From Patient to Researcher

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So I started doing searches. I was looking at the relationships between my diseases. so I did a Google search and that one search changed the rest of my life.

It was, what is the relationship between interstitial cystitis and atypical pneumonia? Welcome back to this episode of the Think Well, Age Well podcast.

We're delighted to have you here today. And I'm delighted today's guest as well. She is one of most fascinating stories you might ever hear. The intersection of science and medicine and healing, personal transformation.

Everything changed, however, when she became seriously ill herself. She was experiencing frightening neurological symptoms, she was eventually diagnosed with Lyme disease, chlamydia pneumonia, and other chronic infections.

And after successful treatment, rather than simply returning to her life as you might expect, She dedicated it to understanding why infections contribute to chronic illness.

and bringing together the world's leading scientists to investigate these questions. Please join me in welcoming Nikki Shultek. She's the founder and principal of Intracel Research Group, executive director and co-founder of the Alzheimer's Pathobium Initiative, founding director of The Pathobiome Research Center, research assistant professor at the Philadelphia College of Osteopathic Medicine, and She has helped launch groundbreaking research and collaborations at academic institutions around the world, exploring the role of microbes in Alzheimer's disease, in addition to other chronic illnesses.

Her work is helping to reshape how we think about Alzheimer, not simply as a disease of aging, but one that can be influenced by infection, our immune system, or inflammasome, and the complex interactions between our bodies and microbial world.

I'm so happy that Nikki's here with us. Welcome, Nikki. Thank you, Heather. I'm so grateful to be here and thank you for such a kind introduction. You have this interesting web of pharmaceutical industry experience, your own health journey, and then now these initiatives that you've created in the research world.

Can you take us back to that time when you were in pharmaceutical and faced with becoming a patient yourself with Lyme disease? Yeah, so I actually have this great gap on my resume where I was full-time with my kids for eight years and I wouldn't trade that for anything.

They're now 15 and 17 and they're why I do everything I them and other people that could potentially one day get a diagnosis and be told it's idiopathic.

And that can maybe be the worst thing a person can hear, right? That you don't know what a terrible disease is being caused by, so how do you stop it?

diverse set of different things that I've done, but they all kind of converge in a way. And I always was interested in science from the very beginning, and that's how I ended up in the pharmaceutical industry.

In fact, I thought for a period of time I might want to be a doctor, But I was also concerned about the level to which I'm an empath and how i take on other people's pain and wasn't sure that i could deal with like the day in and day out of potentially losing people.

So I thinking with some advisement from a family member, getting a business degree. I studied marketing and international business in French, and then you can work in industry, that's exactly what I did.

And I worked for Pfizer in sales, then I ended up getting the position working in a hospital sales unit where I was working with, ironically, medical microbiology labs on drug resistance and bacteria that get resistant to the antibiotics we have.

because Pfizer had a drug in that portfolio, and then working really exclusively with hospitals, which taught me a whole lot about our healthcare system and how things work and just how siloed everything is on the care side of things especially.

And then I had the privilege to work as a clinical specialist for Genentech, a biotech company. And in that role, it pulled me in to neuroscience, which is cool because that's involved in what I do today.

I got to working at that point with 50 different hospitals in Maryland and Virginia. And I was a part of this consortium that was linking all these different hospitals together, getting people talking to one another, or getting them out of their silos in order to expedite care of patients that are experiencing an acute stroke.

which is a blood clot in your brain. It's an emergency. We call that a brain attack. And so I had all these interesting experiences that I think led into what I ended up doing today.

Then I have my first son. He was a premature baby. I've had amazing support from Genentech. it's a wonderful company. But I decided to take on a full-time role at home taking care of my son and making sure he was healthy.

and I did that for eight years. In the final stages of that, I got sick. I was living in Connecticut and got ostensibly, I never got a bullseye rash, but I found an engorged tick on the ground.

And then in subsequent weeks developed a flu with no respiratory symptoms, you know, like body aches, run over by a truck feeling fatigue, horrible malaise, fever.

That went on for a few weeks and then that dissipated and led into the toughest year of my life.

Pharma Career and Early Illness

You've lived on both sides of medicine, and as both a patient and now a research leader, as someone who worked in the pharmaceutical space and in hospitals, why do patients living with chronic illness understand that researchers and clinicians sometimes don't share that perspective?

They overlook maybe because they've never been in it as a patients. Yeah, so I would say all of these experiences I collected along the way, whether it was working in the pharmaceutical industry or biotech industry, being a mom and advocating for kids that were preemie and NICU and all of those things, even figuring out how to breastfeed somebody who was premature.

I count these all as experiences that are incredibly formative. Watching amazing people do their work, the connectors in life that know how integrate themselves in a team fashion in order to make things happen, like lactation nurses, for example.

With my chronic illness, I essentially had their drifted. I had all of these different symptoms, right? And like many Lyme or chronic infection-associated illness patients, you get these strange things all over your body, and you sort of start to wonder, like, oh my goodness, what's happening to me?

This is wild. So I kind of fell apart over the course of the year. My asthma which had previously been well controlled went like completely severe and refractory which led my asthma clinician, which was sensible, it's what they do, they put you on prednisone, right?

That made me sicker which is really weird, made the air hunger worse. I had a swollen and painful joint at the onset. This is all after this flu, in the early spring, late winter in Connecticut.

And finding a big giant engorged nasty tick on the floor thinking maybe it fell off my dog. You know, when I got sick, the thing I noticed when i worked in the pharma and biotech field became all the more clear, which was how siloed everything was.

Not just like silos for the different parts of my body, right? Like the GI doctor helping me to try to figure out why my food wasn't digesting properly.

The cardiologist to find out I had an arrhythmia. the pulmonologists, multiples of them why I couldn't breathe, ENT that was brought in, ear, nose, throat doctor for the breathing.

My goodness, you name it. You know, EuroGYN doctor because I had a bladder pain disorder called interstitial cystitis. That was horribly painful. all of these things happening to me, and I'm going to each of those physicians, what ties these thing together?

You know, I was relatively well. I had lifelong asthma, but it was under control. It was running half marathons. And I never smoked, always took care of myself.

Always been into healthy eating. What changed, right? I just started just to have this intense curiosity. Then the most frightening thing that happened were the neurological symptoms and neuropsychiatric.

So toward the tail end of this terrible year with all these different diagnoses, I got some really frightening symptoms that my primary care doctor, who was roughly my age and with children, she was really disturbed and thought, you know, You could have MS, especially because I'd had this intense fatigue.

I've been really, really tired all year. You know when I developed this, terrible pain behind my eye, almost like a hot poker was being poked through my I like intermittently almost rhythmic.

Like I could count the number of seconds in between. And then I actually woke up on my birthday, my 34th birthday with terrible numbness in various parts of my body.

And I had developed what they call muscle fasciculations or spasms. Things were moving by themselves, like one night my finger was just going like this on the couch.

So I talked to my doctor about all these things, about my primary care, and she sent me to a neurologist. Mind you, this is Hartford, Connecticut. We're in literally the state where Lyme, CT is.

And I go to see a neurologist after a very lengthy wait, by the way. And he was sort of very vacant, which hurts naturally. I have to say that I endured a lot of trauma over that year, seeing different people that made me feel like I wasn't seen.

It made feel that my case, if anything, intimidated them and they just very quickly wanted to be out of it and send me to somebody else because it was just, and I guess in a sense I didn't And since I don't blame them, you know, healthcare provider burnout is incredibly high.

It's a really hard job. There are a lot of issues there. So I like to reflect back on it with kindness and understanding that that human across from me may have had their own stuff going on.

But cases like this are the type of case where trauma can happen to the patient because you become what you feel like, I call it a human hockey puck, pass to somebody else.

You want someone to say to you, I'm with you. You know, I am going to stick with until we find a solution. I may not have the solution myself, but I will connect you to doctors or practitioners that can help.

We're going figure it out together." So that's what you really want, right? When you're hurting, whether it's physically or emotionally. The other thing I developed, which a lot of Lyme patients and infection-associated chronic illness patients develop, and I was afraid to mention it for fear of being gaslit, was terrible fight or flight symptoms.

So I would wake up in the morning during all this and it was like my heart rate would suddenly skyrocket. My bowels would empty. Sorry to be graphic, but like this is the real stuff that happens.

It was such an anxiety feeling that in earnest and sometimes four in I felt that if I had to live like that the rest of my life, that I couldn't tolerate that level of emotional pain.

So, of course, through all of this, I have a psychologist, which was great, and I recommend it to anyone that's been through so much trauma. And I always am an advocate for mental health.

Having someone to talk to about cognitive behavioral therapy she really was bothered by this autonomic or sort of automatic switch that was happening.

And she said, you know, this really feels biological to me and this feels like something is physically, especially in light of all of my other physical symptoms.

She was very reassuring and encouraging me to continue asking questions. I thank goodness I did. How did you figure out what was going on? So I ended up starting to read the medical literature and the point at which I got there, you know, I'm a mom with two little kids.

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It was, what is the relationship between interstitial cystitis and atypical pneumonia? Because atychal pneumonia was one of the first things that came up on the radar when I had that terrible air hunger and asthma exacerbation.

X-ray was a little cloudy, so the doctor had given me azithromycin antibiotic, right, the ZPAC, and that alleviated the

air hunger, but it was only a 10-day course.

So, of course, as soon as it ran out of my system, I relapsed. Fast forward to today for everyone listening. I now know that back then nearly, so it's 11 years ago, 2015, I had babesiosis.

characteristic symptoms that patients will get is air hunger. And I had another symptom that went along with it, rib pain, like this terrible pain in my ribs.

The airhunger, even though I have asthma my whole life, was very different than asthma.

Reading the Literature and Finding Clues

It felt like someone had a belt around my rib cage and every breath was unfulfilling. I felt I needed more oxygen, I need more air, and it was particularly terrible at night.

So when I did this Google search of atypical pneumonia and interstitial cystitis, I came up with a study Very small study, though. Actually, just an article about a study first, and the article is from Vanderbilt University, okay?

And it was a small-study done by an infectious disease and medical microbiology specialist named Charles W. Stratton and a urology colleague where they took 18 women's urine and analyzed the urine if they had interstitial cystitis and also if did not.

They had no bladder pain disorder and tested it for this bacteria I had never heard of. It was called chlamydia pneumoniae. I go, chlamedia pneumonia, that's interesting.

This is a respiratory bacteria. I started reading the study and it said essentially that nearly all the women with this incurable bladder pain disorder that's inflammatory had this organism living in the urine, but that this organisms would not be picked up on by the routine cultures done by your primary care doctor or even your gynecologist.

or urologist. It's a organism that, a bacteria that has to live inside human cells, inside your building blocks, so in the lining of the bladder. And you can't pick it up by usual methods because of where it lives.

I go, my goodness, this is wild because the comparator group, the people without the Bladder Pain Disorder, it was absent in nearly every one of them.

And the conclusion was, hey, this wasn't a very big study. In science, we really like to see large studies to show there's a relationship, right, the statistics issue.

But the confusion was kind of chilling. It was like, We should really be looking into this because this is a terribly debilitating disease, one of the most painful things a person can suffer from.

And if this infection is there, it's treatable and it should be addressed, but it is not something that can be address with a short course of antibiotics.

It requires lengthier treatment and with multiple drugs. And then the next search I did because I'm going, chronic respiratory bacterium, I've had asthma my whole life and somewhere in my heart, the asthma story never made sense to me either.

I remember being a little kid and having these terrible breathing issues before there were even inhalers to help you feel better. They used to have me put my head in the shower with steam, I went to the ER all the time.

I had epinephrine when I was like three or four years old because my airway closed. Okay, and I remember being a youngster asking the doctor, because I noticed that when i got sick with a cold, like a bronchitis and a respiratory infection, this would get worse.

you know, what about infections? I was poking around and they said, no, asthma is an autoimmune disease. Your immune system essentially is attacking your lungs.

And that's how it was explained to me. Well, when I looked up this bacteria, chlamydia, pneumoniae, and asthma on PubMed, which is where you go for medical publications, thousands of papers came up.

It turned out that there is a really strong link between that bacteria and developing specially severe asthma. And my mind was forever changed. I started reaching out to the people that were in the study, and this is Dr.

Charles W. Stratton. And I keep him on my desk with me here. He went by Chuck. he was the doctor that did that interstitial cystitis urine study. The first study I found, I emailed him.

. I snooped around. They knew that I could find his email on his medical publications. and I said, i'm going to email this guy's going think, um, you know, Wild, wild.

I think a lot of researchers, it takes some effort to find their email addresses, but they love hearing from people who are really interested in their work.

i want to make the connection between Alzheimer's and your story. Yeah, go ahead. Many of our listeners are here really interesting in how they can protect their brain as they age.

And so, you know, and I think they've heard the story because we've had several Lyme experts on the podcast. A lot of people have heard this story of like LyME can be part of that process.

It can trigger that neurodegenerative process and you've become this collaboration architect kind of helping people make these conclusions, find out these answers a little sooner.

Can you fast forward to this connection between Alzheimer's and LyMe and Alzheimer and other infections? I want to take a moment to share something really exciting with you.

This is something that's been a long time coming for us. At Sulseri, 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 salseri.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.

People will say to me, Nikki, how did your journey lead you to work on Alzheimer's? Okay, so we identified myself and a group of chlamydia experts was how my group began, right?

I started connecting people to each other, studying this one bacteria. And it turned out this singular bacteria had also been strongly associated with Alzheimer's disease by a researcher named Dr.

Brian Balen. So the asthma-Alzheimer's connection actually is not as tangential as it sounds. The lungs and the nasal passages actually are interacting with the brain.

I, you know, me, when I got better, I get treated, and I'll fast forward to that, with a combination of antibiotics. My treatment has been ongoing for many years.

I've used herbals, a lot of different tactics with the help of naturopathic doctors and ILAD's doctor, the International Lyme and Associated Diseases Society of Clinicians, which I highly recommend.

Did you ever do hypothermia? Never did hypthermia. Sorry, what was the other one you asked about? Those are intense interventions and you haven't needed to go there.

Sounds right. Well, I've done a lot of intense things. My treatment with Dr. Stratton, he was a chlamydia expert. It also covered Lyme. I tested positive for Lymes-C-pneumoniae, chlamedia pneumoniae.

I took for a very long period a combination of rifampin and minocycline and azithromycin. The asthma went into a period of prolonged remission, which was crazy and cool and amazing.

My bladder pain disorder, I don't have that today, fast forward to that. I do not have multiple sclerosis, my neurologic symptoms are gone. I did learn very much later that I had babesiosis because it actually was negative multiple, multiple times.

And then it was found through a study at North Carolina State, thanks to Dr. Ed. So I only embarked on Babesia therapy in December. For many of us, like those of you listening, thinking about brain health, your life is a continuum, right?

And especially as women, two-thirds of Alzheimer's cases are female. And we experience these hormonal changes that are very pertinent to how we age and our well-being as we aged.

But basically the connection over to Alzheimer's came very naturally because of all the symptoms that I had during this horrible year, The cognitive symptoms, like I felt like was losing sharpness and I was only 34 years old, were the most disturbing.

And then when I really dug into the research and saw how compelling it was, not only that chlamydia could potentially be a driver of Alzheimer's, but things like Borrelia burgdorferi, that there had been decades of research on that in association with Alzheimer.

that we already knew that syphilis bacteria, treponema pallidum, the old sexually transmitted infection that ravaged for thousands of years before penicillin came out, that causes a dementia.

And I started going, for goodness gracious, we know that infections can cause dementia now. Just for everyone listening, dementia is your umbrella category and Alzheimer's disease is underneath that umbrella serving as the most common form.

The pathologies, the things that show up in the brain, Lloyd-Beta and P.

Connecting Infections to Alzheimeru2019s

Tau, The Tangles, which people have referred to as Tinder and Flames, these things are part of your innate immune system or the immune attack that is there to help something.

And one of the thing they are there is to fight infection. And so this has already been published. And we really leaned hard into building the team. My aim was to let's get not just chlamydia experts, but people studying all different types of infections, fungus, bacteria, viruses, parasites, people that are experts in the immune system, and people who are neuroscientists, data scientists and mathematicians, veterinary medicine, And our team is literally now, fast forward 11 years.

I figured out the way that I could help was by building collaborative scientific teams. But I love science, I loved to read broadly. And I pull these folks together and together we write grants, we right papers that we publish in the medical literature.

Also write op-ed pieces that mirror the Medical Literature papers so that it's accessible to a wider audience because I came into all of this as a patient.

And I feel that people have a right to know what else is happening in the medical and research realm, not just the ads that are on TV, you know, which represent a very thin slice of what's happening.

So I'm curious, when people are concerned, is their Alzheimer's, their neurocognitive decline about an infection? Help us understand, like, when does someone ask for more testing?

There's nuance here. And what's the difference between saying microbes might contribute to a disease versus saying that they're the only cause? Can you talk us through that part?

Sure. So, The way that I say it is that microbes can cause dementia. They can. Individual cases, absolutely. We documented 86 cases of dementia, all different types, including Alzheimer's diagnosed patients in our study in 2023. And this is something that is known.

Human immunodeficiency virus, HIV, back before there were really good antiretroviral treatments for patients. Basically, you could develop this HIV-associated form of dementia and that, the brain would be taking a hit.

And what HIV does is allows other infections to really take over that patient's body. It's immunosuppressive, just like Lyme and Lyne co-infection. So COVID joins the list of immune modulating, immunosuppressive infections, certainly in certain individuals.

And some incredible research teams have demonstrated this. So where's the line drawn? I personally believe everyone with neurocognitive symptoms should be screened for infections.

It is a known driver of neuroinflammation. it is accepted that neuro inflammation plays a role in Alzheimer's disease. But there are caveats, Heather, you know, so it's really tricky.

Just asking the average practitioner to order tests for things like herpes viruses, the cold sore virus that has been linked with Alzheimer's, to orders tests, for Lyme disease and tick-borne infections, To order testing for chlamydia pneumoniae.

Some of these organisms, The testing is not incredibly accurate, or it is even not directly looking for those infections. the testing is looking for your body's immune response to those infections.

And your immune responses can in fact be impaired by the infections, and so it's nuanced. Then the second issue is, that's really troubling and challenging, is if you get a positive result, let's say a Lyme test, you have some bands that are positive.

You might even meet CDC criteria. If you're at an average practitioner, they may not know how to handle that case and how treat that effectively. I mean, it's depending on how long someone has had an infection with something

like Lyme disease, Borrelia burgdorferi, or some of the co-infections, and usually do require a very tailored treatment regimen that takes into account a lot of different factors.

So you really need an expert. So typically when people approach me and they say, Nikki, based on the research you guys are doing, what would you recommend doing today?

What can you do today?" Well, one thing that I often recommend is for patients that have memory concerns, to look into seeing an ILADS practitioner. It's the International Lyme and Associated Diseases Society.

And people may say, well, I don't think I have been bitten by a tick. I Don't Think I Have Lyme Disease. Well, these practitioners that are a part of ILADS, they're not just focusing on Lymedisease.

First of all, They're looking at a lot of different infections. They are looking a a of other upstream potential drivers that can contribute to memory problems.

You know, there is, as you pointed out, it's multifactorial. It's not like any one thing is likely the singular thing happening. Also, our research is showing that there are what we call polymicrobial infections.

There's more than one bad, you know, member of the party that shows up. So, if a patient, let's say, has evidence like a frequent herpes cold sore reactivations over and over again, Research shows these things can be a bit like traumatic brain injuries.

They cause inflammatory response. It's bad. You don't want to have repeated reactivations. they can even be happening when you don' get a cold sore and they're, they ca be induced by stress.

Like life is stressful, right? And then the other issue is that, you know, They could have more than one thing happening, and they more likely do, because when you're living your life as a human being, from the time you were a child, you are exposed over and over again.

Some of these things you get reinfected with over a lifetime. And so you can't just look at one things. You have to look bacteria, viruses, fungal infections, parasites.

You want to see if the patient has nutritional deficiencies. You wanna ask about diet, socialization, how is their hearing. So there are these modifiable, and you know all about it, given the nature of what you do and the book that you wrote.

There are things that can be done that modify trajectory. And I know also too, Dr. Dale Bredesen's protocol and approach does take into account infections.

So I would always recommend people at the first signs of cognitive issues to be screened for infections, but by getting connected first with the right practitioner, because just ordering tests can be you know, very time consuming.

It can be costly and it can a waste of time because sometimes the tests are not incredibly accurate and they don't end up setting patients on the right path toward recovery.

Yeah, we were having this conversation with a patient this week. The tests, they're like negative value, right, if you pay for them and then you don t have someone who knows how to interpret them.

And part of that, especially in this world, in the chronic infection world is that if you are only looking at immunoglobulins and immune responses to these infections, you're going to miss a lot.

You're gonna misinterpret a whole lot and so we have to use a combination of things depending on the microbe. But we also see, I think you kind of alluded to this, we do screen everybody, all of our memory patients for basically everything that you've discussed, but also P.

gentivalis, the gum diseases that can trigger amyloid synthesis. Of course, HSV1, a whole laundry list of immunoglobulins that we do look at as a screen.

And then a lot of it is the conversation, where if you lived, have you had a tick bite? And it's just going to shift the priorities because running some of these tests, like if we're going run aigenics, it can be $2,000, right?

It can't be very costly. So I think that it something you want to navigate with the Bredesen train provider who understands, all right, how do we prioritize these things based on your financial reality?

on what else is going on in your picture. You helped create this Alzheimer's Pathobium Initiative. What is a pathobiome for people who have never heard that word before?

And how does this thinking sort of represent a shift in how we're looking at Alzheimer? So a Pathobiome, we love that world because it's a newer word.

A lot of people know the word microbiome. Now it's become a decent part of common vernacular, right? And when I hear the word microbiome, how do you can tell me if you agree?

I think about like, you know, all the different organisms hanging out together harmoniously, a community perhaps. They've got their little campfire going.

Maybe they're in my gut and everyone's in harmony and they are happy and coexisting. Your pathobiome… patho means pathological and bad. So these are organisms that collectively are harming you.

They're driving an inflammatory state, they might be taking energy from the powerhouses of your cell called the mitochondria, and they're translocating going places they shouldn't be.

And they might be outnumbering some of the good guys and gals that are there that could be good for us, right? The commensal stuff that might very helpful to us.

Not just in the gut, but elsewhere in body. The other thing we love about the word pathobiome is it takes into account the immune response of a person.

So some microbes. Can be colonized or living in somebody and not be a problem at certain points and people are tolerating and they're coexisting with them But at some point something tips the scales and one of the things can be aging In and of itself the immune system is aging And some of the pathobionts, if you will, the ones that can be inflammatory, can start to outnumber and overwhelm essentially the other organisms there and become problematic, where previously maybe they were there, and their numbers were different.

So we loved the word pathobiome because it took into account the terrain and the members walking on the And I think, you know, in the brain, I certainly had this perspective 10, 15 years ago that the bring was sterile, that there's a blood brain barrier and that nothing is crossing that.

And we know now that that is just, but that it's not true. And Dr. Bredesen has brought this up in our conversations, and I hadn't really thought about it before recently, but like that there's probably a good microbiome in the brain, because we know that these are these negative things, right?

We've mentioned pageantabellas, HSB1, excuse me. I'm spirochetes, COVID, you know, there are a handful of these things that we no directly trigger that amyloid cascade.

And they're found on autopsy in the amyloid plaques. And we know that p-tau and amlyloids are antimicrobial. So we that there's this very distinct connection.

That's just what we now, right? If you put into PubMed pretty much any bacteria, any virus, infection, and Alzheimer's, there is often somebody who's done a little bit of work that shows some connection, so we hope…

The gut bacteria. Right. The brain connection, of course. Of course, and yet there's this kind of like other layer of nuance of, like, well, but if there are good bugs in the gut and good bug in sinuses and in, you know, the lungs or in genitals, there is probably some good right?

But we don't even know that part yet. It's so interesting to just kind of like think about. There's just so many exciting aspects of this work and the new possibilities through both prevention and treatment and infectious burden being part of the whole Alzheimer's puzzle.

And you, I mean, you are really at the forefront of it, spending years working on it. point, same question we ask, and it raises a lot of hairs. People get pretty upset in the scientific and medical community when you suggest the possibility, the hypothesis, that there could be a brain microbiome and that it could there from a very early age.

Life wasn't there.

Building the Pathobiome Initiative

work coming in the coming months and next few years that will really help out of our consortium, which is what the Alzheimer's Pathobiome Initiative is.

It's a consortia of researchers that we have a beautiful culture, first of all. We meet every single week for years, for 30 minutes every Wednesday. The team is all over the world.

They're here in The States, but they're also abroad, and they are looking at a lot of different things. We are pressure testing one another. We're essentially what I see happening.

And my observation, of course I'm biased because I think that the idea of cross-pollination is so key, is that they're innovating better and faster together.

It's also created a really wonderful forum both for tenured scientists and clinicians and also for the junior folks that are newer to the field. to get that mentorship and to be ignited by these great questions.

So to your point, you know, it's always been believed the brain is sterile. Is there an example of an insider brain through that you feel like became possible because these people who normally wouldn't collaborate were meeting and were having these conversations?

So you mean, just to clarify, like, how did we do it? Like, How did get? No, is there something that there was there like an aha moment you can point to a breakthrough or like some some new thing that happened because of those Wednesday morning sessions?

Oh, sure. I mean. Yeah, we have. And I can't discuss it in depth yet because some of this stuff is unpublished work, but we really took on the task in our 2023 paper, which I'm sure we can put in the show notes.

And then I wrote an article to go with it because that medical paper is really dense. But we pointed out the fact that these different testing methods, like if you took a person's blood and you tested with five or six different types of tests to look for infections, you'll get different results.

That's kind of not good, right? We started to try to engineer and reverse engineer the question. So if we know that in certain cases, infections can get into the brain, using specimens from people we already lost to these terrible diseases like blood, their spinal fluid and brain specimens, how would we look for infections there so that we could then take those tests and determine what was the best sample we can take from a person while they're still here with us?

Could it be saliva? Could be blood? Would it have to be spinal fluid in order to look for infections? And which tests would we use? What combination of these tests?

So we already made a connection that there was something missing in a test. And again, it's not published yet, but we figured out that one of the tests that is relied upon was missing an important organism because of the way the organism behaves and we figured out why.

And so by coming together, you know, the people that, let's say, invented a particular test at a university They want to know if their test is missing something, right?

These are real scientists, like anyone truly that is a scientist is open to being wrong and facts they expect that they will be and that we only have a quarter baked idea of everything at any given point.

You know, so that's been a big thing. The other huge thing that has come out of it is the biggest aha for me that I love, that i'm obsessed with, is that we're not just looking at Alzheimer's because these inflammatory infection associated brain disorders, things like Parkinson's, epilepsy, ALS, and the pediatric disorders.

MS. We're doing now, we've expanded our research. The team that is studying Alzheimer's brain specimens is also looking at these other disorders and we're looking for commonalities in terms of, you know, do some of these things show up in different diseases across the human lifespan?

And why is it different? Like, why's the pathology different, are there similarities, and what kind of infections show at the scene? So that for me too has been one of the really cool things that's emerged that by bringing these people together, they're hearing from people in other labs and it's inspiring them to look at things they may never have thought about.

That's really exciting. You have a roadmap paper that outlined a pretty vigorous rigorous scientific framework for studying microbes in neurodegeneration.

And if you imagine us executing that roadmap over the next five to 10 years, what do you hope we'll discover and be talking about? And how do feel like that will change the conversation around Alzheimer's?

What we would have with the five-year roadmap, and we're really hoping we've submitted a lot of grants and have some research funding and are already working the plan to an extent, we really want to fully operationalize it.

So we have been unbelievably thankful for foundations that have reached out. And we are obviously going to the National Institutes of Health, the NIH, to apply for grants.

Those are very challenging to get, especially on the scale that we're looking at with all these different centers working together. We cannot be working in silos.

The outcome in five years would be to have a testing panel. and to know which specimen to take from someone, and even to start to develop a pathway where we say, you know, like you're starting to get a mammogram at 40 or a colonoscopy at 50, we're going to screen you.

We want to if you have, for example, the genetic testing is valuable. The APOE4 gene, people with two copies, they have an enhanced susceptibility to chlamydia pneumoniae infection.

to HIV infection, actually, and also to injury from herpetic viruses, like the cold sore virus. So there's a connection to infection in the immune system, even with APOE4, the Alzheimer's gene.

What we hope to have is a testing panel. that can be leveraged not just for Alzheimer's disease, but infection-associated brain disease. That can reveal the majority of microbes in a specimen and also tell us, are those infections or are they just colonizing or hanging out, that they're not causing a problem?

And then from there, and I think what we talk a lot about is what can we do in tandem there are patients we could be helping today. So we are advocating for precision pilot studies, you know, that would evaluate patients looking for infectious agents and treat them precisely based on what's found.

And the work of Dr. Michael Wilson from UCSF actually inspired me to co-found AllsPI. It was When I was reading a medical textbook about chronic meningitis, which is just, you know, this chronic inflammation that most of the time is infectious, they used really neat technology to look for germs in spinal fluid from those patients at UCSF.

This test that would pick up on all of these organisms in the specimen, ideally, and knowing that things will always be missed, by the way, we're not perfect, the human tests aren't perfect.

Also, will never be sterile, right? We can treat with antibiotics, we can trade with the antimicrobials and like we'll reach some place where we're done and we are sterile.

It's like that also, you know, is not, that's not a realistic goal and it's probably not what we want. No, no. But certainly, in cases where someone has a neuroinfectious disease, like meningitis, or even neuroabrileosis, there's a place for obviously traditional medical care to save their life and to stabilize them, but then totally agree like long-term strategy, right, is to work that terrain, you know, to take, really nurture the host and make sure that the person, strengthening the immune system, keeping someone healthy on the heels of something like that is major.

But that work really inspired us at LSPI, and that's how the consortium was really born, was like, let's get to work on this problem in a way that allows us to develop testing panels that are better and then use those to assess patients and see How many folks actually have a primary infectious process that is contributing to their disease?

And the idea of it isn't that it's used alone. It's that would be used in conjunction with other precision protocols, you know, looking at hormones, look at all the things that you, would, be able to speak to in a very knowledgeable fashion.

And then, integrative approaches and naturopathic approaches that can be leveraged. That's really exciting. What do you think will represent the biggest paradigm shift in medicine over the next decade?

You've had all of this experience from building this consortium to being a patient, advocating for yourself and your children, and then also working in pharma.

Do you think it'll be precision medicine, the pathobiome, infectious disease, immune health, you mentioned the silos and kind of really working hard to put not only the professionals back together, but I think of putting the human body back Or you can get something else entirely.

What do you think the biggest paradigm shift needs to be? I think I guess maybe like me being an optimist factors in here heavily, but what I would love to see is for there to an emphasis on upstream drivers.

in general. That when I would watch television at night with my kids, that I wouldn't see all advertisements about biologic drugs targeting pathways to suppress effectively the immune system.

When I think about the way industry has gone, It's really been about treatments that, in many cases, patients have to take for a lifetime. And in the Alzheimer's field, the monoclonal antibodies for amyloid, they're not very effective.

Future of Testing and Precision Care

They're particularly safe, and they are not particularly accessible because they were unbelievably expensive. they really aren't, they do not represent a meaningful change for patients with Alzheimer's.

So I think that the best thing that we could see, and I Think we are part of that, but we're not alone. The ALSPI, we welcome and love the fact that there are other groups out there.

There's the amazing PANS Pandas community, there's The Poly Bioresearch Foundation in the long COVID communities, There are people like the HHV-6 Foundation, my friend Kristen Loomis.

There were amazing people there. Oh, people looking at fungal infections. They are groups that are like pushing

forward with different ideas. And obviously people, like Dr.

Bredesen, Dean Ornish, you know, there are very good things happening, I think, in an aggregate that will, I believe, in the next five to 10 years Yes, there will be acknowledgement of the pathobiome in chronic human disease.

Yes. There will more emphasis because patients are going to ask for it. You know, we really need to, everyone needs to rise up. And this isn't just something where we have to have the research community aware or the clinicians aware, practitioners aware that this is going on.

Patients have know and I think with social media, as much as it can be problematic, and concerning. It's also a vehicle for people to, you know, aggregate and come together and say and coalesce and go, okay, this is a problem.

We have to be asking better questions. Like, if this can happen, is this what's happening to me? And then from there, we need to see a whole lot change about awareness, also about how practitioners are educated and what to look for when it comes to patients with especially complex chronic illness.

We definitely have a chronic disease epidemic on our hands. And I think it's something that could be modifiable if we just keep looking upstream. Yeah.

I want to switch to a more personal note. This podcast is called Think Well, Age Well. And, I like to end by asking everyone, You know, you've experienced so much as a patient, as researcher, a mother, and as leader.

What brings you the most joy? At work or at home? Just in life. All of it. Definitely my little family and my best friends. And that includes like my work family too.

Honestly, like the crew that I work with. Some of them I credit with saving my life, honestly. Dr. Stratton saved my live. He passed away four years ago.

We have these unbelievable people, you know, like Dr. Brian Bailen, Dr David Corey, and Dr Garth Erlich, or Dr Or Shamash, Lavinia Alberry, these people.

Some of them, I've worked with them for a decade or more, as much as we are colleagues, we genuinely care deeply about each other. And some of these relationships have been the most enriching ones of my life.

Because what I get to witness is people that, in spite of how difficult it is to suggest new ideas in medicine and in science, they keep standing up and saying it over and over again because they care about saving lives and they follow the evidence, not the crowd.

And so that ties into my general sense of gratitude for my family, because this really has, like one person's illness in a household, it reverberates through the whole family as everyone listening knows.

Right. And then, you know, that comes to also the community that I've been thrust into, the people that, a life-saving tactic for anyone, like anyone that might be listening, going through a complex chronic illness of any kind or facing a challenging diagnosis of any kind is having that community of people that have that shared lived experience is healing.

It keeps you going. So I guess that's like a lot of things that, but I am generally, and gratitude itself. That's something that I practice. it's been a huge part of reframing a lotta bad stuff that happened and not only taking it in like resetting my expectation of what healthy it looks like after something like that happening because I'm not perfect and I still have some chronic issues that I face as a result of What happened and that may evolve as I age but it's an attitude of gratitude like thinking just about how to really reset yourself around, okay, chances are I can look around and be very thankful for a whole lot of things in spite of challenges.

That's amazing. Nikki, thank you so much for all the work you're doing to solve problems that you experienced as a patient. You're bringing scientists together, you're destroying the silos so that people can challenge these long-held assumptions and open up really new ideas and avenues of research to create solutions for Alzheimer's and other chronic illnesses.

I mean, this is really incredible work that you are doing. And your story is so powerful. It really is a reminder that some of these huge advances in medicine, they start with curious patients.

right? And that willingness, I mean, the grit that it must have taken you to be so ill and then to just decide like, this is, i'm going to figure this out.

If no one else is doing it, when I look to the professionals, they're not doing, it I'm gonna figure it out and that willing to ask questions, hard questions that others haven't asked and to do the work that takes to create collaboration across I mean, it's really impressive.

So to everyone listening today, thank you for joining us for another episode. And if you've enjoyed this conversation, please subscribe, leave us a review, share this episode before you go.

Nikki, Please share with us, how do people find out more about you, about your initiative? Where do they sign up to stay in the loop? And how can they maybe even get some practical information about how to apply some of this to their own health struggles?

Yeah, so our website, ALZPI.org, A-L-Z-P-I dot O-R-G, is a great place. I'm also very actively putting educational information on Instagram at Nikki underscore Sholtec.

And then for professionals, like more of the, you know, science clinician, life sciences audience, I have LinkedIn as well.

Joy, Gratitude, and Closing Remarks

We do have an Alzheimer's pathobion page on LinkedIn, too. And I have my email, it's out there. I hear from people all the time with ideas. We're always keen to hear, from different collaborators and patient resources.

With making this so public, our collaborative, and that there's been awareness around it, people do want to know, what can we do? We really do need to get the page on our website with some resources.

But generally speaking, you know, I've been sending patients for a very long time to the iLADS website, as well as for pediatric cases, the MediMaps group, that helps with pandas, pans, autism.

But then, of course, there are others, right? There are Bredesen-trained practitioners. There other practitioners that may not necessarily fall into one particular category but could potentially help patients a great deal.

Amazing. Well, Nikki, thank you so much for sharing your time and wisdom with us here today. It's been a real privilege having you. Thank you for having me, Heather.

it's great to talk to you, I'm so appreciative and thanks to everyone in the audience for joining us. Thank you so much for listening to the Think Well, Age Well podcast.

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