Unpacking PANS/PANDAS Part 3: Living With PANS/PANDAS Transcript

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Introduction and Sponsor Message

You're listening to the Get to the Root podcast with Hope for Healing. Today we close out our three-part PANS PANDAS series with a powerful discussion on what life looks like for families living with these conditions.

Dr. Paula Kruppstadt shares strategies for parents, ways to reduce shame and guilt, and tools that bring real hope to children and their families. This podcast is for education and encouragement.

Please consult your healthcare provider for personalized medical advice. Now a note from Dr. K about our sponsor. Knowledge is power, especially when it comes to understanding the immune system.

That's why at Hope for Healing, we use genetic panels like the immune, autoimmune, and inflammatory panel from our partners at Fargon These tools help us see how an individual's immune system is wired, where inflammation is not decreased naturally, and what's needed to calm the immune system.

We're grateful for Fagran sponsorship of this podcast and for making this level of personalized care possible. You can learn more in the show notes. Dr.

Kate, thank you again for joining me for part three of the Pans Pandas. And this is where we're gonna be diving a lot into what does the family's lives actually look like and how they can be supported.

But to set the stage, can you remind parents why it's so important to refrain symptoms instead of calling it like misbehavior or defiance, but as brain inflammation?

Like, why is that important? Well, the very nature of inflammation is you have good days and bad days. That's inflammation. And a child has the same thing going on.

They just don't have the ability to articulate, I feel angry and I don't know why. And they don't know why they lashed out.

Why Brain Inflammation Shouldn't Be Called Misbehavior

So instead of saying they're disobedient, they're disrespectful, you have to take a step back and go, well, They don't like tags in their clothes. They don't want to wear underwear and they are fearful of a parent leaving the room.

So that's all about biochemistry, neurotransmitters, and it has nothing to do with what kind of child they are or what their character is. So when a parent or a grandparent or a teacher names it as bad behavior, but it's truly something that the child really can't help on the worst of their days.

um If they're having visual or auditory hallucinations, you're shaming them and they will feel shame instead of realizing that many of these children have profound remorse after the fact and go, I don't know why I did this.

I love you, mommy. I love you, daddy. So basically you don't want to create shame. Well, yeah, because shame puts this, I think it grows the mindset, right?

So it means, grows the mindset that I am the problem versus there is a problem and that can be addressed. Do you think that shifting that mindset can help parents, schools and communities respond differently to something like Pans Pandas?

uh Absolutely, and we've seen that in our practice. Instead of expelling a kindergartner for throwing a desk across the room, she had circulating autoantibodies and now she's thriving.

So it's all about presenting the data and saying, this is brain inflammation, this is biological, this is chemical, and we need to treat this child as if they have an illness, which they do.

You said this before, Shame says, am bad, not I have a condition, just like if a patient or a child had cancer or diabetes, you would not shame them if their blood sugar went too high or too low and they lost the ability to communicate or they were cranky.

So that's a better way to look at it. which we know to be true out of all your years with working with children in the Pans Pandas community and families, really, because when someone has Pans Pandas, it is a family involvement.

There is not a single person that can really play like, I'm just gonna step out today. So specifically when it comes to parents with Pans Pandas, we know this can be exhausting.

Are there any practical ways that parents can take care of themselves without feeling guilt and shame themselves for the situation? I think one thing to do is to surround yourself with the community, either in person or online, or work with a therapist of people that understand what's happening.

We have a referral system in the area. if you can find other parents, now here's the thing though, it's a two-edged sword. You can get into an online community and you have all these parents telling you things, but.

they don't know your child's specific medical history and all of that.

Supporting Parents and Reducing Shame

it's all about framing it for your child. So parents need to not have toxic, leechy people in their community or speaking into their ear. And it may even be your own parents.

You just need to be very kind and respectful and go, we're doing the best we can. This child is not like this child. and we're seeking help, and this is a medical diagnosis.

And when you show them the literature and you show them the Aspire.care website, it's almost like this relief for the parents to know, I'm okay. parents, they need to eat well, sleep well, get the therapy they need.

They need to move their bodies and get breaks. Hmm, that's so good. Well, okay, so you kind of mentioned that sometimes those that are closest to us have an even bigger issue, right?

So whether that be the grandparents or aunts and uncles. So how can parents, and you kind of mentioned this with the Aspire website, is do you think that's a really good way of having those conversations?

Whether that be a spouse, a grandparent, or an aunt or uncle in order to have a united front with this condition? Yes, I think using the Aspire.care website, but also Just remember family and relationships is so very important.

And many of us, our family members don't understand our medical conditions, but we are called to respond with love and kindness and respect. And as parents, we tend to be mama bears or daddy bears.

It's like, Please don't say these ugly things about my child. Please don't attack me. But if you, think coming at it from a place of curiosity, that's just the best way to look at it.

You know, whenever we have people that look at the outside, not knowing what's happening on the inside, it's easy to judge and blame. So I think stepping back, seeking to understand and asking more questions.

I think it's really important too, Lauren, for people to realize that, and we spoke about this in our earlier episodes, is that the diagnostic criteria, meaning it's a clinical diagnosis, there's not one test, is very narrow for PANS and PANDAS.

But it's very common to have brain inflammation from other things. And in our practice, we look at living within the interior of a water damaged building or workplace or school or having an illness that makes a toxin like Borrelia, which is Lyme disease.

And you may not, you or your child may not meet the strict criteria for PANS-PANDAS, but it's a broad category of brain inflammation. really love that you're mentioning that Dr.

So, like, before you go into all of that, because I think what's important to know is at the end of the day, if your child doesn't end up having Pans-Pandas or if it doesn't have that, that doesn't mean they don't have brain inflammation, which will lead to behavioral issues, which will lead to attention deficit disorders, which will lead to all these other things.

So I really love that you're mentioning this is not only are we looking at this very specific. pans pan does and it's like, my child doesn't have it.

Understanding PANS/PANDAS and Other Causes of Brain Inflammation

So it does mean I'm a bad parent. And you're like, no, it means that they could have other sources of brain inflammation. And I really appreciate you mentioning that and taking the time to go that direction.

Is there anything else you'd like to add to that? No, just think that they may not tick the boxes for pandas, but just as you said, it can be other things.

So it's internal pain, it's imbalances of all these things, and you can get better. Yes. Let's talk a little bit about things that people, for people who maybe don't understand compulsive disorder, like obsessive compulsive disorders, or don't understand panic or anxiety attacks.

It feels like sometimes in our culture it says, well then just stop focusing in on it, or stop freaking out about it, or don't fear. And it's so much more than that.

Can you talk a little bit about what's actually happening to the brain and it's not as easy as just stop it when children manifest these symptoms as more of like mental health issues.

I'd like to use pandas as an example. That's pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections. Group A beta hemolytic strep, but there's another case report of group, species of strep.

So what happens with that? There are certain types of immune cells that literally have been traced that migrate up through the nose into a portion of the brain called the basal ganglia.

The basal ganglia is like a command and control center that controls a lot of things or exerts influence on multiple things. For example, obsessions, where you start to think about certain things.

It's biological. It involves dopamine receptors. It involves destruction of something in the brain called tubulin. elevation of certain biological markers, but specifically in strep.

And this is why if a child or an adult that has PANDAS does not have their tonsillar or adenoidal tissue removed, you have this ongoing attack on the basal ganglia in the brain.

And it's like you get better. and then instead of going back to baseline, you're not at baseline, then your next set of strep, you get even worse and you're getting worse and worse and worse and destroying parts of the brain.

So if you've never experienced an obsession, meaning, you know, a simple example would be an earworm, but this is an obsession where you're thinking about something to where it occupies all your thoughts, like tornadoes.

and sharks, and these children say these things over and over and over again. But a compulsion, which also

comes out of neurological and chemical imbalances, is when you have to do something or nothing is right in the world and you have to do it in order to move on.

Like you have to push that door closed and you have to make sure all the doors are locked. and your hands are clean. So back to the whole pandas thing, there is a type of T helper 17 cell, TH 17 cells that have been found in the basal ganglia and they've traced them through the cribriform plate, which is the base of the skull in the front from where you smell.

And so there is evidence to show this attack. And if you don't stop it, you're just going to continue having brain inflammation. Although it can sound really scary and hopeless, it's actually a real encouragement for parents to go, hey, it's not that your child is just not listening to you.

What Happens in OCD, Anxiety, and Panic Symptoms

It's not that they are just being stubborn or defiant. There is something going on in the body. And that is ultimately why we want to decrease inflammation in the body, is to say, hey, we see what is going on by doing tests.

And what we can't see, we study and we look into. we want to ensure that they know that there is hope. And that's kind of what I feel like is really important in transition too, because I think what we've done in the past two episodes is really discuss the severity of this condition and really trying to affirm the things that these parents are going through and these families are going through can be really scary.

And what we want to constantly hear and what I love that you constantly do Dr. is we don't shame here and shame just perpetuates the situation. So what I'd really love to talk about right now is when symptoms flare, when things start moving forward because that will happen, are there any strategies that a parent can use in the moment to stay calm and supportive?

That's an excellent question. Remember that you need to address what's happening from an issue standpoint, not a personal offense. And that's difficult if your child has hurt you or hurt another child.

Look at it like an issue, an issue that you need to overcome. Now, many times when you see a child going off the rails, the first thing I typically hear or my child's not sleeping very well or they're starting to wet or poop their pants or they're explosively angry.

Nobody's sick in the family or somebody else is, but I'm like, you need to test them. You need to determine what's happening. So strategy wise, looking at it, it's like an issue, staying very calm yourself, trying to breathe.

And then one of the tools that we use that works incredibly rapidly is using something called palmitoyl ethanolamide. It's a big long fancy name or PEA.

PEA stabilizes some Pac-Men cells in the brain called microglia. It also stabilizes the microglia of the gut, which are called Kupfer cells. So when I see a child or an adult in a pan's pandas flare, I recommend two to three PEA, three to five times a day.

This has literally taken people from being suicidal to not being suicidal within two to three days. the other thing, because when this is happening, that means there's some type of immunologic attack going on.

I recommend doubling the vitamin D3 plus K2 for a few days, like seven to 14 days, because vitamin D is not really a vitamin. It's called the secosteroid, and it modulates white cells.

It modulates the immune system. using PEA and liquid D3 plus K2, appropriate amounts. The other is liquid, dye-free ibuprofen. Why? Because ibuprofen…

Yes, nonsteroidal anti-inflammatories are hard on the gut, but the beautiful thing about ibuprofen is that it crosses membranes throughout the body and it lowers cytokine levels.

So you should never take ibuprofen more than 14 days because it's hard on the gut, it's hard on the kidneys, but if you use the appropriate amount on the bottle, just some ibuprofen help.

And then lastly, As far as simple strategies, I like to use a liquid turmeric matrix. We have one that's liquid. using that twice a day is also incredibly helpful because it works on a pathway in the body called tumor necrosis factor alpha and then also NF kappa B pathway two.

So it's basically modulating the immune system with all these different tools in the arsenal. So the PEA, the vitamin D3 plus K2, the turmeric matrix.

I think it's super important. because PEA is swallowable, I think it's really important to say like, my child won't swallow capsules. isn't there something that you can do?

Like, can't you open them and how to help people?

Calming Flares and Immediate Support Strategies

Yeah, PEA does not do well in liquid. It's really good to like mix it with some applesauce or maybe some coconut yogurt and use a syringe to try to get that in.

It's so powerful. It also helps with constipation. um Lauren, one of the things that you brought up previously before we kind of segued into what if a child has a flare or is…

breaking down in front of you. One of the other things that I just wanted to bring some light to is that I treated hundreds of children and adults that have circulating autoantibodies to their brain or meet the clinical criteria for PANS-PANDAS.

And still there is a schism of understanding and belief in the medical world. We have pediatric neurologists, ear, nose, and throat doctors, and One of the things that I like to bring to people's attention is that you need to listen into the people with the more experience.

Instead of someone who has a silo, like an ear, nose, and throat doctor, they do the operating. They don't see the patient before and after. So just recently, I was working with a family that has an adult child with autism with severe obsessive compulsive disorder.

It wasn't until we were able to help them understand that there's brain inflammation, not necessarily meeting the strict criteria for PANS-PANDAS, but the definition of insanity is doing the same thing and expecting different results.

So when you know that your child's immune system or adult child or adult's immune system doesn't work like everybody else's, and it doesn't tag the foreign invaders, and the tonsils and the adenoid may not be big, that doesn't mean that there's not disgusting, horrible organisms living inside of them.

So by removing those, you are removing one of the factors that leads to OCD that's severe and impacting the life. So I just had to get that off my chest.

Right. Well, and again, I think the reason why, which is so important and we're trying to understand how to support, and so I do think sometimes that suggestion can feel really invasive, right, and really scary.

Yes. And our hope is to get some interviews of patients who have literally walked through that life and to see that drastic. And so we are not ignoring the fact that saying, get your child's tonsils and anodes out.

It can feel really intimidating and also when you don't understand the connecting dots, it can feel very like, why? They're having behavioral issues and you're like, well get this out and those dots aren't connected.

So I thank you for taking the time to connect those dots. Something exciting is that I'm working with a professor at Texas Children's who is an ENT and we're trying to design a prospective study for hospitals across the nation so that we can gather data, it's prospective, so set it up, have our criteria and show what grows out of these tonsils.

And in our experience, It's these nasty bacteria that survive without oxygen that make toxins that are known to cause brain and body inflammation. So it's exciting to know that that's in progress.

But if you don't have a family member or a child or anyone that kind of meets this criteria, you're just like, this is so freaky and weird. just get over it, you like you were saying about obsessions and compulsions.

Right. So I want to dig a little bit into the school and community component. And if you had either suggestions or places for them to look like for parents who are trying to advocate for their children at school or in like community, external community events, is there anything they can do or look for?

Yes, the Aspire.care website, if you go to the resources tab, there's a drop down menu there and it has school counselor interaction and we've been very grateful here in the Houston area.

The Department of Health and Human Services a few years ago had an online event teaching school nurses. school counselors, diagnosticians to be aware of this.

School Advocacy and Community Resources

And so when we've requested homebound or modifications or 504B and individual educational plans, IEPs and ARDS in the school district, as long as it's documented appropriately and Aspire.care has those resources, there's booklets.

And so many teachers, so many people have never had a panic attack or have struggled with OCD. I really love that you consistently point to this website that has multiple tools.

So if there are things that we didn't cover in this episode, please just take a look at the website because there's more than we could ever cover in an episode to be helpful for you.

So now as we kind of come to a close with this episode, what I really would love to know, as we've said a lot of things, a lot of tips, a lot of helpful, but is what does or maybe the better question is, is remission possible with the PANS/PANDAS Absolutely, yes.

And I hate it when people take an illness and they make their life about it instead of going, I'm a person who's struggling with X, but I am getting better and I am moving out of this.

So absolutely 100%. So one of the things that's observed with pandas is that something happens around pubescence. know, when kids go through puberty, a lot of times the symptoms go away.

That was me. I've had 13 different strep infections up until puberty and just with no description of what my tonsils look like. Well, I'm an old geezer.

I'm 61 years old. But I have my medical records when my daddy was in the Air Force and we moved all over. And I went through there and I'm like, my gosh, not a description.

So it was at adolescence. And I remember as a child, OCD, and it was debilitating. ever, here's the conundrum, if this is not addressed because this is immunologic, for example, you can have ongoing destruction if you don't deal with it, but remission and recovery is completely possible.

One of the things that I'm going to bring out because so many experts don't talk There's a condition called chronic inflammatory response syndrome. I've mentioned this, that sets the stage for a person to be vulnerable to developing PANS-PANDAS.

And so that condition is a biological toxin illness. And if you address it head on, you can indeed move into remission. But remember, this is autoimmune.

When you look at your family, Look at your family history. Is there autoimmunity? Is there ADD? Is there autism? Is there MS, ulcerative colitis, Crohn's disease, Parkinson's, Alzheimer's, autism?

You want to stop the progression of this. And it's just finding someone who believes you using pandasnetwork.org. There's even a place for doctors who've never heard of it, seeing your first patient with pandas.

But it's not just pandas. m all these other things kind of important about what you said though is like, look at your family history. I think a lot of people don't have their family history.

And so I think that can be very hard to be like, well, is it? I've never heard it before. And I think like, I mean, I remember talking to people of all ages who are now finding this out and they're like, well, I feel like I'm the first.

Remission, Hope, and Next Steps

And I said, no, I think there was just a period in time where we didn't know how to address it or we hit it. it within ourselves and like, well, we wouldn't talk about our obsessive-comulsive thoughts or we would keep those behind closed doors.

And I think we're hitting a day and age where those things are more talked about. And so if you're expressing, experiencing this, and I know Dr. K would agree, if you're experiencing all these things and you've never seen it in your family history, that doesn't mean that you aren't the first to be able to take a stand for like, no, my health is important and I deserve to live an optimized life.

like, and I can advocate that for my child. I can advocate that for myself. And so I just, I just wanted to like, I just know we've talked to several patients who are like, they feel like they're the first problem child in their family.

And so just wanted to touch on that. When we think about pans/pandas and brain inflammation, it's all about inflammation. Since we focus on genetic vulnerabilities, if a person wanted to know where to start, I would start with the immune, autoimmune, inflammatory panel that we offer.

um The thing is though, because of the seriousness of PANS-PANDAS, you really do need to partner with someone. so even if you purchased the immune, autoimmune, inflammatory panel, you could just do genetics alone to start.

And that would help you as a parent or as an adult or an adolescent that struggles with this to target the inflammation in your body. And that alone can lower the impact on your daily life.

And just start there. And that shows so many things and gives you so many clues. So if I was picking, that's what I would start with, with Pan's Pandas.

I really appreciate that. Last and final question, and you know, as we are Hope for Healing, I always love ending with hope. What is your final encouragement you would give to parents or people, individuals who are expressing and experiencing this overwhelmed, isolated feeling because of Pans Pandas or even the possibility of having Pans Pandas?

Well, you stated it, there is hope. But I would say now that you've heard about this, it's time to reach out and have someone partner with you. And the best place is looking at aspire.care and then finding someone in your area or state that number one believes you.

And It's always, it starts with the question, I think that my child or I might have this condition. Can you partner with me to help me do that? And if not, find someone else.

And parents are a great resource for directing people to folks that can help you in your community. But remember, Be present and don't move into shame or the guilt that you as a parent may feel like I've done all these bad things because I didn't know.

And you don't know what you don't know, but it's about forgiveness and self-care and self-love and seeking help and letting your kids know that you love them.

getting out on their level, looking them in the eye, even when they lash out or they may seem like they're possessed because so many times the torment that your children are going through, you've completely lost them.

And so that's critical. Absolutely. love that you, one, mentioned the thing that we mentioned, I think, in other episodes is that you have a medical provider here saying she believes you and that you're not crazy.

so looking for a provider that will do that, whatever state that you're in, is that to say, hey, you're not crazy. You're not like this is a real situation and that you find a place of safe, supportive community.

And again, like always, not only do we really love hope, at Hope for Healing. We also love operating grace and giving yourself grace and your children grace.

And so thank you so much, Dr. K, for diving into Pan's Pandas over the past three episodes. And I can't wait to dive into more conversations with you.

Thank you, Lauren. That's a wrap of our Pans Panda series. We hope these conversations have brought you clarity, encouragement, and practical steps forward.

For additional resources and support, check out aspire.care and the links in our show notes. And as always, remember, there is hope for healing.