When Autism Symptoms Change: What Parents Should Know About PANS/PANDAS Transcript

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Introduction to MAPS Webinar Series

So I see kids, you know, hitting their head. Well, does her head hurt? You know? They're taking and they're like pressing their stomach on things because their are stomach hurt.

You now, or their frustration, they are biting themselves. It's like something is acutely bothering them. And then thinking about an infection, thinking all the GI issues and the microbiome, like what's going on?

Even kids who don't have digestive symptoms can have an admiral microbiom. So you dont always know. Hi, welcome to the MAPS webinar series, Healing Tomorrow's Future.

We are thrilled to be bringing you this series packed with valuable information and education within our community. My name is Honey Rinusella and I'm the Executive Director of MAPPS, the Medical Academy of Pediatrics and Special Needs.

Within these webinars, we're able to empower clinicians on the knowledge and tools to support patients facing a variety of health challenges.

Dr. Debbie Hamiltonu2019s Background

For more information on MAPS or to register for a conference, please visit us at www.medmaps.org. Thanks for joining us on this journey towards a brighter, healthier future.

Welcome to the Maps Podcast. I am extremely excited to have Dr. Debbie Hamilton here with us. And Debbie, why don't you tell us a little bit about yourself?

Sure. So I'm a pediatrician by training, did general pediatrics, and then did research nutrition. But I've been doing integrative pedics for 20 years.

A long time. Long time, yes. We're here at the MAPS conference, you gave three case studies yesterday. Can you tell us a little bit about those case study and maybe what inspired you to talk about that and share that with the other clinicians in the room?

So I presented on children who have autism who then develop PANS, PANDAS. And PANs, Pandas is an autoimmune neurologic issues. They present with really severe behavioral issues, like right over the top.

Autism, PANS, and PANDAS Case Studies

It's an Autoimmune issue. So, I had two children with autism, who had really Severe Pans, Pandas. One of them, they actually can be from Lyme disease. But this child, one of my most severe children with autism, is doing IVIG and we did antibiotics and herbs and everything that we usually do with these children.

And I had another child with PANS who did all the things, went to Children's Hospital had plasmapheresis, the labs completely normalized this child recovered.

And it was amazing. I'm like, this would be a perfect child to send to a children's hospital. So I sent him and the neurologist like oh, he has autism so he can't have his pants pandas.

This child had positive neurologic antibodies, positive thyroid antibodies. A lot of autoimmune disease. That doesn't

make any sense. And before I knew that, I'd sent another patient for the same thing, and they were told the Same thing.

Like, autism, you can't have pan-spandas. So I'm like, this makes no sense. If you know children with autism their immune system is not working. They have autoimmune disease, which just means that the body is actually attacking itself.

And if it's attacking parts of the brain that involve behavior, you get really severe behavior. And we know children with autism have that behavior but if all of a sudden they're worsening and there's like a consistent pattern of worsened behavior we need to think about it.

Absolutely. But things aren't always what they seem. I mean, there are probably parents listening with children, with Autism, and children can expand those.

Sometimes it is really hard to distinguish. So I spoke on three different cases. The first was a child with autism, diagnosed early in life, abrupt change six months.

This child was suddenly wetting the bed, suddenly had to eat food off the table, couldn't have food on the plate. You know, a lot of restrictive eating issues, which are common.

severe regression, aggression, a lot of behavior. He was actually going peeing on the floor. My mom's like, this is really not him. And so came to me and I'm like yeah, his pants pain does.

Of course, parents are very educated. She's, like that's what I thought. I am like all the symptoms, just classic. So we treated him, he did great. Great.

Really great. So then at some point, maybe a year later, he started developing like flares and regressions, and he's doing humming. He's like chattering his teeth.

It's a little bit different. We switched things around and didn't get better. Then mom noticed something in his tooth. he got his teetfolds fine. Absolutely, because we know that dental issues or anything that involves the oral microbiome can absolutely cause a flare in our children.

Right. And so that was kind of something that I think people don't think of with panspamas. So I wanted to do that case because it seemed to me so clear cut.

Absolutely. Then even thinking about this child had some Borrelia, Bartonella, and he did great. But then the dental fiction, when they flare, you have to think as something else.

Yes. That was one case. Another one was a child who was referred to me for pants pandas, really for prescription antibiotics and all these things. Had it complicated, some kind of learning issues, and initially did really well.

We treated, did initially really, well and then over the years kind went off and on. She came in with a list of medications that she was on for a lot of emotional issues.

So it wasn't as clear cut. And then throughout the period, at some point she's actually diagnosed with autism. And so she was like later diagnosis. And I think girls are sometimes harder to diagnose.

Right. So it was kind of like, was it really, really pants pandas? And when we finally got the Lyme test, totally negative, frat tested negative but she's diagnosed with autism.

And for me, it was like, well, if I had known that initially, I would have addressed things differently and thought about all the other things that might be going on.

Distinguishing PANS from Autism Symptoms

And we looked at gut stuff, but so it's kind of, okay, you know, sometimes to pretend with autism and not have PANS, and this is a child presented with Pans, who really had underlying autism.

I think that's such a valid point that you make there, right? Because with Pants and Pandas, we can see children have autism-like symptoms, but this is a case perhaps where a child did have underlying autism, was not diagnosed properly until they were later on.

And then it's just interesting how your treatment plan would change. So with that, do you treat a child who has autism differently if they also have pans and pandas versus just a Child that just has pans or pandAS?

Well, I think with autism you're thinking like I always want to make sure I mean with both kids you have to address the gut and You know the diet and nutrition you always address that and With autism, like, oh, I would think more about, well, let's look at mitochondria issues and maybe look a thyroid, maybe we look other autoimmune issues, other metabolic issues.

I'm more likely to do an organic acid test or the whole toxin, thinking about that, or detox. Although with your talk, you're talking about all the other causes of Pans-Pandas, which can be toxins and molds.

So in some ways, and again, kind of learning, we probably really need to look at a lot of these factors the same and show autism as Pants-pandAS. Absolutely, and I also see when you talk about the gut, right, with children with pans and pandas, is the treatment is prophylactic or long-term antibiotics, which is going to impact the guts.

And so children, I feel like who have these like constant flares, who don't have the relapsing and remitting pattern that we would typically see with Pans and Pandas.

Yeast could be one of the issues there. And we know children with autism, their microbiome is just different and they are more susceptible to yeast. So it's just interesting.

They end up having similar presentations where my treatment and workup actually looks pretty similar between a child with Autism and a Child with Pans and Pandas now, because there is a lot of overlap.

Yeah. That was kind of my learning curve in that one, cause it was five, six years and the mom would disappear for like a year or so. and then come back.

And so it was kind of learning that you really do, as I said, need to really look at some of the same things, because there's underlying, you know, immune dysfunction, underlying gut stuff that are going to address anyway, if ultimately they're going get better, not just treating the infection, which is what we need And a lot of the symptoms for PANS and PANDAS, there is overlap for a child with autism.

So how would you advise parents to kind of be thinking about Pans and Pandas and not just being set of like, this is autism, these are symptoms of autism or even providers telling them, you know, if they bring up concerns, their pediatrician saying, well, they have autism?

Right, right. I think sometimes you get an exposure history for in terms of, hey, a month ago, They had like a big respiratory infection, and then things change.

And I think with the Pan's Pandas, it's that abrupt change, right? And, I that's the classic thing. They have some behavior issues, then all of a sudden things got worse.

Right. Consistently worse, some children with autism, they have a bad day or bad week, you know, kind of waxes and wanes. But all of a sudden it's like they're worse and they stayed every day was more severe.

And then things like the handwriting regressed or the eating disorders, some of the restrictive eating disorder is a big sign. All of sudden new bedwetting, you now, definitely a lot of OCD behavior.

So I think it does. It's the change, the consistent and the severity. And so, you know, at least what I see in my practice is my children with autism, yes, they can present with OCD and anxiety, but it's a change in that, right?

It's like a worsening, abrupt onset where it is like they're different. This is out of character for them. Right, and consistently out-of-character. Yes, absolutely.

And even with the aggression that you might see, in a child who has autism but later you treat them and you evaluate them, then you find out they have pan-spandas, if they had aggression, What are some of the things that you're looking for to rule out in that child?

If they have aggression, usually it's aggression but other symptoms.

Pain, Behavior Clues, and Infection Triggers

Like I said, some OCD, yeah. Some of characteristic ones, all of a sudden they won't let mom go. You know, so it is aggression plus other things. Yes.

I think I rarely see just aggression. And as I said, usually with kids' autism, as you see that kind of waxing and waning, but if it's kind consistent with other symptoms, especially the OCD things, all of a sudden they're eating like, I mean, children with autism they are always eating three foods, and all the sudden, they do strange things with the food, or the foods can't touch, you know, it is the change.

And something I see, you know, I don't know if you see this in practice with the change in the food and the eating is it's also like their preferences change too.

Like all of a sudden they might become vegetarian or something interesting. And we like accept that as just like, oh, maybe it is like a moral thing for them.

But actually I think it a form of restrictive eating for some of our kids that is more acceptable. But when I see the aggression, too, in a child with autism, you know, I'm also thinking about, like, what type of infections, right?

Because… What's bothering them? What do they have pain? Yes. Well, absolutely. And when you think about pain, where do you, encourage parents to check out?

Or where you do physical exam for a kid that comes into your office? Because sometimes they, you know, kids have sensory issues. Sometimes you don't know if they're in pain and if I can't express it.

Yes. So I see kids, hitting their head. Well, does her head hurt? Yes, they know they are taking and they like pressing their stomach on things because they stomach hurt.

You know or their frustration, their biting themselves. It's like something is acutely bothering them. Right. And then thinking about an infection, thinking all the GI issues and the microbiome, like what's going on?

Even kids who don't have digestive symptoms can have an admiral microbiom. And so you dont always know. I do think they try to give us clues, like the body tries to gives us clue, and it's important to share that with the practitioner, right, of like, you know, my child's always leaning over my lap, to apply pressure on their stomach, or they're hitting their head, it does give clues of potentially where there could be the infection, where's the pain, explore deeper.

for that. And do you find that there's any infection that is more common in our children with autism that they then end up manifesting pans and pandas or?

Mycoplasma is one I see a lot and depending where they're from, actually I don't even know if it matters, but like some of the Lyme disease, especially Bartonella, and I think of Bartronella as this like neurologic angry, aggressive, you know, these kids are rage.

That's like the rage Fartanella. So I feel like I see that. And if they have those, sometimes they see elevated like Epstein Barr. I think we kind of learn pandas as strep.

Maybe it's because if you've been doing this a while, and you start to see the sicker and sickier kids, I don't see as much strev. I completely agree with you.

Like I can't even remember the last like true pandas case that I've had. I would agree. It might start with onset perhaps of strep, but then it becomes pants because they start to be triggered by many other things.

But as you dig deeper, there might be underlying vector borne disease, which actually might the underlying cause as to kind of what made them more vulnerable perhaps.

Right. Right. Or if some kind of exposure or just their immune system. So it's layers. Absolutely. I do want to talk about the last case because that was kind one of the more strange and it was recent.

who mom said that with autism, presented with Autism. He said every time he got sick, he regressed. Normal development till age 17 months. They thought he had meningitis, ended up in the hospital, and his behavior, very aggressive.

A lot of the classic band's symptoms. And once he didn't have an infection, He got better.

Mitochondrial Dysfunction and Complex Workup

Mom's like, you seems fine. Yeah. So when she came to me, nobody had ever mentioned this to her. She's like, I thought so. I was thinking at it, but nobody ever said anything.

But the fact that he's so different, he was diagnosed with autism as a primary. So he came in. Oh, like to meet him and talk to him. He comes in with his toy dinosaur, a four-year-old, sits on mom's lap, looks at me.

Looks at mom, tells me about his dinosaur and how he got it for Christmas. And I'm like, okay, this is a neurotypical four-year-old boy. I am like this doesn't make sense.

And she's like I know. So we kind of, you know, looked at different things, different infections, did an organic acid test with him, really looking for gut stuff and he had had a stool test, he'd seen another provider.

It was the most unique. There's different sections on the O test that are different mitochondrial markers. Mitochondria being the powerhouse of the cell, right?

The energy, and that can get damaged, that could affect a lot of things in the body. Very common in autism. So he had one section where the ketone and fatty acids, which has to do with how you use fats.

And every single marker was abnormal. None of other mitochondria markers were abnormal, So one marker that was supposed to be under four was like 1,500. Wow.

I mean, really severe. OK, there's something else going on. And with that one area, and that has to do a lot with carnitine. So I'm like, OK. We need to look further in.

Is this really a mitochondrial disorder? And then the stress of infection kind of really hurts the mitochondria. Then he regresses. So is it really kind of an underlying mitochondria issue?

Because I'm questioning whether he does have autism or maybe he doesn't have PANS. So now we're doing kind more full, like with genetics, carnitine panels, but also are there underlying things like toxins and molds?

And again, presented with autism, looks like PANs, PANDs. And I am like, OK, there's a serious underlying my mitochondrial issue. Again, things aren't always what they seem.

I mean, to your point of if a child has autism OR Pans, to really look at all the other factors, because it's probably contributing things. So I've never seen, 20 years, organic acid paddle, every single abnormal, but extremely elevated.

I think you do need to look, as I said, this was recent. Still waiting for the Lyme panel, and the Other Infections stool test was pretty normal. Interesting.

Yeah. And that brings, you know, he said he was 17 months. He was four. Okay. But when thinking about our young kids, right, like even younger than four, do you find that it's more difficult to give them a diagnosis of pans and pandas?

Like, I find sometimes parents will notice a difference around like 18 months or something like that. Right. And, that is a little bit harder to distinguish, Was this an acute abrupt onset?

Was it developmentally appropriate? Yes. Was there something else going on in terms of maybe a neurodevelopmental disorder? You know, do you find that to be the case as well in practice?

It definitely is not clear. And I think it's good, like understanding it is probably less clear, I Well, you're right, developmentally, what does an 18-month-old, a two-year- old do?

They're going to get more kind of defiant, the fine, no, there's more independent behavior. And sometimes parents are like, God, I just suddenly became a toddler.

So I think it is hard thinking about, was there a history, family history autoimmune history in the mom or like other things like eczema and allergies?

Is there kind other signs of immune imbalance, essentially? Absolutely. But I agree. You still have to look. And I've seen really young kids who seem, again, you're not quite sure.

Right. Yeah. This child in particular, when you did look in his mitochondrial markers and you explored further in terms of blood work, did anything come back yet with that?

I just sent it off, so I don't know yet. So yesterday I was like, You have tell us what happens when But that's the one I'm like, OK, we looked a little more genetics.

Right. And the mom says something about dad. Oh, dad doesn't process fats. Or dad, he has this thing. I like OK. Just as a clue, is there something else going on?

And before you are getting back those results, did you start him on mitochondrial support?

Herbal Treatment Approaches and Coinfections

No. Well, I usually use what I consider autism-specific vitamin that does have some mitochondria support. So a bit of carnitine, a lot of CoQ10. Yes. So there's a little bit, but not, I mean, if he has a serious carnitine disorder, that's not going to be enough at all.

Yeah, absolutely. Right. So, you know, do some kind of basic support and thinking about potential infections after we did all the blood work or did some herbs in a really low, low dose.

We'll cover viruses, we'll covered mycoplasma, will cover some of the, Varelia Vartanella Lyme disease kind So still putting in the antimicrobials for that three-pronged approach for PANS, you know, while waiting on the results for mitochondrial disease or dysfunction, depending on what you're doing.

And then a lot of them are anti-inflammatory, and they help modulate the immune system. So consider them very safe. Yeah. I don't really want to wait like a month.

if these kids are really sick, or I also don't want him to get sick again and then kind of flare. So I feel like, okay, once we get the testing, let's just start something and see how he does.

Or next time he's exposed, as he gets sick and regress. And in a four-year-old using herbals, do you have favorite ones that you utilize for that population for antimicrobials and immunomodulatory, anti-inflammatories?

Yeah, I like cat's claw. And some people call it cemento as one of them or combinations. Japanese knotweed is one my new favorites. Things like Houttuynia, you know, so there's kind of different combinations.

Cryptolepis, if I'm thinking, is there parasites? Is there Babesia kind thing? So, yes. And you just reminded me, in my practice, I've seen a lot of overlap between autism and Babessia.

Have you noticed that in your practice at all with Babesia? I know we touched on Bartonella. I think where you are, like you're in Connecticut, you know there's a lot of Babiesia.

So I'm in Colorado and the southwest I thing has a little more Bartonella, right? Because it can not be just ticks. You can think of other bugs. And somebody said that, I feel like I see a Bartonella, absolutely.

I think that one is the most common, actually. A lot of us are affected by it because it's spread by eight different vectors, right? Right. But I also think Babesia, at the rate that I'm seeing it, I don't believe that it just spread through ticks because is pretty prevalent.

And it is just interesting the overlap that we're seeing in regards to autism. Or about POTS, which is basically the Autonomic Immune System is not regulating blood pressure, heart rate, You know, temperature.

And then I think about, you know. Abesia. But sometimes that's even hard, those dysautonomia symptoms to see in young kids, actually. Right. Yes. Or is it just like a sensory thing?

Yes, or even like constipation, right? Like maybe their peristaltic movement isn't working as well as it should. You can see some of the temperature dysregulation in the little kids.

I find that the dysaudinomia, it presents a bit differently in our kids compared to our adults, where it's a little bit clearer cut. No, I agree. Well, I always cover for all three, just because I don't.

And, you know, good thing about herbs is they can treat mitiviruses and also babesia. So you can use less and then cover everything. But I also cover, well, it potentially could be this, and make sure that just for safety.

Absolutely.

Parent Guidance and Closing Remarks

As we wrap up, is there any advice that you would give a parent if they were worried about or thinking about their child maybe having pans and pandas, but their children has autism?

I think there's probably more overlap than we think. So I if you think it and you're concerned, you need to address it, and look for it basically. Look for the causes, which can be more than infections.

And I, as you said, the overlap of treatment. But I I you if think about it even if nobody says something, just raise your voice. You know, because it's really easy to look for, and the parents will come to me, well, nobody mentioned this.

I'm like, you're right. Right. Just trust your instincts and you know your child. And if there's a change, then you need to kind of address it. Absolutely.

You don't lose anything by addressing it, right? Because then, it can really help your children. Sooner than later.

That's kind how I think about it And again, I feel like I tell parents all the time, you know that your child is better than the practitioner or better that me, right?

And so if you're thinking that and maybe you are being told that it's just autism, to maybe explore deeper as you said, maybe find somebody else who might listen a bit more.

But thank you for all of your wisdom that you shared and those cases were amazing. And how can people find you and learn more about you? Yeah. Well, I wear a lot of hats, a lotta hats.

As I said, i'm an integrated pediatrician. I'm in Denver. It's drdebby at holisticpediatric.com. And I've said I got a website, right? I work for NutriMedics and I actually help develop products and do education and research.

And I'm involved in, I wrote a book on kind of preconception. And it's really kind looking at trying to get your child or even healthy newborns. So preconceptions, which I think is huge, kind addressing a lot of the different factors.

Or for Neurologic Health Foundation, Which is again, non-profit, looking to try to have healthy kids. Because I need prevention we need to look at. Absolutely.

Thank you for all of your work that you're doing for our children and families. I mean, the same goes to you. We need more and more of us, basically. So, great.

Thanks, Debbie.