illnesses.

But the good news is if you can get that test, right, the brain autoimmune panel, and if it were to start to be covered by insurance companies and in some states that's happening in the United States.

Yeah, their parents have come together and really pushed and there is legislation in certain states in the United States where insurance carriers have to cover testing and treatment for these kids.

If the child has these biomarkers on board indicating neuroinflammation, they can get a treatment that may result in remission for certain kids, immunoglobulin therapy, IVIG, and other kids can also do plasmapheresis in the most severe cases.

These are extremely expensive therapies that are oftentimes last ditch efforts, but if you have a child that's on the verge of harming themselves and that is in such excruciating pain, both physically and mentally, No, we really should be doing something about it and Lyme disease is another trigger for these disorders as well as the co-infections.

And so, yeah, it's really a age, you know, that doesn't discriminate, right? These infections don't just get against it. I'm happy that you commented on, going through the right steps and the stages when you're looking to go through diagnostics, making sure you have the coach to guide you through that process, the physician that's going to be able to actually understand these results that come back.

You know, I had the opportunity. You said galaxies labs. I have the. Opportunity to interview Nicole Bell, which also, you know. Very strong story, with her husband.

She lost her. Husband. And, that's what really motivated her to go into that direction. So. The more I just hear about the industry of infectious disease, there's more than just someone who just went to school to study something and do this as a career to just make money.

There's a lot of passion behind it. Even I had the opportunity to interview Dr. Ebony Cornish, which she focuses on the neurology part. Yes. So you're talking about the neurology part and how it affects the brain.

You know, you guys really have in this group that you just have created a lot of experts in these different fields. But these are experts that are just so passionate on what they're doing.

Absolutely. And the beautiful thing is with some of the other people you've interviewed is that we all are in the same orbit. We're actually working together on projects, many of us.

Nicole Bell's story is incredibly moving and I remember meeting her a number of years ago and reading the manuscript of her book before it was published.

And, you know, people that have lived experience and have skin, in the game, so to speak, of these horrible things that can happen can have a tremendous impact.

They can move people with their story, but they can also become experts and, have that drive that's more powerful than the desire for financial gain. is to, you know, again, watch your children grow up in a world that is going to be safer and healthier.

Absolutely. What are some of the bigger obstacles that you see that, yes, will potentially face as you guys go through a lot of research that. The number one thing that's a stumbling block is funding.

That's anyone that does research, right, for the most part, because you can have great plans, but you cannot fully execute on those plans without adequate funds.

And team science, which is what we're doing. is even more expensive because what you're talking about is an ecosystem, not just funding a single lab. Sorry, I keep touching the microphone.

I'm Italian. You talk with my hands. But having labs working together, sharing data means there has to be a data core. And there are mechanisms for doing work like this.

Funding is a big challenge. You know, obviously, engagement isn't a challenge. We have tons of engaged scientists ready to go, locked and loaded. The challenges, I guess, too, in the future are, you know how to, once you diagnose the infections, how do start doing studies.

Yeah, very challenging to do studies where there's a lot of different presentation or heterogeneity, as we call it in our realm. It's like, you have to figure out a way to demonstrate using the tools of science, using studies.

And I think pilot studies would be a great way. To go group people together that have similar infections, for example, and similar biomarkers and even perhaps similar hormonal changes that they're going through.

Like take, For example a group of perimenopausal women that had Borrelia burgdorferi, Lyme disease and memory issues and treat people with precise protocols in groups.

So I think there are scientific challenges and methodological challenges that we'll face, but those problems are the exciting problems to solve that. We love to talk about and think through and we're ready to think.

Through because it's just really the funding, honestly, because with enough funding. Look at HIV. You can literally prevent it from happening now. At one point, this was a horrifying death sentence.

And now because of a huge federal investment spurred by a patient movement, You have preventatives, you have treatments, and people can live a full and healthy life with that infection on board.

Yeah, that's true. Now, what about at the point in time that all the research and the studies you guys are doing have to be reviewed? You know, I remember you, we talked and you were talking about there's a peer review.

Is that correct? Yeah, so if you apply for federal funding to, let's say, the National Institutes of Health, and I can't, by the way, say enough good things about Dr.

Jay Bhattacharya, who runs the NIH now, had the privilege to come up to D. C. in January and hear him talk about the new NIH. And it's like I couldn't be nodding more emphatically.

I felt like was going to have a neck ache at the end of the day. He's talking about rigor and reproducibility. he's taking about high risk, high reward science, getting younger investigators, newer people, new ideas to the forefront.

Well, one of the greatest challenges you just brought up is something that a lot of people don't realize, is that you can get a team of global experts together, and we did this, build a beautiful plan, work with that agency.

You know, let's say for us, you know let say it's the National Institute on Aging or National Institutes of Neurologic Diseases and Stroke. So the NIH is the top of umbrella, then these other agencies sit underneath it.

you would talk to the team and you say, we're going to apply for a grant. They say okay, that's great. You have preliminary discussions with them so you don't come in cold.

They know what your ideas are. You build this amazingly challenging proposal with a ton of different collaborators. You're up all night, you know, work around the clock, do it, hand it over, and then the people that were sort of guiding you through the process, they're not involved in the decision at all after that, really.

It goes to a random group of reviewers that's not paid, that overworked and tired, it can be called study section. and they may not have your subject matter expertise if you're in a niche, which we are.

Our grants need people that understand infections, that the immune system, and that understands Alzheimer's. And getting that is challenging. That's almost like everyone we work with is most of the experts in the world.

There are other people outside our team that don't have conflicts of interest that could review our grants, And that's one of biggest challenges is getting through that gauntlet.

You know, we had one comment from a reviewer that made literal no sense. It was just very frustrating. And it was that they didn't understand the relationship between inflammation and infection or how we were trying to draw that parallel.

Testing, Treatment, and Lyme Disease Challenges

Now, if you go to the National Library of Medicine and you look up inflammation, there are multiple things, obviously, trauma, you, twist your ankle, inflammation.

Right. Hit your head. Infections, though, are the primary driver of inflammation in the human body. and that's just 101, right? So we really are constrained groups that are doing high risk, high reward science, groups, that have credible ideas that Dr.

Bhattacharya spoke about, like really good ideas, deserve a shot, you know, they deserve the chance to swing away. those are gonna have a really hard time coming through study section because of dogma, because people that are sitting there looking at the grants, if they're, let's say, a traditional Alzheimer's disease reviewer, they are going to say well, number one, I don't know anything about these bacteria, right?

Number two, this is tangential. You know, you could just hear it, and you get feedback, when you're rejected. But when the feedback isn't logical, constructive, it's not something that you can utilize to make your proposal better.

It's just indicative of a lack of subject matter expertise. Then you start to say, wow, we really need some reform. And that's the thing that if I could change anything or request anything, the reviewers that look at grants that are you know, high risk, higher reward, cutting edge, new fields, that those groups of people selected to review them are very carefully selected, especially in areas where we need it the most and where there's a high level of probability that there is, you now, smoke and that are flames there.

And this is a higher area of probably. Our government knows that. Infectious diseases are a huge threat to, Increasing risk of neurodegenerative neurological disease and psychiatric disease, especially for armed forces, you know, that are exposed to a lot of it.

Yeah. Wow. So. You know, one of the things that is happening in the world of Lyme disease is that there's a lot of these conspiracy talk, right? And a lotta this controversial talk out there, and there are investigative journalists that actually have taken the time to go out.

What is a message that you can give to the people of where they need to keep their mind when we're talking about these infectious diseases? I think, for me personally, focusing less on, you know, things that we can't change about the past and focusing more on the future, what we Can change, personally.

You know like you said, there are investigative journalists that are digging into history. And looking at the origin stories for infectious agents that may have been, you know, involved in government projects.

And, um, that's a separate matter for me, and separate from our team, we're really focused on the lives that we can save. With the innovations that can move forward with to address the problems.

You know, not really. It's not our wheelhouse to really weigh in on how we got into these problems. We're just trying to fix them. But there are people that are doing it.

And I'm thankful for those people because we do need to ask questions and understand how things originate. Do you guys collaborate with those individuals?

I've talked to Chris Newby to commend her on some of her writings in her work and her fortitude. Um, we don't have any active collaborations as of right now.

Because, you know like, um, You know, obviously, I participate a lot with the Make America Healthy Again movement. Yes. And even though we want to focus on a of these chronic diseases that people have and we're looking at root cause and were talking about the toxins in the food, they still go deep into who's behind putting these toxic chemicals, the dyes and everything in their food.

But I haven't seen such a separation on that side, which I do think that you should have a group of people that are just focused. that like leave that alone, let someone else handle that and just focus on.

Right. Let's let's crack the code to figure out how to cure these people. So I appreciate what you're doing. Where you don't get too tangled into the mess.

Yeah, we're we've got our sights set on developing better tests, you know, studying these brain specimens, looking at blood, yeah. Looking at what infections are there, understanding who we who can save, and then what innovations are going to address the unmet need.

The collaboration is not bad though. I'll tell you what, it grabs a lot of additional attention. Because for some reason, the majority of people always like this conspiracy stuff.

It's even with like the whole coronavirus. People are more concerned of what happened behind the scenes with the Fauci guy and this in China versus how do we take care of the post-COVID issues that people are having.

So I would have loved to have seen more, you know, drug repurposing actually happening, and we, I think there's more we could have done along those lines, that's for sure with regard to COVID.

And it is important to understand where we came from historically to prevent it from happening in the future. So I definitely appreciate the people that are, you know, the ones doing, that forensic looks back in time, figuring out, do we have to be looking into things that we're doing?

Are those leading to problems, right? Where, where we're endangering ourselves effectively. We have to pay attention to it. No, no. Yeah. Listen, I appreciate these people that actually go deep into the cave to do a lot of this investigative journalist stuff.

You know, yesterday I was in D. C. I flew back this morning and I met an investigative journalists who says, you know I'm doing investigation in the longevity space.

And I said, oh, that's it? And the lady that was next to him, younger Asian lady, she's like, this is going to get very dark. This is gonna be interesting and the guys he's a writer for I think it's epic times.

Okay, and He's talking about the longevity of of Of the black market of organ donors. Oh, wow And like it''s a real thing like in these other countries on the other side of the world Where they actually have like farms of actual humans that and it´s crazy So I'm actually gonna bring him on a podcast because He took too much of my time yesterday when I was there.

I wasn't really why I. Was there, but it was a very interesting conversation. So these investigative journalists, man, they do some crazy stuff because they go, you know, go undercover to try to figure things out.

Absolutely. And it's important to know. You know if if dark things are happening there there's a gentleman named Charlie Pillar, Charles Piller, who did a look at, you know, Alzheimer's research and found a just an incredible amount of fraud, actually decades worth of That's a more recent book that came out.

Is it going to happen on that side too? Yeah. Well, you know, the thing is that what we have to be careful of is, and anyone is susceptible to it. Like if people really marry an idea in science and they get hooked into something being the answer, And then they put on blinders, which can happen as human beings, You know you, become emotionally attached to something.

Um, that has kind of happened with the amyloid, cascade hypothesis, The plaques and the tangles are the cause of the disease, where actually I use the reference of them being the firefighters, the evolutionarily conserved firefighters.

Some of our teammates have actually shown that these things show up in response to infection. So you can recruit, you know, amyloid beta or cause, Tao to become tangles with infections and that evolution conserves things that help us.

There may be a possibility that what we think is the villain is actually the firefighter. Wow. Interesting. Yeah. So we're going to have a little fun here just to get get to know you a bit better.

So one of my favorite podcasters, Steven Barlet, with the diary of a CEO, came out with these conversation cards. Cool. You'll you'll open that up and just take two cards out of anywhere.

They'll read the card and answer. OK, can you describe what winning means to you? That's a good one for you. I can, we would have the ability to do our full research plan.

We would start with Alzheimer's disease using this methodology that we published in 2023. we Would effectively operationalize it. And then someone would come to the forefront and create an institute.

that would allow scientists to work collaboratively in the same building that are on the team. Let's say they're called the Alzheimer's Pathobiome Initiative.

And then we would go after diseases one by one using our framework and using out team and the methodologies. So we can literally take it and use it over and over again.

One by we show the world that these diseases can actually be intercepted and prevented. Amazing. That definitely sounds like a win to me. What else we got?

Okay. How do you take care of you? Well, lots of different ways. The number one thing actually that I decided takes care. Of me is laughing. Oh yeah. Yeah.

I don't think we laugh enough. You know, adults don' laugh. Enough. Do you go to comedy shows? No, I just, um, silly and goofy and I love to laugh with my husband.

We joke humor is, you know. A great way of healing. It's a great. Way of staying centered. And we love. To laugh, with our boys. We enjoy watching funny movies.

We have two teenage boys. I love to laugh with my best friends. Um, we crack up over, you know, next to nothing and, um, loved ones is recharging. Another thing I do to take care of myself is surround myself with people in my community.

So I am a chronic illness patient. At the end of the day, I have a giant pill box. I take really good care myself. That

can be sort of like lonely and exhausting.

You know, so having my fellow like partners in crime that I can get in touch with, that, you know we're living in the same sphere as me and, having been through a lot of same things I've been And so I also always suggest that to people, if people are out there struggling with something, finding other people that have a similar struggle, whether it's a chronic illness or something else, really is a way of actually healing and staying well by bonding with other that can see you and feel your experience firsthand.

And then, of course, all the other good stuff like sleep and eating healthy and But really, laughter and kinship, I think, are so community is important.

You know, my my sister went through two different kidney transplants. Oh, boy. Not too long ago, about a year ago. She got diagnosed with with cancer.

So sorry, cervical cancer, And she's going through her treatments. She's doing very well. But while she was going to her treatment, she ended up going this thing that our company participated in, which was a nonprofit that was created for It was created through one of the fire chiefs, his daughter passed away from cancer.

So what they do is they raise a lot of money for kids with cancer to really help the families. And kinder's kisses, very kinders kisses. That foundation, they did a whole stand-up comedy, speaking about laughter, to raise money, so they brought all these…

big comedians. And it was the first time my sister actually got out of the house throughout her chemotherapy treatments. In her going there where there were other people, you know, that have had cancer kids.

Sure. Right. It made her think, get it to yourself. Wow, my cancer is And it really that that made her change her mindset about things where now she feels more comfortable getting out of the house.

She doesn't feel so uncomfortable about not having hair right now. Sure. You know, so that community and getting into that group of other people that are dealing with the same, you never know what that can do to the other person.

Absolutely. I mean, you might even save someone's life. Absolutely, like talking to someone you you never know how a chance conversation with someone that you don't know, how much they're struggling.

And that's one thing that this the whole experience has taught me is, they always say, don' judge a book by its cover. But truly, people like me have had a lot of people say to me, well, look, sick.

Well, and I didn't look sick when I was my sickest. Had been training for half marathons. What boy was I sick? And that's like so challenging when how you appear isn't matching with how.

You feel, and I think it's a it. It's. A real disconnect to, unfortunately, like for providers, when you look at someone, you're like, well, buck up. Look at you, look fine.

But then you have low oxygen saturation, for example. You know, cloudy x-rays, chest x rays. You have a borderline high white count. So it's like you just literally never know when you encounter another person what they're going through.

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And that has been the greatest takeaway for me. and something that I also try to impart in my kids is that, you know. When you look at somebody else and you see their actions and their behaviors, know that you really don't know their story until you.

Know their. Story and to always, assume that people have. A lot more going on than you can see. Yeah, I totally

agree with that. So. I'd tell you, I've interviewed a lot of scientists, a lots of doctors, very highly educated individuals on my podcast, hundreds.

Throughout my career, obviously I have a network of over 5,000 doctors that I sell IV therapy products to. I tell ya, you're very well spoken. You're probably one of the best well-spoken people that i've had on this podcast.

So whatever you doing, keep on doing it because you articulate your words very You know, I could have kept that to myself, but I want you to know that I do interview a lot of experts and you are just very, very well spoken.

It means a. Lot and I I read constantly. You asked me earlier. I mean, have you always been like this since you were a kid or? I've always been a scientist in the sixth grade.

They asked us, like, for the yearbook, what do you want to be when you grow up? And I said I was going to. Be a botanist plant scientist. Like, how random is that?

That's not what I do, but I I'm just curious, you know, so I'll fall down the wormhole on PubMed is what. I call it. So I. Will be reading a study, and I get all these alerts.

Like I set up alerts through NIH, you can get NCBI, if people are curious. You don't have to have any degree, You can start reading. Literally you could watch experts on YouTube today.

We have so many educational materials at our disposal, right? If you want to take the time and effort and if you are well enough and it's something you care about.

Let's say you have a sick child. I mean, how many times have I seen parents with kids with rare diseases literally become subject matter experts on their kids disease.

And it's because of love. Love is what drives me to keep learning. It's that I look at the kids, look and my husband and I say, like, I want to live this life.

Like I. Want the chance to be here. I've been given I feel like I'm given a second chance. Do you feel that at. The point of the height of my illness, was nearly to a point where I could.

My life was in jeopardy. And so having stood at that edge, I don't take anything for granted. I do wish like that I could be, you know, in my 24 year old body with my twenty four year-old version of my brain, with like fire in me belly and desire to be awake and learning and reading.

Like, because I can't burn the candle at both ends any longer since being sick. Have to. Be cautious. And when I. Do do it like when we're submitting a grant, for example, and I You know, slip up and I don't take my own advice and get in bed at proper times and, you know, feed myself, the right amount of meals at the rate timing, drink like twenty seven cups of coffee.

You. Know, I pay for it with fatigue and muscle weakness and other things that people like me face. But, the driver is to keep learning and growing and that in the time I have here, to try to do as much good as I possibly can.

And what that looks like for me is, is bring people together. So the learning is definitely a huge part of it, but I think most importantly, where I'm going with it is the way you speak it.

Thank you. You have to take that and you need to be on more podcasts. So whoever's listening out there, you need to go on the podcast because you articulate your words very well and it's very clean and you're just really good at what you do.

So, Nikki, as we wrap up here, if someone's listen to this podcast or viewing this podcasts and really resonates with today's message, what is that last thing that you can read?

It's that, you know, it depends on who you are. If you're sick and you not sure what you have, um, your drifting from one specialist to the next, and some of your symptoms sound like they could be multi-system, consider infections, considered getting a root cause practitioner, that ILADS group is a great place to start.

If you are someone that is an innovator or you have a foundation or work for the government and you're listening, it's that we have plausible ideas that can intercept chronic diseases that consider to be idiopathic.

We just haven't leveraged those yet, but that people in science are ready to do so and that our team is one of those groups. Amazing. Nikki, if people want to find you, where can they find So I have tons of activity now on social media, um, been doing a lot on Instagram, Nikki Schulteck.

I do a ton on LinkedIn, uh, making a lots of video content now to try to reach a broader audience. Uh, you could also go to www.allspi.org. So it's A-L-Z-P-I.

And I. liked that for Pathobiome Initiative, but also Private Investigator, because that's kind of us digging into root causes. And there you can also see our team of collaborators.

That is a website mainly geared toward providers and scientists and innovators. But I do hear from patients from all around the world because I've opened up about my story.

So there are people that reach out and are in a very dark place. Like when I emailed my Dr. Chuck that day and didn't think I'd hear back, I answered those emails.

And I try to give people resources so that they can find their way to a provider that can help them. Absolutely. I love it. Nikki, it was a pleasure having you on a healthy point of view podcast.

Thank you. It was. A pleasure to be here with you, thank you so much for the time that you take to spread information to change lives. Sam, guys, you heard Nikki.

You have questions, people have question. There's answers out there. You just have to go in the right direction. Make sure you have someone to guide you through that process.

If you know someone, or maybe it's yourself, that's experiencing some of the things that we talked about today, make sure that you take this podcast and share it with those friends and family.

Take the next step to get yourself feeling better and take control of your health. Make sure you like, subscribe, do all that other fun stuff, and we'll see you for the next one.