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

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## Introduction to PANS/PANDAS and Sponsor Message

You're listening to the Get to The Root podcast with Hope for Healing. Today we close out our three-part Pan's Panda 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 Begwan. These tools help us see how an individual's immune systems is wired, where inflammation is not decreased naturally, on what's needed to calm the system, We're grateful for Fuguan 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. This is where we're going to 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 misbehavior or defiance, but as brain inflammation?

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' know, why they lashed out. So instead of saying they're disobedient, they are disrespectful, you have to take a step back and go, well, They don''t like tags in their clothes.

## Why Brain Inflammation Should Not Be Called Misbehavior

They dont want to wear underwear and they Are fearful of a parent leaving the room. That's all about biochemistry and 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 teacher names it as bad behavior, but it's truly something that the child really can't help on the worst of their days, If they're having visual or auditory hallucinations, you're basically 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. So basically you don' want to create shame. Well, yeah, because shame puts this—I think it grows the mindset, right? So it means—grows the mind set 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 panspandas? 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. So you

said this before, Shame. Shame says, I am bad.

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 Bandits 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, oh, I'm just going to 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 and if you, you know, can find other parents, now here's the thing though, it's a two-edged sword.

## Supporting Parents and Reducing Shame

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.

So it's all about framing it for your children. 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 are seeking help. And this is a medical diagnosis.

When you show them the literature and you showed 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 needs. They need move their bodies and get breaks. 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 kinda mentioned this with the Aspire website, is do you think that's a really good way of having those conversations?

Whether that'd 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' attack me. But if you, I think coming at it from a place of curiosity, that's just the best way to look at 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 is a clinical diagnosis, there's not one test, it 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. So I really love that you're mentioning that Dr.

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

## Understanding PANS/PANDAS Symptoms and Brain Inflammation

So I really love that you're mentioning this is not only are we looking at this very specific pans-pandas and it's like, oh, my child doesn't have it, so it does mean I'm a bad parent.

And you are like no, it means that they could have other sources of brain inflammation. I appreciate you mentioning that and taking the time to go that direction.

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

So it's internal pain, its 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' 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 is not as easy as just to 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, another species of streps.

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 basally ganglion is like a command and control center that controls a lot of things or has 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 tonsil 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 getting worse, and worse.

and destroying parts of the Brain. If you've never experienced an obsession, meaning, you know, a simple example would be an earworm, but this is an obsessive 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 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 in order to move on.

Like you have to push that door closed and you 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 front from where you smell.

And so there is evidence to show this attack. If you don't stop it, you're just going to continue having brain inflammation. Right. Though 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.

It is not 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 body is to say, Hey, we see what is going by doing tests and what we can't see we study and we look into, and so 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 to really discuss the severity of this condition and really trying to affirm the things that these parents are going through and these families are go through can be really scary.

And what we want to constantly hear and what I love that you constantly do Dr. Shay is we don't shame here and like 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 an issue that you need to overcome.

## Managing Flares and Practical Treatment Tools

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 their explosively angry, nobody's sick in the family or somebody else is, but I'm like, you to test them.

You need 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 palmitawil ethanolamide.

It's a big, long, fancy name, or PEA. PEA stabilizes some Pac-Men cells in the brain called microglia. It also stabilises the micro glia of the gut, which are called Kupfer cells.

So when I see a child or an adult in a pand 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 suicide within two or three days.

That's incredible. 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 7 to 14 days because vitamin d is not really a vitamin.

It's called the secosteroid and it modulates white cells and modulate the immune system. PEA and liquid D3 plus K2 appropriate amounts. The other is liquid dye-free ibuprofen.

Why? Because ibipropen, yes, non-steroidal anti-inflammatories are hard on the gut, but the beautiful thing about ibeproben 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 is hard in the kidneys, but if

you use the appropriate amount on a bottle, just some ibiprofene help.

And then lastly, as far as simple strategies, I like to use a liquid turmeric matrix. We have one that's liquid. And 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 So, it's basically modulating the immune system with all these different tools in the arsenal.

So the PEA, the vitamin D3 plus K2, and the turmeric matrix. And did I say something else? I can't remember. We'll pull it all. All of it will be in the links.

But no, I think it's super important. And because PEA is swallowable, it is really important to say, my child won't swallow capsules. Isn't there something that you can do?

Can't you open them and how to help people? 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. Also helps with constipation. 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 other things 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 adults' immune systems doesn't work like everybody else's and it doesn' t tag the foreign invaders and the tonsils and 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.

No, right. Well, and again, I think the reason why, which is so important, we're trying to understand how to support.

## School Advocacy and Community Support

And so I do think sometimes that suggestion can feel really invasive 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.

So we are not ignoring the fact that saying, hey, get your child's tonsils and adenoids out. It can feel really intimidating. Also, when you don't understand the connecting dots, it can very like, why?

they're having behavioral issues and you're like, we'll get this out and those dots aren't connected. So I thank you for taking the time to connect those.

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 is exciting to know that that's in progress. 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 know, 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.

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 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 is more than we could ever cover 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, has we've said a lot of things, a lots of tips, lot helpful, but is what does, or maybe the better question is, is remission possible?

Absolutely. 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 You 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 puperty and just with no description of what my tonsils look like. Well, I'm an old geezer, and I am 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, like, oh my gosh, not a description.

So it was at adolescence. and it was debilitating. However, here's the conundrum. If this is not addressed because this 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.

## Remission, Recovery, and Hope for Families

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. If you address it head on, you can indeed move into remission. But remember, this is autoimmune. When you look at your family history, is there autoimmunity, ADD, autism, MS, ulcerative colitis, Crohn's disease, Parkinson's, Alzheimer's?

Autism. You want to stop the progression of this. 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, it is all these other things.

Yeah. I think what's kind of important about what you said though is like, oh, look at your 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 remember talking to people of all ages who are now finding this out. They're like well I feel like I'm the first. I said no, I just think there was a period in time where we didn't know how to address it or we hid it within ourselves.

We wouldn't talk about our obsessive-comulsive thoughts or keep this behind closed doors. 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 your 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 cannot advocate for myself. And so I just, I wanted to like, we've talked to several patients who are like they feel like their the first problem child in their family.

Just wanted to touch on that. When we think about pans, pandas and brain inflammation, it's all about inflammation. So 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.

The thing is, though, because of the seriousness of Pan's Pandas, you really do need to partner with someone. And 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. That alone can lower The 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 pants 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' know what you do know, but it's about forgiveness and self-care and love and seeking help and letting your kids know that love them, getting 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. I 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 your not crazy.

And so looking for a provider that will do that whatever state that 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.

Thank you so much Dr. K for diving into Pan's Pandas with us over the past three episodes. 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.