Introduction to Demystifying PANS and PANDAS

about a third of eczema can be caused by food allergies or sensitivities, and dairy and eggs are the two big culprits. It's not always those two. It can be other foods, and it's usually more than one, and that's more in my experience.

The second thing is the skin microbiome. We've got these trillions of bacteria in the gut. But we also have all of this bacteria, fungus, viruses on the skin.

We have them in our mouth and our nasal passages. So we need to pay attention to that. And when the skin is not intact, that changes the pH of the skin.

We know that kids with eczema and adults have a higher bacterial count on the skin. Welcome to Demystifying Pans and Pandas, the podcast where we uncover the mysteries, breakthroughs, and hope behind these life-altering conditions.

I'm Dr. Nancy O'Hara, a board-certified pediatrician, educator, and advocate with over three decades of experience helping children and families navigate the challenges of neurodevelopmental and neuropsychiatric conditions, especially PANS and PANDAS.

These disorders can feel overwhelming, but here we'll break down the science, explore transformative treatments, and share stories of resilience and recovery.

If you've ever wondered what's possible for your child or how to find answers, this is the place to start. Let's dive in. Welcome back to Demystifying Pan's Pandas.

And I can't tell you how excited I am to have one of my favorite people on, Dr. Sheila Kilbane.

Welcoming Dr. Sheila Kilbane and Her Integrative Approach

Sheila's an author. Great book, if you haven't read it, by the way. And she's a board certified pediatrician, trained in integrative medicine with Andrew Weil.

And she's the founder and medical director of Infinite Health. that's in Charlotte, North Carolina. And she's really dedicated her practice to identifying and treating the root causes of childhood illness and specializing in eczema.

And she published her book, Healthy Kids, Happy Moms, which I love, which is seven steps to heal and prevent common childhood illnesses. It has a seven step process and she's treated thousands of kids.

And Sheila and I have worked together on many of these children with PANS, PANDAS. And she also takes care of kids with eczema, asthma, allergies, recurrent ear and sinus infections, constipation, GI issues, the gamut.

And I love your approach, Sheila. I love your team. And I really am thrilled that you're on today. So thank you. Well, thank you. And as most people listening know, you were the original that inspired so many of us to do what we do and have the courage to do what we do.

So it's been my absolute professional dream to get to know you better. So thank you for having me. Well, right back at you. Thank you. But I really love what you do.

You know, I say it all the time, but from an eczema perspective, one of the things I love is you treat it from the inside out and from the outside in.

Can you talk a little bit about what that means and how you implement that? Yeah, and I think this is also why I love working with you because we are always, it's always the yes and.

We do not throw away anything that we need from conventional medicine as we use. And that's where when people come to me, sometimes the families are, they've tried so many different things that they wanna do completely NAFRA, which is what our goal always is.

So when we are looking, my process, we always, no matter what's going on with the child, whether it's eczema, asthma, allergies, whatever, is we go through and we have to identify where the root of the inflammation is, right?

So it's food, environmental allergies, environmental toxins, infectious diseases, and stress. And for these kids with eczema that really have that bright, red, angry-looking skin, that's a staph infection.

So we treat that while we start to control histamine, and then we begin to build healthy cell walls while we strengthen digestion, right? We need fat.

We need good magnesium, zinc, we need all of those minerals. But we have to take it one step at a time. And the way I always talk about it at first is we have to put out the fire, is we've got to control, we've got to get the skin under control.

we do that with this topical that we use, and then with an antihistamine. And not until we get the skin under control, because there's newer research that when the skin is not intact, that actually contributes to that leaky gut, or the permeable test in the inflamed intestine.

So if we're trying to add a whole bunch of supplements in, or even new foods, before we get that skin back into balance, they're going to keep reacting to things.

One of our big goals is, if at all possible, prevent reactions. Do one thing at a time for three to five days or longer before doing the next thing. So that if we have a reaction, good or bad, we know what they reacted to.

And, you know, one of the things I love about you is that we're thinking, like you said, in the same way. I mean, you're talking about atopic conditions, eczema, allergies, et cetera.

You're talking about the integrity of the skin barrier. But somebody that tunes in and says, wait, I thought we'd talk about pans and pandas on this. It's all the same.

They are more related than they are different.

Treating Eczema from the Inside Out and Outside In

We talk about the same things, that we have to treat the symptoms. They may be neuropsychiatric symptoms as opposed to skin symptoms, but that leaky gut, leaky skin, leaky blood-brain barrier is all very similar.

And treating all of it, you know, not just getting at the root cause, but making sure that the symptom that they're coming to us for is also calmed down, ameliorated, looked at, you know, rather than just, okay, well, we know it's this food, let's get rid of this food and everything else will get better.

You know, so I think- Yeah, and that was- Yeah, and I think what's happened, because I've been doing a bunch more research and writing right now for this talk, and I think we make things more complex than they need to be.

And I think sometimes we're looking for the zebra and we're just ignoring the thing that's right in front of us. And if you're eating a whole bunch of processed foods, or if you have all of this uncontrolled histamine, We've got to address that.

And the thing with the neuropsychiatric symptoms is histamine, it can create watery itchy eyes, runny nose,

wheezing, but it also acts as an excitatory neurotransmitter.

So when you're seeing those kids, if their tics worsen, if their moods worsen around the time of allergies, That just means we need to bolster the antihistamine support.

We can do that with prescriptions, over-the-counters, supplements, or so many things that support antihistamines. And when we're talking about these kids with pretty severe eczema when we're getting started, we actually usually go more toward the synthetic antihistamines that we could get as a prescription because there's usually less in them that the kids can react to like versus versitin or vitamin C or something like that that we'll add in later.

But we want to, again, we have to kind of put that fire out so that they can start, they can start tolerating things. Right. Absolutely. And I've also heard you talk a lot about, you know, the bucket, which is something else I use a lot in my analogies.

Tell me and tell our listeners and our viewers how you use that, that bucket in your analogies. Yeah. So the example I love to use, but before I Say the bucket specifically, I want everybody to kind of either get a piece of paper out or just get it in your mind.

And you put a little check, like just put a number one next to each thing if you, if your child or if you have it. So it's dark circles under the eyes, snoring, nasal congestion, mouth breathing.

bumps on the back of the arms, the cheeks, the thighs, a lot of acne, eczema flare, bloating, gassiness, either constipation or loose stools. You might have some white marks on your fingernails, all of those.

And you can have post-nasal drip, you can have reflux. All of those can be signs of underlying inflammation or a little bit of immune dysregulation. And so then when we're looking at the bucket, we have, and I always just put in the bucket, right, food, environmental allergies, environmental toxins, infectious diseases, and stress.

And even stress, stress can be physical, it can be emotional, right? Physical, you could have scoliosis, it's going to cause a stressor on your spine.

You might have pain that's going to worsen your pain is always going to put you in that fight or flight state. So we look through those and let's say you've got environmental allergies.

So maybe you've got a tree allergy, trees bloom in the spring. And then maybe you or your child are eating kind of a lot of refined sugar processed foods, and maybe you have a dairy sensitivity.

So you decrease the sugar, you remove the dairy, then when spring comes around and you get that seasonal variation of the trees, Your bucket may go to maybe three quarters full, but you may not get the overflowing symptoms.

So you may not need the medication as maybe not as high a dose. Maybe you don't even need the medication at all. Maybe you can control with supplements.

And when knowledge is power and when you really identify those triggers of inflammation, we can do so much. And that's where it doesn't have to feel overwhelming.

We can never be perfect in every one of those areas. Because I think some people think, I'm not even going to go there because I can't change my kid's diet.

But if you just say, okay, if stress is one of the triggers of inflammation, if making major food changes is going to stress your household, just hold on to that.

Exactly. Identify what their allergens are. I mean, I've had kids where they have a really high dust mite allergy and they're sleeping on a 20 year old mattress.

We just get rid of the mattress and their symptoms improve significantly. It's just a process. Yeah. Step by step, right? Yeah. And so much of the time, you know, parents come in with this huge list of things they want to do.

And they want to know every food that could be a problem. And they want to fix their kids right away. And I'm like, just the stress of everything you asked your child to do.

The Bucket Analogy and Identifying Inflammation Triggers

will increase their underlying symptoms, whether it be anxiety or, you know, eczema or whatever, that stress is such a big part of it. And you're right, if changing the diet is gonna add more stress to the family system, that's not the first change I wanna make.

I still wanna do it, but I wanna think about other changes like getting rid of the 20-year-old mattress that maybe simpler and easier for them and may also produce a win.

Yeah, yeah. And part of that, too, is because when you're even decreasing that inflammation a little bit and that histamine, the kid's going to feel a lot better.

Or the parent, if the parent's taking it. Because the way I look at it is that our job at the beginning is to get the kids out of crisis mode so that the parents can kind of like, wow, I can actually go to the bathroom today.

I can take a shower. And once that happens, and once parents' stress level comes down a little bit, the kids aren't feeding as much off of that. their stress is going to decrease a little bit.

And then it just makes it much easier. So that's where we sometimes, and what I'll say is we're going to let either the medications or the supplements do some of the work at first, and then we'll move on once we get to the other side of it.

Yeah. And that's where using some conventional treatments, topically medications, et cetera, may get them off that edge. Yes. And to your bucket analogy, even though it's a little bit different, it's still decreasing that level in the parent's bucket helps to decrease that level in the kid's bucket too.

Yeah. And it's almost never a straight downhill glide, right? It's two or three steps forward, one or two back. Two or three forward, one or two back.

And then what happens is we get like we'll get cruising along right and the kids are doing better and parents are feeling good and we'll have a backslide and it might be it was a birthday, it was a holiday, they went to the beach, maybe they got some exposures that they don't usually get or food.

And you just see kind of get off the wagon and I have an image of this in my book and I just It's almost like this circular, right? Life is never a straight line as much as we like it to be sometimes.

And so then you just kind of, you just get back on the bandwagon. But once you know, and that's where in your practice and my practice, we're always sharing with parents teaching the why behind what we're doing.

So that when you do have those backslides, you can figure out, huh, which one of those triggers do I think happened? How do we get back and do things, you know, get back on the bandwagon and get things under control again?

Right. And the other thing I've heard you say, which goes along with that, that I think is so important is we all always have something to learn, you know, and we as practitioners have to listen to parents.

and patients and that we learn so much about how to help them and maybe help the next patient by listening to our patients too. And I think that is so important to decreasing that bucket stressor too.

Oh, for sure. That's what I think I may have shared this with you. So one of my favorite, he's one of the pediatric surgeons when I was a resident. And he was probably at least 60, maybe mid-60s at that point in time.

And he would always say, Sheila, every day is a school day. He's got a little bit of a southern accent. But I just thought, here's this person who's been practicing for so many years.

And he still always comes in open-minded, asking questions, being curious. And it's one of the things. So as I've been getting, I'm super excited. I'm doing this TEDx in Nashville.

That's amazing. In August, which is so fun. And you have to hear more about the one that you did. And as I've been writing, I've been writing the stories.

And this is one of the stories I write about in the book also. But I remember it so vividly. And it was a mom who came in. and the little boy had recurrent ear infections and eczema.

And she said to me, you know, I was handing, we'd already actually had the ear tube surgery scheduled and she was kind of dragging her feet, scheduling it.

And then there was an insurance glitch. So she didn't, it got canceled. And in the meantime, she figured out, she took dairy out of her diet. She'd started reading, she was still breastfeeding and his eczema improved.

It didn't go away completely and he still had fluid in his ears. So I said, we have to, you know, you gotta get that surgery scheduled. But then before his one-year visit, she had a huge omelet.

And again, because she was still breastfeeding, he had a big eczema flare. So we talked about it. We were like, OK, so it's eggs and dairy. So let's pull those out of the diet and see what happens.

Well, eczema fully cleared up at that point in time. The fluid in the ear, and you know, I had him come back a few weeks later, the fluid cleared out of his ears.

Eventually, you know, I don't remember how long it was, but we eventually were able to add those foods back in. But that was a huge learning lesson for me because instead of kind of getting defensive and being like, which is what I would have, you know, like, no, right, I've got all these patients waiting.

I can't, I don't know if there's another way. But she just did it. And then she came back and told me, I said, all right, I will call my friends, the naturopathic doctors, and I'll figure out what we're going to feed him.

And at that point in time, when I heard dairy, all you think of is, okay, how are we going to get fat, vitamin D, calcium into their systems, which, first of all, it's not necessarily the optimal fat.

Secondly, There are a lot of other foods that have calcium. And third, it's fortified with vitamin D. It doesn't even have vitamin D naturally. Exactly.

It's this, it's mind shift, but it was just being open-minded and it's hard in medicine because we've got, right? There's a lot of, we have a lot of guidelines that we need to follow and be aware of.

And it's, you know, dairy is one of the things that we're still supposed to be saying, you should have a couple of cups every day. So it's. And that's where people like you starting doing this allowed people like me to keep following what we were seeing.

Cause it was kind of like, I was just, I was telling Jason about that this morning. Like she is my Mick Jagger because she, you all, you were, you were doing this and you were seeing this, you know, these kids on the autism spectrum, you were seeing these neuropsychiatric issues developing.

You didn't have a textbook to open up. You figured it out on the fly, but if you hadn't modified, think of the

thousands of kids that you've seen, is that we wouldn't be any further along.

And so it's tweaking, right? And it's just doing, if our oath is do no harm, do small changes, follow up regularly.

Learning from Patients and the Importance of Open-Minded Care

Exactly. And as you know, everything that I know, I credit to Sid Baker. I mean, you certainly did your integrative medicine with Andrew Weil, who is amazing.

Sid Baker changed my life. And there are so many Sidisms we use every day, including, you know, if you listen, they will come, which to me is you're going to learn more from the kids and from the parents than from any textbook.

And being curious, being that detective, wanting to learn, as your professor told you, you know, it's a school day every day. You know, those are the things that keep me going and helping doctors, patients, you know, families, everybody.

to try to be able to also be curious and figure all this out. But I feel for our pediatric colleagues who either because it's a volume-based business or because they really haven't been able to listen as much as they may have wanted to or be able to learn other ways.

Our governing bodies, as you say, still tell us to the push the milk, the two cups of milk every day, and all the other things they tell us that we don't have to talk about.

Sun is the one that got me on this road, so I had to mention him. Yes, yes. But yes, and it's always the learning. Because I remember a retreat years ago that you and Maureen and Liz and Julie, luckily you all had organized your healing retreat.

And I actually remember because that is the retreat that changed my own health. And one of you said during one of the lectures is, it should only take you the same amount of time to have a bowel movement as it does to urinate.

And I was like, yeah. Wait a minute, what? As somebody that was constipated for many years, I know that is true now, but talk to me about 40 years to figure that out.

Right? I had been through all of my medical school and my integrative training, and I still didn't get it. Right. I was kind of bloated. I went home from that retreat and I pulled gluten out of my diet, even though I'd been recommending it for kids for years before that.

I did that for a year and it was like somebody took a bag off my head. I didn't have brain fog. I could eat more because I wasn't bloated. My skin improved.

Then a year after that, I took dairy out of my diet. And then I was like, wow, I didn't know it could be this good. And it's just as one of the supplement companies has it saying, it's fun to feel good.

Very true. Very true. Yeah. And when we think about conventional medicine, and let's talk for a minute about eczema, the conventional treatment of eczema is often topical steroids, topical creams, sometimes oral anti-inflammatories of those same milks.

But the three things that you talk about that are overlooked, which you've mentioned somewhat, but just talk about them in more detail if you don't mind.

Absolutely. One is nutrition, which we kind of touched upon, and the research shows that about a third of eczema can be caused by food allergies or sensitivities, and dairy and eggs are the two big culprits.

It's not always those two. It can be other foods, and it's usually more than one, and that's more in my experience.

And we can talk, I want to go through the other two, but we can talk more about sort of histamine foods and histamine release if we want to get that detailed.

Yeah. The second thing is the skin microbiome, and that's much newer, and this is where this newer research that's talking about, right, we know that we've got this gut microbiome, we've got these trillions of bacteria in the gut, but we also have all of this bacteria, fungus, viruses on the skin.

We have them in our mouth and our nasal passages, so we need to pay attention to that. And when you get that really rough, dry skin, when the skin is not intact, that changes the pH of the skin.

We know that kids with eczema and adults have a higher bacterial count on the skin, in particular staff. And this is where my mentor, Dr. Aaron, he's an amazing, Dr.

Richard Aaron dermatologist out of South Africa. He created this topical and it's a prescription, it's two prescriptions plus a moisturizer. And it's an antibiotic, it's a steroid, and you mix them in a certain ratio and you apply it, you start and you apply it four times a day for seven days and then three times a day for seven days.

then you modify it based on that. But that has absolutely transformed the way that I'm able to treat eczema. Because when you treat the infection, if it is staph, within two to three days, these kids that have been struggling for a year, for two years, for however long, it's going to improve within two to three days.

It's definitely not going to go away, and we will definitely have more flare-ups. But just like an ear infection or pneumonia, if you have the right antibiotic within two to three days, the illness should be significantly better.

And if not right, we should change the course. So it's and it's actually it's amazing to get to practice with this because we'll add another patient. not that long ago, a little girl who came in and she was a year old, super young parents, so sweet.

Eczema Root Causes: Nutrition, Skin Microbiome, and Gut Microbiome

And they'd seen so many people already and had been offered steroids. They'd made all the nutrition changes. And she had an appointment to get a Dupixent injection two days after our initial consult.

And I said, just give us two weeks. Don't cancel the visit, just postpone it. see if we can make some headway because you're never right. I can never be sure.

I don't ever promise these things. And within two days, she was about 80 percent. Her skin was clear and we've been able and again, it's still we're still working.

But, you know, she had scratch sleeves on. She was up all night and it's just it's a gradual process. And then we have to figure out the other factors that are going on and, you know, whether it's Some people will have some water damage in their home or even in their school.

I'm going to share one other while we're on the skin microbiome. This was a patient of one of my friends, an integrative doctor. This little boy had pretty bad eczema.

He had asthma. He and the mom figured out it was dairy. I think gluten and citrus. So oranges, right, lemons, grapefruit. So they took those out of his diet.

Skin improved significantly, but he still had asthma. So he was using Budesonide, which is a macor. I don't know if it was the brain or the generic. Mom was sitting, because he was getting this perioral rash, and Mom was sitting there one day watching him get his nebulizer treatment.

She opened up the packing slip, and citric acid was one of the preservative agents. So they switched him to a puffer and a spacer, and he never had the rash around his mouth.

So it's just paying attention and knowing the things to look for. And what's very interesting to me before you get onto the gut microbiome and we go back to a couple things on nutrition is just that simple cream that you are meant to develop has the three things in the three-pronged approach I talk about all the time.

An anti-microbial, an anti-inflammatory, and a symptom support. So in this case, it was an antibacterial cream, it was an anti-inflammatory cream, and a moisturizer.

It's those three things in so many of these chronic inflammatory illnesses that we need to make sure we're getting at. So it's fascinating. I always love all the similarities between everything that we do in treating chronic illnesses more than the differences.

Exome is a lot more related to Pan's Pandas than it's different from it. Oh, for sure, for sure. And that's great. We have some patients that we share and we'll be on the calls together like, yes, yes, absolutely, absolutely.

We have such a similar way of practicing. It's always getting at the foundation. You have to set the foundation. And when you do that, and what does that mean?

That just means we need fats, right? You need your minerals that you need. You need digestion so you can digest and absorb the nutrients. And once you replace and you make sure the kids have their natural resources to produce their neurotransmitters, to produce their hormones, to make their bile, you don't always have to go after certain things.

Like we usually will retest before we start adding antifungals or antibacterials. It totally depends on the case. So then the third thing is the gut microbiome.

And that's, again, where we go back to all this collection of these trillions of bacteria, viruses, fungi. And just think of it like a garden. And that's kind of how I wrote about it in my book, is you've got to fertilize and feed the garden.

And what fertilizes it is fiber, fiber from foods, fiber from nuts, seeds, fruits, vegetables, right, plant-based foods. And what the research shows is that people who eat 30 or more plants per day have the most diverse microbiomes.

And so that is what, that's the thing is we just want this nice diverse microbiome. And it's And we just have a really gentle process. We'll dose our probiotics with breakfast and dinner because we know that when you eat, you get a bump in inflammation, right?

You get those bacteria that can sometimes translocate across the wall of the GI tract. And then that's what triggers that cascade of inflammation. So we're doing those, you know, we do it on, right?

Do it around meals. And I have a really wonderful, super simple, just an eczema jumpstart guide, which people can find right on the website. So that's how we approach all, right?

Food, the skin microbiome, and the gut microbiome. And then that's where we start to see all of these really wonderful shifts happen. Now, I heard you say 30 plants a day.

Did I hear that right? Well, a week. A week, okay. Okay, I heard a day, a week. Okay, I can buy a week, so then it takes me down. I'm like, 30 a day. I think I have a pretty good diet.

I don't know if I have 30. I'm trying to figure out how we get that in. But 30 a week, a lot of parents may be saying, I can't do that. My kid doesn't eat anything.

You know, maybe a cucumber, now and again. How do you help parents navigate that? that bringing this good stuff, this fiber, the veggies, the plants into our kids' diets if they didn't start that way early on.

Yes. One of my favorite things is to do a green smoothie in the morning. And we have an amazing health coach in

our practice, and she calls it the starter smoothie.

And so she'll do more, we might do like a leaf of lettuce, because we usually, we don't put raw spinach in to begin with. for all kinds of things. I won't go into all that detail this moment in time, but we usually will start with lettuce or I love microgreens, love bok choy because it's super mild and it's got a lot of highly absorbable calcium.

So you just do a very small amount of that, then you put more. And berries are great because they don't have as much sugar, like maybe a fourth of a banana.

And then you can start to add like a half a teaspoon of chia seed. Eventually you get up the chia, hemp, and flaxseed. Those are the ones that all this great fiber, they've got a little bit of protein, they have omega-3 fats.

And if you do happen to have mold exposure, those are natural binders that are going to- Absolutely. Street. Yes. And if they kids don't, so then, and I love water as the base, but you might need to do coconut milk or something else at the beginning.

And you can even freeze them. If they don't love to just drink it, you can freeze them in trays or, you know, get the popsicle sticks. And that's a great after-school snack.

And you know, they're getting, and it's, you can feel it. I have, you know, I do, I've done smoothies for many years and you, your whole system just, it's like this.

Yeah, yeah. And as I say to parents all the time, you do it. You see the difference. Because a lot of times, the parents are trying to force something into the kid.

And I'm like, no. You know, it's not just put your own oxygen mask on for yourself. It's you're also modeling. You know, taste it. If you think it tastes terrible, your kid's going to think it tastes terrible.

Add some things in there that help it to taste a little bit better. Know what your child's palatial are. Often, I'm talking about, you know, a couple of things of frozen mango or frozen strawberries that might help it to taste more like something they'll take initially.

And it's like a super easy starter is also a little banana and strawberries. I mean, who doesn't love that? And then you go on You go on from there, but you made me think of something when you said, taste it, it just left me, but it was something about, okay, it will come back to me, I think.

Okay. Well, let's talk a little bit more about nutrition because I do think histamine and other cytokines, other mast cell overactivation is really important in all of our kids with ATP, eczema, allergies.

you know, asthma, but also very important in our kids with pans, pandas, especially those with tick-borne disease and mold. So talk a little bit more about the histamine part of all of this.

Yeah. So I'm going to break it down into the ways. I have a table in my book and it's the five ways food creates inflammation, right? So we've got these different pathways and this is important because especially early on in my career is people would go to the allergist and they would either get skin prick tested or blood work for it and that's going to be an IgE-mediated allergy and it would be negative and so they would say even if If they had seen an improvement off the food, they would put the food back in the diet and say, well, the constipation came back.

I said, okay, this is what's happening. So we've got an IgE mediated, those are the kind that are more easy to test for from a conventional standpoint, skin, prick, or blood work.

Then we have a food sensitivity. And those are where really the gold standard to test that is, so I'll just, my example with gluten, if I take gluten out of my diet, I can have a daily easy bowel movement.

My skin is more clear, all the things. If I put it back in, it worsens. So that's a food sensitivity. There are a lot of

different ways you can test. I don't do a lot of testing with that because if you've got an inflamed gut, A lot of things are going to come up positive, and I know you and I agree on this.

And so it can be very stressful to get a test back with all these positives. all of the good gut work and, you know, if they're still on gluten and dairy, right, those are an entirely different inflammatory category.

The research shows that those are inflaming whether you're sensitive to them or not. So those, we usually will start with those. Okay, so we've got food allergies, food sensitivities.

Then we've got celiac disease.

Histamine, Food Reactions, and Mast Cell Support

So that is, it's a different test. We look at an IgA, we look at IgG, and it's a T cell mediated disease and it's antibody mediated. So we can do blood work for that.

You can do an endoscopy for that, but that's important. That's important to figure out. That's where it's a gluten, you know, it's an autoimmune condition.

your body gets inflamed from being exposed to gluten. And the research shows that 97% of people who have celiac disease don't know it. And it's the easiest thing to test for.

I mean, we pick up probably two or three a year. We test every kid with it. Were you going to say something else? Well, I was just going to say, do you test for their HLA sensitivity, for their susceptibility to celiac disease?

We, usually what I have been doing, but I think I'm gonna change what we do now, is we will weigh, we'll test the antibody, and then if they have respond, like if it's negative, but they respond off of gluten, then usually in the second round of testing, we'll do the HLA testing, because you can do it right through LabCorp.

There's so much blood that we're getting at that initial blood draw that it's usually, it's hard to add anything else on. However, right, most of the SNP tests, like the, the cheek swabs or the 23 and me's you can do those on that.

But we may start one of the reasons and I'll just break this down. So the HLA typing right it's sort of it's part of the gene and it's If you have the HLA, you know, one of the positive alleles, you are 30% more likely to get celiac disease.

However, people who have celiac disease, 90% of them have this. So it's not a perfect one to one. So that's why you can't say, we're going to do this and then it's positive.

So I've started using it. I don't always get it either at the first visit for the exact same reason that you said that it often is more blood than I really want to get.

But I am one of those cases that all of my life I was gluten light at most. Much of my life I was gluten free, but I knew I had the HLA susceptibility.

For some reason in my 50s when I started dating my husband, and he had all these great Italian restaurants with great pasta and great bread he was taking me to.

I forgot about that susceptibility somehow and started eating more gluten, thinking nothing of it, and developed the rash that's called dermatitis herpetiformis of celiac disease.

And actually, that's how I discovered that my susceptibility had turned into actual celiac disease. And so I use it now also if at that initial visit, I always talk about being gluten free and dairy free.

And as you said, you know, it's different than all the other foods. It's inflammatory in other ways, even if you're not

allergic to or sensitive to it.

But I find that if I then say to a family, and this just came up with a family I talked to this morning, your child is susceptible to get celiac. It makes them a little bit more likely to take that initiative to go gluten-free.

So I will use it if I have somebody that is being resistant, but I'll always get it at some point if they're not. really following the program. Yeah. And that is, I have done it before when one parent or the other is more on board and we need to get the other parent on board.

So that's interesting with the dermatitis or pediformis because we had a patient who we took, he didn't have celiac but we took him off of gluten and the dad went off of gluten and he'd had this rash for a while and went off of gluten and it went away.

And so then he put it back in and then went to his dermatologist and the dermatologist just said, yeah, that's what it was. They were, of course, over the moon happy because he had had all these aches and pains.

He had been struggling with all kinds of other things. Yeah, but it goes to what you were saying that so many people don't know that they have celiac because they're not presenting with classic symptoms.

Yes. And so, so important and different in this country with the gluten that we have here also, you know, for a lot of people. Yeah, it's just processed differently and it makes it more acclaimed and it would be an entirely different song.

So let me, I'll give it a go. Yeah, I interrupted you. You were going through all the different pieces. So food allergies, food sensitivities, celiac disease, and then we've got food intolerances.

So that's things like lactose intolerance. food protein-induced enterocolitis. So that's where a baby might have a little bit of blood in their stool.

And if you take dairy out, the blood goes away. But if you do an allergy test, it's going to be negative. And that's the one that all pediatricians don't want, right?

That happens all the time. We don't think about it. But some of these other things, we just don't think about much. There's not an E. Those are more a product of knowing the situation, pulling the food out and if they improve.

You don't always have to do testing. I've never done a lactose intolerance test. GI doctors will do it sometimes. But the other thing to be cognizant of is a lot of times that I'll see is that the pediatrician might say the baby has a lactose intolerance and so they'll do a lacto-free meal.

Often they're also reacting to the casein, which is the protein that's in the milk. And so you really, we just don't go on any of the cow milk, you know, you do.

I mean, I prefer kids, if it's a baby, right, they've got to do a formula or breast milk, but you, we would just go to water. know, if we have to use a different milk, we figure out what we're going to use, but water is great.

So those are the food intolerances. And then the last is histamine intolerance. And this is the one that I think gets a lot, especially in this world, it gets a lot of press.

And I think there's so much, I think there's a lot of fear around it because when you've got kids who are reacting to foods, then you start to go crazy about, oh my gosh, what are they reacting to?

What are they not? I put a list in my book of histamine-producing foods or histamine-triggering foods, and this is where We do more for how do we stabilize the mast cells?

And if you have practitioners who listen to your podcast, which I'm sure you do, we love ketatophin, that old- Don't

we though? I know. It's an antihistamine, it's a mast cell stabilizer, and it works so well.

And so what we'll do is we'll talk through some of those things. Like you want to be careful. I mean, she's all of the normal, players, right? Cheese.

Many fermented foods. Foods. Thank you. Things like strawberries, shrimp, spinach, and things that are healthy foods, avocado. So that's an easy one, right?

As a practitioner, if somebody comes in and they get a huge eczema flare after the baby started eating avocado, doesn't necessarily mean they're allergic to avocado.

They probably just ate too much at that moment in time. But once you get the downstream things balanced, they usually are able to tolerate those foods.

So we rarely do a full low histamine diet. We just will say, be careful, be careful doing leftovers. If you make meat or something or soup, freeze it and then you can eat it that way.

And don't eat a huge bowl of strawberries. Don't eat a big, huge thing of shrimp. So, but those are the different ways. And when you understand that, I think it makes your life a lot easier so that you're not guessing of what's happening.

There's still trial and error is what I would prefer to call it. Right. Exactly. And as a parent, we need to be open to that too.

Building a Long-Term Healing Roadmap for Families

And I always talk to people about patterns, patterns at the time of the month, patterns with the seasons, patterns with how you eat, how you play, how you sleep, all of that.

And that more than spending another several hundred dollars on a test can really help us help to understand the triggers for our kids, whatever they may be.

Yep. I read her book long ago. Dr. Rapp, she was an allergist. And the one thing that I really liked from her book, and this was food allergies, is you take your pulse and then eat the food.

And if your pulse increases, I think it was 10 beats per minute. Yes. are reacting to it and I can if I eat gluten I can feel that in myself and it's another like as the kids get older because the kids feel their bodies and it's really encouraging them to get connected to themselves and feel what they're feeling And they're going to be a good little historian to help you figure out what's going on.

Yeah, exactly. And I also talk to parents about helping their child to see that, whether it be that they get hungry, their mood is off when they're hungry, or after they eat all that carb, they're brain foggy, or whatever it may be.

Pointing that out in a non-judgmental way, but starting to help them be able to read their own bodies and see how the foods, especially how any negative foods for them may make them feel more negatively, so to speak.

Yeah. Yeah. Because it is, we have to, I think, face the reality that we're swimming upstream with our conventional food system, is you just, kids are offered a sucker, a treat, candy, around every turn.

And so if they can start to feel what it feels like in their body, I don't think we can wait for these billion dollar companies to say, I'm not going to make sugar water anymore.

I'm not going to market this stuff to kids because it's just not going to happen. I should say, it may happen someday. But in the meantime, help your kids see food labels, help your kids see how they're reacting after a particular food.

Yeah. Now, I know a lot of what we've been talking about is already talking about creating the long-term roadmap, you know, controlling histamine and balancing the immune system and creating healthy cell walls.

Could you talk about that long-term roadmap just a little bit more? Yeah. So, the way that, how I always talk about with families is that normally what we do together is we, and you can do this yourself, right?

get my book, you get Nancy's book. And the goal is to figure out, usually kids are coming to us from a place of depletion. So we've got to correct those things.

But once we do that, then we figure out what does that child or what does that adult need? What is their foundational need? So For, let me, I'm going to use myself as, as an example, right?

So I know that I need to be gluten and dairy free. I can do dairy a little bit. Gluten is kryptonite for me. So I just don't do that. And then I don't detox well.

I'm not, you know, I'm all of it, all the things that all the kids have that we have MTHFR. So I have my collection of supplements, right? I use their multi-vite.

I take magnesium every day. I take glutathione. And I've got a whole bunch, I write vitamin D in the winter time. And I just, when I travel, right, I have my little baggies of supplements.

I really do smoothies most days, not all the time, but I have created my life so that that stuff is doable. It's not, right, it's kind of like getting in shape is it's a little bit of a pain in the butt to get there.

But once you get to that place, it's so much easier to maintain. And so that's all. And that's what we talk about. Have a cooler with you wherever you go.

Think about, I like families to plan the week of food. The same way you plan a trip. Where are my tight turns? When do we have a pickup and a drop off?

And you gotta go to soccer, so you need a treat or a snack before and after, right? When kids are doing a lot of vigorous activity, give them food, carbs, and protein right when they finish.

They're gonna recover more easily. So it's just right. And for me, I have to do hot yoga at least twice a week. I've got to sweat so that I get all that out.

And it just makes things function better. And I'm not a morning person, so I pack my smoothie up at night. And then I just have a little, right, I use one of those little ninjas.

So I just stick it in my bag and I take it to work and I blend it up at lunchtime. And so that's just figuring out your systems that you need. And having those healthy things at the ready for yourself and your kids in the car, in your lunchbox, you know, so that it's not running down the street and getting the Doritos because they're starving.

You've got those things in your glove compartment or in a little cooler in your car. Yeah. And it just changes the baseline so that when you, because that is inevitably going to happen, but you're like, I've got one of those bars in my bag.

We don't have to stop at and get the burritos. Sheila, I could talk to you for hours and hours, but your book is Healthy Kids, Happy Moms. It is. And your website is?

SheilaKilbane.com, just S-H-E-I-L-A-K-I-L-B-A-N-E dot com. And we have that eczema guide on there. It's just, if you go to SheilaKilbane.com and then it's forward slash eczema guide, but it's, you'll see it on the website or look under resources.

And it's a really easy website, everybody. And I really recommend it. And is that how they would find you if they're

looking for you also? Yep, if people if you're in Charlotte or if you can travel to Charlotte and you're looking we we take on a small number of patients each month and it's you just schedule a You schedule a call with our amazing patient care coordinator and she'll kind of talk you through What that process looks like?

Yeah, and Sheila has an amazing team really health coaches nutritionists other You know professionals that work with you and of course you they're just they're amazing.

Yes Yeah. And are there any words of wisdom or anything else you want to share with the parents or practitioners that are listening or watching the podcast?

My thing is, get this, the most fun things in life, right, are having those belly laughs. And when, like sharing a moment with a kid where you have like a little inside joke or something and you just laugh until you're crying, that's the stuff.

All doing this work to feel better, That's the goal of it. And if we keep that in mind, I think it makes it a little bit easier to do. I love that. I love that.

Closing Thoughts and Podcast Wrap-Up

All right, everybody, go have your belly laugh today. And Sheila, thank you. And much great luck on your TED Talk. I'm so thrilled that you've been asked to do that and that you're doing that.

And also just thrilled to work with you. And thanks for joining us on the podcast. It's such a huge honor. I appreciate you so much. Thank you. Thank you.

That's it for today's episode of Demystifying Pan's Pandas. I hope you're walking away with insights, tools, and hope to help you and your child on this journey.

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And if you have a moment, leaving a review helps us reach even more families who deserve answers. Also, for more information, training, and community, check out our website, drohara.com, and join our annual membership.

And remember, every step forward, no matter how small, brings us closer to healing and understanding. Until next time, be present, be hopeful, and we look forward to seeing you next time on Demystifying Pan's Pandas.