## Introduction and Guest Welcome

And so the reason we did this is because on the market there was just low doses. So 800 micrograms, I was having kids having to take full bottles a day.

So number one, having a child take that many pills on top of everything else that we're asking them to do, the cost piece of it for families to be doing that was insane.

And it was really not a good solution whatsoever. And so this is what came out of it. And we're having really great results. Similar to what I would expect with glucagon, it's the same form of full and acid without the added ingredients.

Welcome to Doctor Talks, the podcast where every episode leads to a healthier you. Join us as we navigate the world of optimal health, uncovering groundbreaking strategies to conquer chronic disease.

In each episode, we'll bring you the latest insights from leading health experts, medical innovators, and wellness warriors. If you're seeking to transform your health journey, or if you're looking for answers to burning questions.

You've come to the right place. Get ready to unlock the secrets of lifelong health and vitality. This is Doctor Talks, real talk from real doctors on the issues that matter to you most.

Well, I am so excited to, introduce to you a wonderful friend, colleague, mother, doctor. I cannot say enough great things about the person. You're just about to hear and see, Doctor Lindsay Wells.

So, Lindsay, welcome and thanks so much for joining me. Thank you for having me. It's such an honor to be here. Well, Lindsay is an incredible naturopath.

In fact, one best young naturopath several years ago. She has a wonderful practice. We were in practice together. But we we've expanded in different ways, and Lindsay now has a wonderful office.

And as I said, she's an amazing mother, an amazing practitioner, and another expert on pans, pandas. And all we do for our kids. So, Lindsay, tell us first just a little bit about yourself more than what I've just said.

Okay. Well, I'm a natural, empathic physician, and now my office is in Trumbull, Connecticut, and I focus my practice on children with pans and pandas, other vector borne diseases, autism, and my real reason for kind of getting into this field, was to try to keep families together, because I feel like those conditions, it doesn't just impact the child, it impacts the whole entire family structure.

And so my practice, I say even though it's pediatric based, it is family focused because I will also see the immediate family members of the child who has pans and pandas or autism.

And I feel like it really gives a beautiful, well-rounded view of how I can help to support not only the child, but the family.

## Lindsay Wells and Her Family-Focused Practice

And when I feel like the parents are feeling well and all aspects of the child also feels better and we see improvement. So, that's a little bit about me.

Yeah. And you know, in your spare time, you, you even wrote a wonderful children's and family book and it's I always joke, it's a great book for those MDS and dogs that don't know anything about pants.

Pandas, but Super Sam and the battle against Pans Pandas. So just tell us a little bit about that book first and and then the impact of of Pans Pandas on caregivers.

Yeah. So this was actually a maternity leave project that I did about four years ago. And it really stemmed, again, coming from my passion for helping to support family members, because what we see with children with pans, pandas or any other type of chronic illness is they take up a lot of time and energy from the family.

Right. And it can it it does impact the family structure. And often what I was hearing from parents was kind of the guilt that they felt about, you know, the amount of effort and attention the one child gets over their other children and they worry about that other child or other children.

But the resources are going to the other one right now. And, you know, I grew up with two siblings. I have a younger brother and sister, and my life is so much better because of them.

And having them in my life. But it was very clear the struggles that families were experiencing with one child who was sick and how that was impacting the other children in the family.

So I wanted to provide a resource for families to use to read to the other children so that they could kind of understand that there wasn't a favorite in the house.

There wasn't. You know, there was really an underlying physiological medical condition going on with the siblings. So it could just help to, number one, help the mental health of the sibling, but also allow for that sibling to have a better understanding, to keep that relationship strong between the parents and, their, their sibling.

That was ill. And so, you know, I feel like it's great for ages like six and above. And I've had some really wonderful feedback from families on, how it allowed their child, like even reading it to their child who has pans and pandas like how it validated them and made them understand their bodies better.

And they have been given that, given donations to like their school and to their teachers to read to their classmates. So it's not just, I guess, about the sibling, but it's also about their peers and, the child understanding themselves better.

Have you heard about cerebral fully deficiency? If not, or if so, this is a diagnostic test you need to know about the folate receptor antibody test or Fret detects auto antibodies that block fully transport to the brain, critical in conditions like pandas, pandas and autism.

Early detection means targeted treatment with folic acid, improving brain function, reducing inflammation. So get the answers your child or patient deserves.

Fret testing may be the key to unlocking better care, and those at religion are revolutionizing diagnostic testing by equipping health care professionals with cutting edge tools for early detection, targeted interventions and improved patient outcomes.

Their innovative solutions, including the Foley receptor antibody test for Pans, Pandas, and Autism, provides critical insights into neurologic and immunologic related conditions with a commitment to scientific excellence and personalized medicine.

Religion Rd empowers clinicians to make informed decisions and optimize treatment for every patient. For more information, please visit Frat now.com or religion x.com.

Yeah, and I think for the practitioners that are listening or watching, having the book in your waiting room or copies of the book, I have a practitioner I work with that asks for copies all the time, and it's available on Amazon.

You can very easily buy ten copies to have in your office and give it to your families. You know, it's it's not expensive, and I think it really it tells the story well about what Pens and Pandas is and, a way that it's

understandable.

And also gives a message of hope, not just for the kid that has it, but for the family. Yes. And so it's essentially just talking about, like, the super powers of the family at the end and the strengthening of the family unit and how the family dynamic might look different, but they're still super in their own way.

And so, I really wanted to make it encouraging for the whole family and the child to, reads it. Yeah. So what are you seeing in when pans pandas affect a family?

What are you seeing in the siblings and and the family members and and what do you do to help them? It's a great question. I, I feel like our kids in general are getting sicker.

I'm sure you would agree with that. Yeah. And, you know, I used to not see so many, like when one child had pans, pandas. It was like that was enough for that family, you know that that that's plenty.

But unfortunately, what I'm seeing is that it is running in families. And so one might be the most ill, I guess I would say are the most affected, but the other siblings or maybe one sibling will start to have some soft signs.

And so what I encourage family members to do is to establish care quickly with those other siblings, like at the first onset, or inkling or gut feeling that there's something that could be going on with the other child.

## Super Sam Book and Supporting Siblings

It's just establishing the relationship with their Pans Pandas provider, so that if anything were to progress, we'd be able to quickly nip it because we know how difficult it is, number one, to get the correct diagnosis, and then sure as heck to get the right treatment.

And how with every subsequent flare, things can get worse. So, luckily, what I've been seeing in my family is of when we're approaching a case like that, it stays extremely mild and it really doesn't progress to anything more because we have them on that three pronged approach.

It just looks it's like a gentler, more balanced, not as aggressive approach. Right. But it's still a prophylactic antimicrobial. Some symptoms support.

And what I see really with the kids is like the siblings is some anxiety, some OCD, some ADHD type of symptoms. Right. It and then of course we have the immunomodulatory.

So like a very benign anti-inflammatory in there. And that seems to be working really well for my family. And it's just trying to decrease the stress of having another child go into a more severe case.

What? And why why do you think that is? I mean, we we both know is and probably everybody on here knows there there is a genetic predisposition. So that's certainly possible.

And we live in a very toxic world. Certainly mold may be affecting everybody in the household or more than just the index sibling. Any others that you think about why it's affecting the, you know, other family members?

Yeah. I mean, one suspicion that I have, and I think you would agree with me is just the prevalence of tick borne disease. And people in general. And I really believe we're pretty much all walking around with it.

But some of us have that genetic susceptibility to actually present with symptoms. So it's very likely that mom and dad may have had or have some vector borne disease that's then being passed.

And I think that kind of is just it sits there maybe in that child, and then it's an infection like strep or mycoplasma that just pushes it over. So I think that's part of it.

And I have strong suspicions for that. But I also think it's just the environment that we live in in general where, you know, our food sources are depleted from nutrients.

There's so much inflammation, the toxic burden that our children have. And it's just unfortunately there is that genetic piece. So all of that combined then leads to the manifestation of pans and pandas occurring.

Absolutely. And I think the other piece that we talk about a lot, and I know you do a lot of work on, is helping parents, particularly moms, put their oxygen mask on because, you know, whether it's they're so tied up in dealing with the the sick kid that they may neglect the other one or neglect themselves.

And I speak to that a little bit too. Yeah. So absolutely, I feel like it's more of the neglect, neglect of themselves more than anything. Right. And so again, I am a firm believer that when, parent takes care of themselves, they're and they feel better inside their child feels better without us doing any intervention.

And I did a small survey in our practice, actually, and 50 mothers responded, which I thought was pretty amazing. And, the results were over 80% agreed that they notice when they're not feeling well.

So like, say, they're feeling anxious or overwhelmed. They noticed an increase in behaviors in their child. And so this is not just for children with pans pandas.

This is also other chronic diseases including autism. But what's been amazing is to see there is research coming out now about caregiver burden and pans and pandas.

And what was most shocking was the first one that I think came out, which was probably about two years ago. It was kind of a they included a narrative where they interviewed parents, and then they included quotes from them.

And it was the quotes that we hear in the office all the time, like, you know, I, I felt like I lost them, you know, every single time they have a flare, it's feeling like I'm back to the beginning and the trauma that comes with it.

And like, feeling like I couldn't do anything besides take care of them. Like I felt like I couldn't even breathe. And it like, it gives me chills to think about because it is significant, the burden here.

And they actually were even comparing it to taking care of somebody with all timers or taking care of a child with RET syndrome, which is significant.

And, how the ups and downs of the flares make it. So this the nature of this illness not only so challenging for the child, but that caregiver, because we're in that constant state of fight or flight.

And unfortunately, as we know, there are flares. So any time a little flare happens, it's like as a parent, you're jumping right back to the beginning of like, oh my God, what is this going to look like?

And that's then not helpful for, you know, our children pick up on that type of stuff. And it's so it's important to prioritize ourselves. It's important to recognize and work on ourselves and to regulate ourselves and to not feel guilty about that either.

You know, and I, I have a, a membership group where it's moms, it's called the Well Minded Mamas Club, where it's all moms who have children with complex medical conditions pans, pandas, autism, tick borne disease, mold disease.

And it's fascinating that thread the commonalities between all of us and the community. And, we have similar feelings but experience it in a different way because every family is different.

But, the research is out there. The communities are out there of moms, but it's still so we could say all this, but it's still so hard to implement it.

Right? Right. And and I think, you know, your well mind is mom club. I love it just just the way you provided an online community for moms and provided resources provided, you know, discussion, all of that.

But also, you know, help with the day to day, just taking that extra breath, going outside for those extra few minutes, taking that cold shower, you know, being in the dirt in the, you know, the sun, whatever.

It is so important because as you know, you know, our kids are so symbiotic. I'm sorry, dads, but with us as moms, you know that they feed off of our anxiety, whether it's pans, pandas or anything else.

Yeah. And one technique I've been finding very helpful for some of my moms in the group is just something called the physiological side. I don't know if I've shared that with you, Nancy, but it it's just breathing in through your nose, kind of getting to the top and then breathing in again and then letting out a little exhale through the mouth.

And so it goes. And it can be an audible sigh or not. And repeating that and actually, research has shown that that particular breathing technique was more effective for shifting people into parasympathetic tone, compared to for box breathing or some meditation.

Now they were saying it at five minutes. I think that's a long time to breathe like that. But I think even doing like three of those breaths, like before we respond to something to, to regulate ourselves.

And the other thing I've been working on is I'm calling it a mom timeout, where we're literally just taking a few minutes, intentional minutes to be like, I need a few to refocus, to breathe, to rebalance before I show up again, and kind of working through that mom guilt that we have of stepping away.

But we are the benefits that come from that are so profound. They're way it means way more than the five minutes that we take to recenter ourselves. Right? And we're modeling it for our kids.

## Caregiver Burden and Parent Self-Regulation

We're, we're we're showing them. And also, you know, mommy needs a timeout, you know, and just breathing in front of them just can go so far. I mean, we talked so much about medications and herbs and nutraceuticals and, you know, CBT and DBT.

But just these simple lifestyle things can go so far to help our moms and our dads, you know, and leave them out. And our kids and their siblings. And the whole purpose of this is to empower the parent.

Rather like there is no guilt, there is no shame, there is no blaming here whatsoever. It's just empowering you to realize that you hold a lot of power actually.

And it we can view it as a burden, or we can actually view it as something that, is very beneficial and again, powerful and beautiful to have such a deep connection with our child that when we take care of ourselves, everyone else around us benefits.

Including them. Yeah. And and we've thrown around a few things and, you know, we never know our listeners or viewers. Some of them are practitioners and are, you know, way down this road.

Some are just listening to this at random and never heard about pans and pandas. But I want to just highlight a couple of things you said because I think it's important.

You know, you mentioned the three pronged approach, which of course, we we certainly believe in the antimicrobials doesn't need to be antibiotics. You know, the the immunomodulatory therapies and, and the which can be as simple as ibuprofen.

But lots of again, herbs, botanicals that are so good at that. And then the the symptom support including therapy and including again nutraceuticals etc..

Do you want to expound on any of those? One of those that you know are really important to you? I think the biggest one that I see being left out is the, prophylactic antimicrobial support.

I don't know about you, but I feel like we focus a lot on the symptoms, which I understand because we want the child to have relief. We want the family to have relief.

But I often think we're just not. We're still missing the underlying cause. And if we're treating the symptoms and we're putting in, say, we're putting in a immunomodulatory, but we're not putting in the antimicrobials, we're leaving that child.

You know, we're not, doing our due diligence, I think, to prevent a future flare and perhaps it getting worse. So that's the biggest one that I see when people come to the office and say they have been treated for pans and pandas, they've been under the care of others.

It's that prophylactic antimicrobial that it's pretty amazing to me that that's usually left out. Yeah. And we're not talking about long term antibiotics.

They can do it verbally. Absolutely. Yeah. So and and then you mentioned about our sympathetic parasympathetic. And I think we should just define that a little bit better for people that may not understand what that is.

Yeah. So the parasympathetic mode, it often has to do with the vagus nerve or the limbic system. And essentially what this is, is just getting into that fight or flight which we can see in our children. Right.

So we see that their pupils are dilated. We see that they can go from 1 to 100 in a split second. We can see that, well, we can't see this, but they might say that their heart is racing, or they might get an upset stomach and have to run to the bathroom.

That's or not be able to fall asleep at night because they're worried that's all that fight or flight. And I think a lot of parents know that they can recognize that in their kid.

What we, Sorry. Yeah. What we what we really want is to go to that. Don't mess up and say that it was parasympathetic and that you started with parasympathetic.

But I think everybody. Right. So we we know but essentially the parasympathetic is that rest and digest. And that's like when we're able to calm the nervous system and we're able to, you know, just relax essentially.

But our kids unfortunately aren't sympathetic. Excuse me. And that's that fight or flight where we see all those symptoms that I was talking about. Right.

And so what we want to well, we want to focus on is more of like, how can we shift from that sympathetic nervous system to parasympathetic. And that's really focusing on like that vagus nerve and that limbic system.

And that's the simple things like breathing. Right. That could be making sure that we're getting enough sleep, that could be making sure we're pooping every single day.

One that I love, that I find so easy is humming, actually, because humming vibrates that vagus nerve and shifts us into parasympathetic. So sometimes I have patients or parents come to me and be like, they're humming or they're they're coming to themselves during certain periods of time.

Like, is that a tic? Is that some is there something wrong? And it's like, not at all. That's just them knowing that this is a self-soothing mechanism to help shift them when maybe when they're feeling anxious or they're feeling dysregulated into that more parasympathetic mode.

So that's super simple to hum. Yeah. So yeah. And I think that's a great one. I remember just a few weeks ago I had a kid come in that was one of our spellers that could never express herself before.

Now she's spelling and can express herself. But all these years she's been humming sometimes softly, sometimes really loud. And in asking her, that's just what she was doing.

This was the only thing that could bring her out of that fight or flight. That huge sympathetic, you know, limbic. Vagal what? Yeah, yeah. So and then the other thing that you mentioned that I know both of us are passionate about, but I know you do such a great job in treating is tick borne disease, you know, and treating verbally, which we both agree has such benefits and good research behind it.

And being in the northeast, you know, it's it's more than 40% of the ticks have Borrelia, Baeza, Bartonella. And you've done a lot in working with these kids.

So do you want to just mention a little bit about about any one of those. Yeah. So I think my I have a big passion for Bartonella, as you know. And the reason I am so passionate about it is because when kids are presenting with dysregulation, when they're presenting with anger and aggression and rage like that's not their normal state, all children want to please, they want to be loved.

They want to be nurtured and like, you know, praised. And so they don't want a present like this. And so it was just so fascinating going through like the years and my clinical experience, just seeing the pattern of like these children, they don't want to act like this.

And I truly believe it. And there is a reason underneath. And that's that tick borne disease in particular, Bartonella. And I also find it so interesting about sensory sensitivities, because that's another big one that we see, especially in the autism population as well.

And then to see how that's connected to Bartonella or bobcat. And so what I really see is those are the two that I rule out the most. I know that Lyme disease and Borrelia burgdorferi and relapsing fever and or lucky osis and Anaplasmosis, all of those are potential as well.

But when it comes to pans and pandas, clinically, what I see is it's more commonly. But Bubka Bartonella same thing with autism. And I feel that when we first started, like I first started my career with Pans and Pandas, it was very it was possible to see a pandas case like just strep where it didn't turn, you know, it wasn't pans.

I don't see that anymore. It's, you know, our kids are sick and they're being affected by all types of germs. But what I also would see a lot of is the waxing and waning pattern of like, they would have a flare for extended period of time, and then they would get better and not have a flare and like return back to baseline for again extended period until we had the next one.

I don't know about you, but that is not what I see in practice anymore. I call them constant flares where the child has the onset, and then it's just very difficult to get them back to baseline.

And when that occurs in my in my approach and how I look at that case is like, you have to rule out vector borne disease, particularly of a BCM, Bartonella, yeast overgrowth and mold disease, but often with neuropsychiatric symptoms.

It is it is the vector borne disease. So I feel very passionate about rolling that out and and also uncovering that and treating that. And so, it makes it makes a significant difference in the child's symptoms.

And I think we would both agree that like pans and pandas, Bartonella bibs, we cannot diagnose by conventional labs. And in fact these are really clinical diagnoses.

So if you have the index of suspicion because of the daily rage or because of the severe night sweats, or because of the the stream with Bartonella or whatever, the symptoms may be, treating verbally is safe and effective. Yes.

And so what I see is I don't see a difference in the length of treatment or even the outcome when we're using antibiotics versus herbals. I do tell people if they use antibiotics, I will always support them in whatever they

choose.

But you should put in the herbals as well, because you're going to be treating for a long period of time. These are very stubborn germs, so a minimum of a year you should expect at least two years.

And I'm always like celebrating after a year of testing. And like we got an infection down our like resolved. It's like a it's a celebration rather than some people being like, oh, but it's not totally gone.

It's like, yeah, but you got you got one down or you got, you got it's just it's for a celebration. So, but what's also interesting is I think it was the it was American Academy of Pediatrics.

They put out their own paper in 2020 where they looked at the most common cause of infectious encephalitis in children. And guess what? The number one bacteria was that caused encephalitis in children.

It was Bartonella. And shockingly, how many pediatricians are actually looking at Bartonella? I, I think I can count on one hand how many people have come to me with with conventional labs just through the standard lab where a pediatrician ran Bartonella, which is very sad.

But then also, if you have the standard lab and the Bartonella comes back negative, you can't necessarily trust that because it's only looking at two species, right?

So it's only looking at Bartonella Quintana and Hensleigh. And same thing with the VCA, McRobbie and Duncan, when in reality there's many different species there because it's a family of germs.

And so that's why we have to go more to the specialty testing, because we're ruling out pretty much all of them that we know of. Yep.

## PANS, PANDAS, and Tick-Borne Disease

And I agree with you that we're seeing a lot of kids with daily flares, but we're also seeing some with the waxing and waning. And some of that is because these diseases, particularly may go dormant, may go deep within cells with, you know, in the body.

And one measurement in time from a conventional lab that's only testing two of the many strains, you know, you're looking for a needle in a haystack, whereas if you have the symptoms and can treated safely and effectively or Billy, you know, it just makes so much sense to me.

Absolutely. Yeah. I'm so glad that that's one of your areas of passion, because I think you're you're helping a lot of kids in doing that care. But one of your other areas of passion, and one that you totally, took the lead on and did all the work for, was the article that that we published, with you as the lead author this summer, on Foley Receptor alpha antibodies in children with Pans and Pandas.

So I'd like you to talk about everything about that. What about cerebral folate deficiency? So start wherever you want to on that. And yeah, so I think we were looking at cerebral folate deficiency quite often in the autism population. Right.

Because it's most commonly I guess tested for there to help with speech and communication and language challenges. It's also a manifestation that occur can occur in epilepsy.

But what's lesser known is that cerebral folate deficiency can occur in treatment resistant depression, anxiety, psychosis, schizophrenia, memory loss.

Dementia now does that sound like any of the symptoms that we have for our children with pans and pandas? And so with that we started to investigate in our initial consults.

Which I really loved that we did it in the initial consult before we like, we got on a lot of treatment. Right. And what we found was that about 64% of our temperament pans and pandas have cerebral folate deficiency.

And when we treated them appropriately with high dose for clinic acid, what we found was that there was improvement in their symptoms. So improvements in OCD, anxiety, depression, tics actually was a big one.

Two and one area that I'm exploring that I'm kind of excited about because I have one case study is speech. This fluency, which we know children with pans, speech, dis fluency.

The article showed about 54% of children and a flare will present with speech disfluencies. So that could be like stuttering or putting in unnecessary words.

Selective mutism. What? And one case study that I have, when we that child has cerebral folate deficiency, when we put in high dose splenic acid, they're stutter completely resolved.

And so I think that kind of gave us I got that kind of thought just from the children with autism and the speech and communication piece. And then I am seeing that kind of follow over with pans and pandas and that symptom in a flare.

So, I, I guess I encourage, I feel like this is it's very possible that cerebral folate deficiency is a part of maybe why a child is susceptible to pans and pandas or the manifestation of their symptoms.

Right. And as you reported in the in the article, you know, small numbers, 47 kids, but 63.4%, had cerebral folate antibodies. That's not a small number.

And as you said, the symptoms really overlap a lot. So it should be something that's looked for. So just taking a step back first, just talk a little bit about the pathophysiology of cerebral fully deficiency so people understand what's going on.

No problem. So we I'm sure you've heard of folate. Folate is known as vitamin B9. And we hear a lot about folate in the importance during embryogenesis or when we're pregnant. Right.

That we need to take folic acid, which may not be the best form for somebody. But still nonetheless, we know the importance of fully. And when somebody doesn't get enough folate during pregnancy, it can lead to neural tube defects.

It can cause a child to be more susceptible to neurodevelopmental disorders. But it's also extremely important. And RNA and DNA synthesis, amino acid metabolism, neurotransmitter synthesis, myelin production.

There's so many, areas that that the body needs fully. And when somebody is folate deficiency has a folate deficiency, we think about okay. Anemia that's a very common thing.

We think about other pants sites apenas other immune dysfunction, neurological disorders, but also mental health disorders. And what we have found is that you can have very normal levels of folate in your serum.

So as you can when you check the blood, your full eight levels could be completely normal. But that doesn't necessarily mean that you're getting enough folate into your brain.

And so what cerebral folate deficiency is, is you just not enough folate in the brain. And there are many reasons to why this could happen. There's about like five different potential reasons and mechanisms to not be getting enough folate in the brain, but the one that we focused on in our study.

And what I think the majority of studies look at is the receptors on the blood brain barrier specific for either for clinic acid or methyl tetrahedral folate, known as folate receptor alpha.

What can happen is that there can be antibody that antibodies that the body produces, that either block or bind to the receptor, that doesn't allow your body's normal levels of folate to get into the brain.

And so the solution is to essentially load the system with the linick acid, to the point that the brain utilizes a different carrier transport. It's called the reduced folate transport that then shuttles that for lytic acid and methyl tetrad or folate into the brain, and that then helps to normalize the levels.

And we're so fortunate that we're now able to test this through blood. Previously, this was only available through a spinal tap and looking specifically at the cerebral spinal fluid.

But what we've seen is that when you do the spinal tap with the cerebral, excuse me, this, the spinal fluid, it's very similar the results to what we're seeing in blood.

So this is like, less invasive. Way to be able to diagnose somebody with cerebral folate deficiency and then get them the proper treatment, which is essentially high dose for Winnik acid. That's based on their weight.

Right. And and for those of you who want to look into that, the the website is frat now.org FR8. So folate receptor antibody test now and Warburg. And it is a great test.

And just from your perspective I'm curious Lindsay, you know, we know about the research that Doctor Frye, Doctor Rossignol, Doctor Rainmaker, Doctor Quadrant have done.

And I'll be interviewing Doctor Frye. Also on this podcast talking about this in autism. But but from your perspective, this, this blockage, these antibodies, do you think that it's something lifelong in our kids with pans and pandas?

Do you think it's a cross-reactivity? What's what's your thought about that? I think it is more lifelong. Because just thinking again about the nature of pans and pandas, how it is a pediatric, you know, disease and illness.

But we're really there's like two periods in time where it resolves, right, where we're thinking puberty or adulthood when the blood brain barrier closes.

But although our children may, they outgrow this. They still have some inklings of a little bit of OCD or, anxiety. Or maybe when they get stressed, a tick will come out and it doesn't interfere with their life to the extent, but we still see some of that.

So I'm suspicious that this is more life long at just the how it, manifests and how drastic it is might change. But we do know that the folate receptor autoantibodies, they fluctuate throughout life actually, and at different times.

So again, it would be interesting to look at in our pants community like the kids who were in flares, rather the ones that aren't in flares like what those antibody levels look like.

But we know diet plays a role too. And I'm sure doctor Frye will talk about this, about how the folate receptor autoantibodies, we're seeing those in parents as well.

So if you have a child with it, you are seeing that it's also, present either in mom or dad or both. And even in some of the siblings who are not affected by autism.

So there's a very high suspicion that this is a non-genetic, heritable condition. And so I do think it is in our population, lifelong. It's just we might not need to be aggressive in treating it for lifelong, because other burdens in general are coming off of our kids.

But, I do think we need to treat longer than maybe we previously expected or thought we did. Got it, got it. Now, you mentioned diet. The big one that that parents need to be aware of is that milk all animal milk protein also block these receptors.

How do you talk to your families about that and and implementing that. You know, I find that them taking the high dose, feeling like acid is much easier for them to implement the dietary change.

## Cerebral Folate Deficiency and Folate Receptor Antibodies

But I do kind of tell them, like, you know, if you're not putting taking out the dairy, we're kind of just chasing our tail. Because what was really interesting, it was an article by Doctor Rainmakers.

I mean, this was a while ago now looking at a milk free diet. So it wasn't a totally dairy free diet, and it was also only cow milk. But when somebody took out that milk, what they saw was there's a drastic decrease in the autoantibodies.

But yet when they reintroduce the milk, what happened is it spiked even higher than what it initially was. And so the reason this happens is because our body will like that homology is very similar between the folate receptor alpha from milk.

And then also in our body. And so I think this is also a reason as to why we see autism like it's more common the diagnosis between say 12 months and you know, 18 months.

Because I think that's when, you know, in America we're told to give more cow milk, right? As like a supplement for breast milk. And that should be a really big source of nutrients for them.

And, but that's a little bit off topic. But I do think that that's why we see the changes maybe in development around that time if the child has, you know, autism and the cerebral folate deficiency.

But the other piece of it is even though the research is only saying cow milk, it really comes down to all animal milk. And dairy. So I've had patients ask about like cow, sheep, buffalo.

Most recent one was a practitioner about donkey milk. And it's like camel milk. Yeah. Oh camel milk. Yes you're right. And so it's my advice is still to avoid all animal dairy because what the research shows in regards to the ability like the homology of the similarity between the structures, it's across all of the animals rather than just cow milk.

Yep, yep. Totally agree. And and there are so many milk alternatives that that we have available for our kids that are very healthy. I mean, you know, we we may want to avoid all the rice milk and certainly soy milk and, and maybe not too much oat milk either.

But there's pistachio milk. There's almond milk there. There's coconut milk. You know, so many out there that that are available to our families to consider that our kids are like, you know, taste way better now than it used to.

Yeah, I absolutely, and then, you know, as you mentioned, kalinic acid, gets around that block through the reduced filet carrier and we want to use very high dose, certainly in Frei and Doctor Rossignol and other studies. It was 2mg/kg.

And, you know, you and I have talked about how silly the Connecticut legislature is in not letting, naturopaths prescribed medications, but, you know, all of Doctor Frye's studies and others were on Luke Avorn, which is the prescription form of for clinic acid.

But now you have come up with a high dose for clinic acid that's available as a supplement. Can you talk to everybody about that? Yeah. So this was really burst out of frustration.

I think that my families weren't able to get the treatment that they needed because of the limitation of the scope of practice. And even if they were able to have they had a physician that they could work with that could prescribe, there was a lot of pushback if they weren't in our community.

Because, look, Avorn, unfortunately, is characterized as a chemotherapy drug because it's a rescue for chemotherapy, for the depletion of folate when you're going through that treatment.

So, without really looking into it, a lot of physicians were like scoffing at the idea of prescribing it. The other thing about, Luke Avorn is it does contain some dairy product in it, too, depending on where you get it from.

So it's kind of counterintuitive for us, right, to be telling somebody to come off of dairy, but yet putting them on a medication that contains that. Also, there was supply and chain, issues and so this was, as I said, birds out of frustration.

And so it is a product. The company is called emphasis. It's m e p h y s's. There's only one product there. It's called hi clinic. And in one capsule we get 15mg of splenic acid.

And so the reason we did this is because on the market there was just low doses. So 800 micrograms I was having kids having to take four bottles a day.

So number one, having a child take that many pills on top of everything else that we're asking them to do, the cost piece of it for families to be doing that was insane.

And it was really not a good solution whatsoever. And so this is what came out of it. And we're having really great results. Similar to what I would expect with Luke Avorn.

It's the same form of full and acc acid without the added ingredients. And, I'm really proud of it, and I'm really happy that it's an option for people.

Right. And so again, it's emphasis mepa y sis.com. But I you do recommend that that parents work with a practitioner to make sure that they're using the correct dosages, etc.

in getting it. So absolutely, I do think, you know that there has in some of the research they say that like there's minimal side effects. So if you want to do a trial of high dose for the acid, I am not in that camp.

I really think you should know if your child has cerebral folate deficiency or not before you implement the treatment. The reason being is you're already doing so much with your kid.

We already asked them to do so much. It's one more thing. It's really great to have the data, before moving forward with this, because it also isn't like you just go up to the dosage of the weight appropriate dose.

You have to build up to it. It's a commitment. There could be some side effects from it. Not serious, but still some side effects. And so you kind of have to work with somebody that understands that can help navigate you.

And again, your number one job is to be their mom or their parent. You're not supposed to be their doctor, too. And so my hope is that you can find somebody that is familiar with cerebral folate deficiency and help with guidance for treatment with that.

Yeah. So I think it's you know, I know you've gotten a lot of great feedback on the study. And I think it's really an important piece, that goes beyond the scope of the three pronged approach that we were talking about before.

That goes beyond the tick borne disease, the mold, all the things that we all see that that I think practitioners and families need to ask about and, and look at.

So I'm so thrilled you did that. And, and, keep me abreast next of your ear. You're going to do another one. But that I think it you know, it it could be, another game changer in this population.

But as you said, in many other kids, not just pans, pandas or autism, but others with anxiety, depression, epilepsy, sleep disorders, speech, dis fluency, whatever it may be, this could be something that that is affecting their child.

Absolutely. Or affecting them too, in the adult population. And so, you know, I'm I'm really proud of us for getting that, information out there because I do think it's a significant, finding for our population.

And it just, you know, sheds light on the fact that cerebral folate deficiency, you don't just have to think about it for autism. You don't just think about it for epilepsy.

There's really a lot of mental health conditions that it can make a significant difference for. And even the thing that I love about it is if part of that symptom support is you putting on, antidepressant or an antipsychotic, if your child's not responding as well to it or as what we would hope, which we know children with pants, about 50% of them don't respond the way that we would hope for.

Either they have side effects or, you know, they can't go up to the tolerated dose. Adding in splenic acid or methyl tetra hydrophobic can potentiate that medication to make it work better.

So again, all it comes down to is like getting your child or you more relief from your symptoms and making maybe some of the other, you know, interventions that you've been putting in more effective.

Yeah, yeah. Absolutely. All right. So so we've talked about your book and, and the well mind is Mamas Club and the article on cerebral folate deficiency.

You also have a course that's called Pans Pandas Power to tell the moms and dads and everybody out there what that's about. Yeah. So this is a course that I put together mainly for parents who have suspicions that their child could have pans, pandas, or if they're having a really hard time getting into a provider.

And so it's it's supposed to be that interim because, unfortunately this condition there's urgency behind it. We need to get our kid relief. We need to get them out of a flare.

We need somebody to listen to us. But then all the people who are specialists in this area have extensive wait. And this was a way that I felt like I could kind of maybe combat a little of that to get the child and the family some relief.

So there's modules in there about what is pans, pandas, about the three pronged approach. Antimicrobials, immunomodulatory and symptom support, as well as what to do as the caregiver, how to manage flares.

And it's all based on natural natural plastic supports that you can implement now. And so it's pans pandas power to get you the relief for your child.

Now not waiting nine months to see somebody, 18 months to see somebody. And, you know, so that that's what that is. And I'm proud of it. And I think it is very helpful.

And there's a lot of information in there. There's, you know, resources. There's some, dosing instructions, like there's the herbals to consider. So I feel like it's very jam packed with what you might need.

But again, the goal is to still work with somebody, when you can get in. But it's kind of that in between when you need. Yeah. Okay.

## High-Dose Folinic Acid and Practical Resources

Yeah. I like I like the now part of it too, because it is so unfortunate that so many of us have such long waiting lists, you included, and and that we, we can't be there for everybody.

So having a course like this is, is invaluable. So I want to ask you if you had to go back to your younger self, like maybe in naturopathic school or even before that, or when you first started, is there anything you would tell yourself differently, like knowing what you know now?

Anything the the that you would tell your your slightly younger self? I would probably tell myself to just continue and

to trust and that because I feel like I'm what got me on this path was a little confusing.

I don't have a child with pans pandas, I don't have a child with autism, and I sometimes contemplate like, how did that younger Lindsay know this was the way she should go?

Right? And, you know, my gift that I have gotten from working from this community is really the moms and the parents, and seeing how they're so devoted, so determined to get their child well, how they the unconditional love that you really teach me how to be a mom.

And that's the greatest gift. And so that's what I want to give back. And I think I would also, you know, let that younger Lindsay on the back for being pretty persistent and her life and, you know, thinking, you know, I don't hear just keep going until you hear and know.

And I think that helped me in my experience and in my journey to working with you. Nancy. Right. Like, you know, many people don't know this, but I think I harassed Nancy for a long time with no response back.

And I just kept going and going until I got a response which was, sure, we can meet. And, it ended up being a beautiful like it still is a beautiful relationship.

But when that time of us working together. But I think it came from my persistence of being like, until I hear now I'll keep going, you know? So absolutely.

And I for one, am very, very glad you did. And my life is richer for having, you know, made you work so hard to to do it, even though I have no recollection of of the not answering.

But I am so glad we we had our years working together and so glad we we have this stage in our lives to continue to, to be in each other's lives. So. And I'm so grateful as all the parents who work with you are for for all the things you're doing, your book, your clubs, you know, your, your, course and the care that you give to all of your patients.

So any last words you want to leave our families with? I really want to leave the the families that are listening to continue to trust your gut. You know your child better than anyone and so don't doubt yourself.

And you really are doing an amazing job. So on that hard days, be gentle with yourself because your child is so lucky to have you. And so I mean that from the bottom of my heart.

So, so true and so important for for our parents to hear. So thank you. And, and again tell people where they can find you. You can find me my website.

It's Lindsay Wells, indeed.com. All of my information is on there. My office address, my phone number, the email, my the well, minimum as the course, everything is there.

And if you want more information on the high dose clinic acid from emphasis, you can always reach out. So. But you could find that there or find me on Instagram.

I'm not as active as I used to be, but I do love to post about the research and talk about Bartonella and cams and pandas so you can find me there. Yeah.

So Lindsey Wells, Indeed.com, and it's Lindsay with an E as it should be. And thank you, Lindsay, I so appreciate you being on and so appreciate all the work that you're doing.

So thanks for being here today. Thank you. Thank you for tuning in to Doctor Talks. We hope today's episode has enlightened and inspired you on your path to optimal health.

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