Unraveling The Mystery: Infection, Immunity And Neuroinflammation In PANS/PANDAS Transcript

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Introduction to PANS and PANDAS

Welcome back to ADHD, Autism and Chronic Disease Parenting Summit. I'm here with the fantastic doctor Scott Antoine. Also the author of the Comprehensive Physicians Guide to Management of Pans and Pandas.

He is an expert in pans and pandas. If you have never heard of it, we are going to learn all about it today. It's something that I see a lot more in my practice and a lot more parents are concerned about it, so I'm excited to chat about it. Thank you for being here.

Thank you so much. I'm glad to be here. Awesome. So this is a topic which is a is a little bit near and dear to me because patients more and more in my office come in.

Their concern. And they've had strep throat or some other infection and they've had some neurological complications, or they're worried that, you know, they googled pans and pandas are like, oh my goodness, you know, maybe this is what happened to my kid.

Maybe this is why they're having their behavioral issues. So I'm excited to kind of clarify what people should be looking for and what it is. So let's just start very basically, so what is what is pans and pandas?

Sure. Be glad to help. So, some children when they get infections. It was first described in the early 90s with strep. After getting strep, there were a subset of children who had developed severe sudden like overnight OCD.

Handwashing, repetitive questioning, religious OCD, quite, quite a few different presentations we can talk about. But, they would also have severe separation anxiety.

And these were kids that didn't really have these issues previous to to getting these infections. Several years later, we learned that can happen with other infections as well.

And how it how it happens is, you know, normally when you get an infection, your immune system should rise to the occasion and beat, beat that infection down.

What PANS and PANDAS Are

But what we were seeing in these kids was the antibodies their body was making to fight the strep bacteria or other bacteria, would cross the blood brain barrier, this sort of selective filter, and get into the brain and attack a very specific part of their brain called the basal ganglia.

And it would produce a very characteristic set of symptoms, I'm sure, as you know, in your practice, I always say when you see a child with pins and pandas, they present very similarly.

It's typically a very similar story. These kids also can have, issues with losing bowel control or bladder control. Typically, they will begin wetting the bed out of nowhere.

They can also have issues with deterioration in school performance and regressive behavior. So they may start baby talking again, or finger painting, or doing things that are just a lot less mature than you're used to, used to seeing.

And then, of course, people talk about defiance being part of the criteria for pens and pandas. And I always object to that one a little bit, because I tell parents what you're likely seeing if you have a child that's being defiant is that

they're scared.

They're scared to death about what you're asking them to do, or they have some intrusive thought about it that they just haven't shared with you. And it can look a lot like, you know, disobedience for disobedience sake.

And it's just not. Yeah. And I think it's a very interesting time in this field because even, you know, I'm not I'm not that old or I haven't been in like practice for that long.

But when I started it was kind of woo woo style pans and pandas. It was like, you know, you're pretty out there, you know, maybe with a strep throat in certain cases that was kind of legitimate.

But but now it's like you know, even in our area there's like the Stanford pins and and pandas lab, like there are major centers that are looking at this.

I think it's pretty well accepted at this point, certainly for, for strep. And pandas. And I think it's becoming more and more, accepted or panned. But I just think it's interesting that we never thought about this for a long time.

And now, you know, it's pretty pretty. I mean, I've seen it, right? I mean, you've obviously seen it many times, but there's no question that it's happening.

There's no question that that there are certain kids that are affected by it. But I think one of the the biggest questions, one of the biggest difficulties is there are so many things going on in the world.

There's so many reasons where kids are having chronic issues. There's so many, factors that are in play with kids, mental health and OCD and behaviors.

And it's certainly not an infection, you know, a good chunk of the time. So how do parents kind of differentiate between your regular old toddler, you know, misbehaving tantrums, issues with OCD or like, not necessarily OCD, but like those kind of behaviors versus is where they should be concerned.

They feel like they should get some laboratory workup and they should talk to their doctor about something like panda pandas like that. That to me is always a, a a difficult.

Well, not always something is very clear, but usually it's difficult. It can be. Right. So now that, you know, in our office, we get quite a few calls, right?

And a lot of the calls we get are from desperate parents who would like to know if what's going on with their child is pans and pandas. And it's difficult because there are the clear cut cases.

In the case of my daughter, where she came to us literally overnight with cracking dry hands from washing them 100 times a day, and screaming and, you know, defiance, if you want to call it that, separation anxiety.

She just literally changed within maybe a week. But there are other cases about 40% of the time where it happens gradually so it can be more difficult to spot.

I would say parents are saying this with a grain of salt, but it's kind of true. Parents are better at diagnosing this than physicians are. A lot of times, I can't tell you how many parents have come to me who were they've investigated.

They found out about pins and pandas, and they've talked to their doctor about it and sort of gotten what you had talked about earlier, kind of gotten the stonewall, because there are places and people that just don't, just don't believe in it.

It's unfortunate. You know, we've known about neuropsychiatric changes after infections since most people, if they've read the literature, would say, well, about 1994 was the first article from the National Institute of Health.

Actually, there was an article in 1926, about children who had very similar presentations after the Great Flu of 1918, and it was published by a guy named Vonnie Kahneman.

He called it, lethargic encephalitis. And so that's this has been happening the whole time. And unfortunately, when we, when we when we saw it at that time, no one knew you know, no one knew about it.

And, so a lot of those children were either, put into the criminal court system. Some of them were, pushed out of their homes, some were, had lobotomies, unfortunately, was terrible time, for medicine.

And then the word went quiet for many years.

Recognizing Symptoms and Sudden Behavioral Changes

And then, of course, in 94, we started talking about it. So it can be difficult when you get a clear cut case, OCD, anxiety, bedwetting, regression in, behavior and school performance changes.

You say, oh, that's obvious. Other times are harder to tell. So it really comes down to getting the all the information you can, looking at your child, looking for changes and sort of, the behaviors these children are having or out of terror, OCD, intrusive thoughts come from the subconscious mind.

They are, irrational. I always tell parents there's thoughts that come with OCD, and the connections these kids made are very irrational sounding. So they they will make connections between things.

And I had a girl just yesterday, I was seeing and her mom said if they're driving in, someone in a car next to them sneezes, all the windows are closed, and her daughter will say, am I going to get sick?

So I always tell parents, I said, subconscious part of your brain. So usually parents will get an idea there's something going on that I can't explain.

It seems really irrational. It's a rational behavior because we've all had. I have five children. We've all had a child. And you deny them, treat or you deny them, or suddenly change their plans and they kind of lose it a little bit, but usually they're fairly reasonable to a degree.

They may have their tantrum on the ground, but these kids, when they get triggered, will, I mean, they will scream for hours until they are hoarse. They will break things.

The behavior is very aggressive. Most parents will use the term rage. So it's rage filled behavior. And we do see it in children with other neuropsychiatric conditions.

So sometimes you will see a child, for example, with autism who's had behavioral differences, you know, neurodivergent since they were young. But suddenly they develop self-injury or what looks like, you know, what looks like OCD.

And that's really the difference. The difference is that it's a a sudden change. And, the change is really it's remarkable. So it's hard to chart a mistake.

Yeah. And you know, of course, with, with especially someone like Panda Pandas, it's very individualistic. There's not any one specific way to go about things.

It's not gonna usually be obvious, like, like you mentioned. So you know, working with a practitioner that knows more about Pans and Pandas is certainly going to be the the most important step for any of those more complicated cases.

But in in the first steps for a parent, I would say if they're worried about this, they have seen some of the things that you said. Maybe it's not 100% clear cut, but they have most of those things.

They go talk to their doctor. Their is not, you know, super old school. And they're like, yeah, you know, I, I could see that being a possibility. What what do you recommend for that parent or the idea of a physician to start with in terms of a little bit of workup?

You know, maybe if they're not sure, they'll send you after. But I think, you know, for me, it's like you can do some strep testing. You can do some some lab testing, but every kid gets sick.

So where do you start? And then how do you tell between like, oh, my kid had strep throat a year ago. Yeah. Well, every kid had stripper, you know, they got a cold or whatever.

Like there's no kids aren't sick. So how do you start that process? So the diagnosis is all a clinical diagnosis, right. It doesn't require, as you know, on any type of letter to prove it or confirm it or whatever.

So it's a clinical it's clinical criteria. For parents that have questions about that, I typically would direct them, to our website, fully functional.com.

And we have tons of articles and blogs about what it looks like in your child, where the workup starts, who you should see, how you find someone that kind of knows what they're doing in terms of a workup.

What I tell parents is I basically tell them there's four things you have to conquer. If you're conquering pans and pandas, you've got to find and treat infections.

You've gotta find and remove toxins. You have to restore the immune system to write a regulation so that it's acting normally. Because these children, you know, to have your immune system suddenly send antibodies across your blood brain barrier to attack your brain, that's signs of a dysregulated or abnormal immune response.

So you've got to restore that, or you'll have a child that every time they get the sniffles, they get sick. And then lastly, work on neurologic loops, which are OCD behaviors with things like exposure response or cognitive behavioral therapy.

But when we talk about testing, when we see them, obviously we we do a long intake process and then do an in-person physical exam, which I think is vital.

And then we end up typically ordering testing. So what are we looking for? So, you know, one of the hallmarks that I always tell people is there's this list of things clinically that you use to to say, oh yes, this with high probability, this child has pens or pandas, but there's also a little asterisk at the bottom of those criteria.

And I talk about that in my book, which is not better explained by something else, by some other neurologic abnormality. So one of the big things I stress to people is the performance of a neurologic exam.

In other words, children with, with pens and pandas data, they don't become lethargic. They don't they're not altered. They don't have an altered mental status where they're sort of delirious.

That's not pens and pandas. That child needs an emergent workup. So there are times, if we have doubts, if there's a strangeness to the neurologic exam, we may do an MRI, or other testing.

Typically, testing starts with the simple things, blood count, chemistry, just to look for other abnormalities or kidney problems. And then we do tests for infections. So how do you do that.

So you mentioned, you know, you can do a throat swab or, swab, around the anal area if you think that they have anal strep, you can do swabs in those areas to look for active strep infection.

Clinical Evaluation and Diagnostic Testing

If a child is not symptomatic, sometimes it's not. In other words, they don't have a sore throat or a red looking throat

on my exam. I don't typically do a throat culture. It's not quite worth the fight.

And that's trauma to the child in the parents because you're trying, as you know, pediatrician, to hold them down. So, we do antibodies typically Aso and anti DNA, say antibodies to look for antibodies to strep.

Now as you know aso an anti DNA antibodies rise a week or two after a strep infection and then go down typically a month or two after. So one of the problems I've seen is patients will go to their doctor's office and they will say, I'm worried my child has pandas.

The doctor will do a throat swab and or aso an annotated DNA so they will be negative. They say, great news now, pandas. Those are negative. But in reality, pans and pandas are very similar to rheumatic fever where you have the infection and typically the symptoms are weeks, two months later.

And so you may have missed the time when the strep those strep antibodies are positive. So yes we test those. We test for other infections I would say of all the kids with pans and pandas we see strep may be the minority of the infectious causes is strange, but we see a lot of children get it from mycoplasma.

Common respiratory bug. We've all had mycoplasma, but mycoplasma can is well described in the medical literature to cause OCD and other neurologic abnormalities.

And as a matter of fact, if you go to a person who's really sick with mycoplasma and they have brain involvement called encephalitis, they all have anti neuronal antibodies very similar to what we see from strep in kids with pandas.

So we test for mycoplasma. And then we also test for other less known infections probably Epstein-Barr has been linked to neuropsychiatric issues. Toxoplasma is a type of a parasite that's been linked to neuropsychiatric, conditions.

In fact, very strong, but a 900%, increased risk of schizophrenia if people have Toxoplasma antibodies. You can see Toxoplasma, in cat feces, also in the soil and in certain rural environments.

It's not common. So don't get rid of your cats. But, we also test for tick borne illnesses. So things like Lyme disease and Bartonella, but those are all, infections.

People don't think of very commonly. But I can tell you right now in the Midwest, we are seeing a ton of children with infections from the busier down Connie, which is a tick borne infection.

And, it tends to cause a lot of eating restrictions. So one of the other criteria these children will develop is eating restriction. They will say they feel like they're choking or they're just not hungry.

A lot of times that comes with weight loss. Some of them will be diagnosed with, avoidant restrictive food intake disorder. Hartford, sometimes end up in the hospital with feeding tubes and it can be quite severe.

But the two organisms we found associated with that are Mycoplasma and Berbizier than Connie. And so fortunately they those things respond to antibiotics and herbal treatments and things.

So those are some of the infectious things we test. What makes the, the, the, immune system not quite work, right? Typically, one of the big things we see in our practice are mycotoxins from mold exposures.

And so, people can be exposed to mold in their homes and in school and their workplace. And mold, we know from the medical literature, will dis regulate the immune system.

It just makes it not quite work. Right. In fact, what it does, I tell people, your immune system is kind of like, kind of like a, a car. It should be kind of idling like a dial.

And then if you get infected with something, it should, you know, be able to turn up the heat, and deal with that infection and then come right back down to idling and waiting in these kids.

We see, obviously, the autoimmune attack on the brain is their immune system on overdrive. But at other times you'll measure and they don't have antibodies to vaccines they may have gotten or, they seem to get sick more often.

Or when you measure, something called immune globulin in their blood flow. So they have a relative immune deficiency. So it's this issue of, you know, wonkiness of the immune system.

So we will test for urine mycotoxins. We also look for heavy metals which can disrupt the immune system. We test for nutrients. We look for I'm trying to think what else for.

We also look for autoimmune markers so that 50% of these children will have a positive anti-nuclear antibody and a for short. We say a and a, it's basically an indication that you've got antibodies against the, the centers of the cells in your body, the nucleus of the cells in your body.

We see positive antinuclear antibody tests in people with things like lupus or scleroderma, these autoimmune conditions, just because you have an elevated DNA doesn't mean you have those things.

But it's it's the type of things we might see. Those in it are 50% of these kids will have it. We also will test for celiac. You can have neuropsychiatric changes from celiac.

We also do tests to look for autoimmune encephalitis of other types. So there are a whole host of, different types of antibodies you can make to your brain.

And some of them require different treatments than pans or pandas might. So we test, we test out those things as well. That's great. And, you know, I like to finish off, with, with positivity always and kind of the outlook on things.

And I'll just say, you know, in my practice, certainly I see some patients that come in with these concerns. I'll do sometimes the the beginning workup.

But, you know, as you mentioned, it can be pretty complex. And, and I even, even personally as an integrative doctor, I still feel like working with someone who's a specialist in pans and pandas, you know, when someone's going through it can be very helpful because it's so complex and there's so many different, issues that can come, so many different tests like that can be very reasonable, but at least from what I've seen, and I'm curious, from what you've seen, the outcomes are usually pretty good.

So I feel like, you know, parents, when they're when they're concerned, if they do work with, a really great practitioner over time and they can identify what some of the issues are and they can can work to, to resolve some of those issues and move in a much better direction.

But I'm curious, you know, you're probably seeing some of the most severe I would guess people are coming to you, you know, as a last resort, a lot of the times they've already been through their practitioner, maybe some other places. And and how are you finding things when you're working with kids over the years?

Are you finding that, you know, obviously not everybody, but a good chunk of them. Once you can figure out what's going on, do better, they do. And so one of the sometimes people will ask me if I'm on a podcast or talking or lecturing.

They'll say, what's one thing you want parents to know? And one, the one thing I will. I always say, is that I want them to know that these this is not doesn't have to be permanent.

You know, there's no guarantees in life. But we've seen such remarkable recoveries. I really think it's because, you know, we look at the cause of immune dysregulation.

We work on fixing that court, removing the clause, treating the infection. And we treat the infection both with with antibiotics and herbals and also with biofilm disruption.

We also emphasize parents working on skills that they can give their child, to do some exposure response at home. That's not as painful for the child as if they were to go someplace and do what we always recommend.

They have a counselor, but there are lots of things parents can do. But if you've restored the immune system to normal, function, if you've removed toxins, if you've treated the infections and you've done some things to break these neurological loop behaviors like OCD, there's no reason to think every time your child gets sick that they're going to flare again.

And I love support and I love support groups, but sometimes online support groups will kind of tell parents, well, you know, once your child has pans or pandas, they're just going to always have it.

And every time they get sick and this is the way it is, and they will even say, like my pans or pan is child, and I always say or don't describe them that way.

They're just a child with an illness. They're not an ill child. And, it's one of the messages I give to the kids when they come. Look, you're not broken.

Your body just doesn't feel safe and OCD is about trying to make your body feel safe. You start making rules because you feel unsafe, and that's what OCD does.

So I tell these children and also OCD is a character positive character trait.

Treatment, Recovery, and Hope

People with OCD are very sensitive. They're very receptive and observant of things around them. So they make really good health care workers, pilots, people that kind of can't make a mistake because they pay really good attention to things.

So I guess that's what I would say is that, yes, there's lots of hope, there's lots of healing. One of the aims of the book that I wrote was, you know, and I started writing it to parents, and I got about halfway through and I thought, this is kind of silly because parents came to me and they all had the diagnosis.

They knew what it was, even if they were being told, that's not what it is. They were right. I never I don't think I've ever had a parent come to me that said, I know my child is pain.

As I said, no, you're absolutely wrong. So I felt like, who needs to hear this is other physicians. And, you know, and I always say, I wrote this book is a love letter to medicine.

The idea that, look, I didn't know about this, like you said. I mean, I trained 30 years ago in emergency medicine. Never heard about anything like this.

Even I was in residency when all the articles came out. I never heard about it, never heard about it in practice. And when my own daughter got it ten years ago, 12 years ago, I still had no idea what it was.

My wife, who's also a physician, we were searching, searching, searching. She found some things, gave me an article, and I looked at and said, oh my gosh, this is what Emma has still couldn't get help where we were and we had to go elsewhere for that.

So yes, there's hope, yes there's healing. You just need to find someone who's systematic about it. And I always tell parents if someone, anyone gives me, if someone's telling you something that just doesn't make sense just about your child, then ask more questions.

And if you still don't feel satisfied, go somewhere else. It's it's your right. It's your prerogative. No one is. You know, people, some may have more specialized knowledge about a topic than a parent might, but parents are pretty smart, so they're usually right.

So I agree. And I think it's, you know, just from personal experience of this, this is one of the few areas where I tell people to travel. I say, you know what? Like this is worth it.

You know, there are not that many people in any state or even in the country that really know this very well. But if you get with the right person, then there's a very good chance that things are going to go in a better direction and you know, I never lie to parents.

That's not going to be cheap. Most people, it's it's a very extensive workup. You're going to be in office for about, you know, an hour, a couple hours.

You're going to be multiple visits. I mean, a lot of places. I don't know how you do it. But a lot of the places that I send people to, I have actually told people about you before, too, but, you know, you're farther away from where?

From where we are in terms of the travel. But then a lot of times they'll go there for a couple visits or a couple weeks in, and then a lot of the other stuff they can do by by telemedicine and go back every, every now and again.

But it's a long haul. It's something that you have to commit to, but I think it's very worth it. And I've seen super great results with, with people going to a practitioner such as yourself, that, that do this kind of every day.

So I think it's a very amazing thing what you're doing. I wish every physician knew it a little bit more. I wish the medical system would support, you know, what, you do a little bit more.

It'd be a lot easier for regular, you know, regular doctors to do some of these workups. It's not that easy. I think people need to also get that, that, you know, a lot of testing it is not going to be covered.

But it doesn't mean it's not worthwhile. It really is. It's just you have to kind of go outside a little bit and hopefully one day medicine will catch back up.

I certainly hope so. I think it's, it's I people always ask me, why is it so controversial? I think that, it forces you to look at mental illness an entirely new way, which ends up being a little terrifying.

Which is, what if people don't just sort of have a genetic risk and like accidentally develop bipolar disorder? Like, what if there are other things behind it or OCD or anxiety or panic attacks, like, what if there are things that we can correct about it?

And so that's really where I've and you know, my my practice now is branching into the, realm of kind of working with those neurologic loops. And so I've been doing hypnosis with patients in the office and neuro linguistic programing and other things to help with some of those stuck points, because sometimes when you've treated the infections, remove the toxins reregulate the immune system.

Boy, some OCD can become really habitual. And when people say I don't get that, I don't or that wouldn't be me, I'm like, okay, when you wake up tomorrow, try and put your pants on with the opposite leg that he usually do and see how that feels.

Now multiply that feeling by a thousand, or think about someone dumping ice down your back and imagine that. And that's what OCD feels like. So I, I completely agree.

I think that we do need to open up our eyes to this being a possibility, because I would I would also agree that probably a fair amount of of many of the things that we're seeing to increase, whether it's ADHD, autism, mental health conditions or not, all but have some aspect where for some people there is some sort of neuroinflammation that's virally induced or toxin induced or whatever.

And and there are things that we can do to help move things in a better direction, just like you see with pans and pandas, just like some practitioners who work with autism, see, with autism, not every time.

There's so many different reasons and causative factors, but we need to rethink the underlying ideology of a lot of this, because I think if we did, if we were open to it, then we would have a lot better success rate, but it opens up the door, I think, to the blame game of like, well, what did I do?

What what, what happened? What could you have done differently? And until people are willing to allow that, until they're willing to be like, well, you know what, maybe the water that I was drinking was toxic.

And that's why my kid got, you know, X, Y, or Z.

Finding Specialized Care and Closing Thoughts

We don't do that. Then we're never going to resolve the problem, make it better for kids. So yeah, I, I agree with that. Yeah, absolutely. 100%. Well, thank you for sharing your wisdom.

Before we go, can you tell people you know where to find you, your website if they want to work with you? All that good stuff. Sure. We are in Carmel, Indiana, right just north of Indianapolis.

Our website is, fully functional.com. You can find us on Instagram at the Panda's docs and also on Facebook at the pandas docs. If you'd like to, check in with us and see what we're about, or give us a call or work with us, we require our first visit to be in person so we can do a good physical exam.

We typically actually do our intake. I'll get on the phone for between an hour or an hour and a half, with parents initially. And then they come in our office and we will do a nutrition and physical exam and then, outline the plan with them, take bloodwork and things.

And that's sort of our process. Follow ups after that typically are, via telemedicine. We do require people to come once a year, but, a lot of times kids are a lot better by then.

So it's, too many repeat year long customers that we see. Which is a good thing. I mean, it's not a good business model. You know, if you do a good job, right, it's like you you get them better, they go.

But that's what our that's what our goal is. At the end of the day. I think the consultant. Right. Yeah. I'm always like if I have nobody to see then that's great.

I'm okay with that. I'll go out of business, I'll be poor. It's fine. But yeah, thank you for being here. Thank you for sharing your wisdom. Thank you for all that you do for for kids.

There's not enough of you out there. And I said this a few times on this summit, but, like, we need 50 of you, you know, so one yourself. And I think it'll be much better for the.

What I do at the book. But thank you so much for having me. Thank you.