From Self-Blame to Self-Compassion: Parenting a Child with PANS/PANDAS Transcript

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Introduction and podcast welcome

We talk so much about, okay, we're gonna give our children this vitamin, we're gonna have them do this, we're gonna do this medication, we're gonna go to this therapy, right?

And then we're just surviving in the background, trying to keep everything together and trying to seem like we are okay, which honestly on the inside, I think most of us are not, right?

And of course, like we could do certain self-care, but I think it's not even just like, oh, it's a nice pleasant thing to go get a pedicure or whatnot.

Like it's actually a necessity that we do some self-regulation techniques specifically just to, for this, I mean, everything else even aside, but obviously if we have autoimmunity ourselves or other things ourselves, we have to do it for that.

Welcome to Demystifying Pans and Pandas, the podcast where we uncover the mysteries, breakthroughs, and hope behind these life-altering conditions. I'm Dr.

Nancy O'Hara, a board certified pediatrician, educator, and advocate with over three decades of experience helping children and families navigate the challenges of neurodevelopmental and neuropsychiatric conditions, especially PANS and PANDAS.

These disorders can feel overwhelming, but here we'll break down the science, explore transformative treatments, and share stories of resilience and recovery.

If you've ever wondered what's possible for your child or how to find answers, this is the place to start. Let's dive in. Welcome back to the Demystifying Pans Pandas podcast.

I'm Dr. Nancy O'Hara, and I'm really excited to welcome Ina Toppler to the program today. Ina is an amazing naturopath, but I invited her because I wanted a practitioner's perspective on parenting a child with pandas.

Ina Toppleru2019s background and health journey

She has her own areas of expertise in thyroiditis, her own podcast, her own practice, and is a wonderful practitioner in many ways, and also a wonderful mom.

So I'm really thrilled to invite her, and thanks for being here, Ina. Oh, of course. I'm so honored to be here. Thanks for having me. No, thanks for being here.

And just tell everybody a little bit about yourself and how you got to where you are today. Of course. So right now, I'm a functional clinical nutritionist and I specialize in Hashimoto's and hypothyroidism.

But as many of us practitioners, we typically get there from our own, um, experience. And so, um, you know, I was someone who was always kind of a sickly child.

I mean, nothing major, but I had colds a lot and blues a lot. I'd strap a lot. And I grew up in Lithuania. I moved to the States when I was 10. And what was interesting is my grandmother, so in Lithuania, my grandma was a cardiologist, which is like very unheard of for a doctor, especially a woman, you know, back then.

But so we had all the best connections, if you will. And so every time I would get sick, you know, we would have a private doctor who would come to the house that was, you know, from the hospital where she works.

And what did they do back then? Antibiotics, right? And so I still remember my mom literally chasing me with like shots of penicillin in my butt. because that's what they did.

Anytime I had a sore throat or fever, and who knows, right? Like, back then, they didn't test. Like, was it strep? Was it something else? Could have been the flu, right?

But antibiotics, antibiotics, antibiotics. And naturally, you know, that led to a lot of GI issues, which then when I moved to America, this was in mine.

The dental care wasn't great there. So I had a lot of cavities because I had a retainer, and apparently no one told me I'm supposed to take it off every day and clean it.

I was nine years old, you know? So I had a lot of cavities and my parents took me to the dentist locally where we first moved here. They didn't know any better.

They're like, oh, you have all these cavities. I got like 16 amalgam fillings put in like pretty much at once. And of course, looking back, you know, did I really have that many cavities or was this dentist drill happy?

Who knows? right? But I had that I also had to get re-vaccinated because even though I had some vaccines there in order to go to school here and my parents again didn't know anything and so I got a lot of the main ones again which then gave me a lot of acne and a lot of more digestive issues and so that went on and I went to college and things kind of just were back and forth like that and when I graduated I worked on Wall Street at first and I was so tired I, you know, at five o'clock, I lived in the city, in New York City, so all my friends would be going out after work and all they wanted to do was go to sleep.

I was tired. I had PMS. I still had the acne. I had, I mean, so many different things, like so many issues. And nothing was super, super serious, but they were all really just frustrating and annoying.

And, you know, I went the regular medical route. which, you know, I had four primaries, a gastroenterologist, an endocrinologist, a gynecologist, a dermatologist.

You know, my labs were coming back normal. They were telling me everything is fine. It might be in my head. And I just literally felt like my body was betraying me at the time.

And interestingly, an endocrinologist at that point diagnosed me with Hashimoto's and I got so excited because I thought, oh my God, that's great. What is this?

Like, let's fix it. And they're like, yeah, well, you know, you're a thyroid. is actually fine. You know, for everyone listening with Hashimoto's, it's where your immune system actually attacks your thyroid.

It's an autoimmune disease. And so what this endocrinologist said to me was your thyroid is fine. So your immune system is attacking, but not so much.

So we're just going to wait and see. And eventually when your thyroid gets really attacked and destroyed, then I'll give you medicine. But for now, we wait and see.

And I was 23 years old at the time and obviously, you know, didn't know anything about this. I worked on Wall Street, but I thought, well, that doesn't make any sense.

And so that's really what got me into research mode. And, you know, back then, this was 2001. You know, there wasn't social media in the way we have now.

There wasn't as much information. I mean, they didn't even have a Whole Foods in New York City. I think they just built one like right around that time.

So, you know, I started learning things like, oh, you know, what you eat matters and chemicals matter and all of the things. And so long story short, eventually, you know, I went back to school to learn really more for myself.

You know, I got a master's and I did a lot of other continuing ed because I wanted to see how else I can help myself. I started working with a naturopath myself and, you know, really figured out that, wow, like, there's all these imbalances, I had heavy metals, I had candida, I had parasites, monal imbalances, copper toxicity, I mean, you name it.

And I worked on all of those things. And obviously it wasn't overnight, but as I worked on all of that, things got better. My acne went away, my IBS went away, my energy improved, my hormones balanced.

And, you know, and then I just, I started doing it first for friends and then for friends of friends. And then I started to practice and 21 years later, Here we are.

It's amazing. Your story is so typical to so many people I hear from. Our own health issues, whether it be infertility like I went through, all the things you went through.

bring us to a place where conventional medicine may not be having the answers. I mean, that's something so typical people hear, you know, well, we'll just wait till it gets so bad, then we'll put you on medicine as opposed to there are things we can do in our internal environment, our digestive systems, you know, all of that.

And also, you know, the degree of autoimmunity that are in our parents, particularly our moms, particularly Hashimoto's thyroiditis, that we see in at least 64, 65% of our kids with pans and pandas.

So we have the children that we have, not because of some big karma, but because epigenetically and otherwise, you know, our children are also susceptible.

Yeah, absolutely. Absolutely. You know, and I think what's really interesting is as a parent of someone who has ASD and Pan's Pandas and also provider, it kind of puts me into this very interesting place where You know, I know what to do.

And, you know, even though I had this history, I've spent years cleaning things up. I did a whole year of chelation for mercury. I had 47 chelation treatments and not that I necessarily would recommend that now, but I had a lot.

And so my husband and I knew we wanted to have children, but I was very adamant about. making sure that we get everything in order. And I probably spent, I would say, at least 10 years.

I mean, really, when I found out and started working on things functionally, it was 2003. Then we decided to have kids and Jake was born in 2016. So I got pregnant in 2015, right?

Parenting a child with PANS/PANDAS and reframing the diagnosis

So that's 12 years. Cleaned out the candida. I did like years of that, the mercury, the hormone balancing, like all of the nutrient balancing. And I felt So much different.

I mean, I felt better in my 30s than I did in my teens and 20s. I mean, I feel better now in my 40s than I did then. And you look better, by the way. I didn't know you back then, but I've seen pictures.

Anyway, you look younger now than you did when you were in your 20s. Well, thank you. Yeah. And also like a big thing too, like I have to show pictures of my hair where like before I really supported my thyroid, it was short, it would break.

I mean, there's just like things you could see. But you know, I think I was, when Jake was first diagnosed with autism, and he's very, very high on the spectrum, but still that, and then pandas, it all kind of came at the same time.

It was a really, it was a very interesting time for me because I was in denial because also I just thought with all of my training, I mean, granted, I didn't specialize in pandas, I did more thyroid stuff, but you know, you hear about it, you learn about it in school, right?

But it seemed to me as this very rare thing, which it's so not, obviously, you know? But it really did. And so when someone mentioned it, and I even kind of thought like, someone's like, well, could it be this?

my child? No, that happens to those other people. Like, do you know who I am? Like, do you know what I do? Like, that can't be my child. And, you know, it was, it took a while to kind of accept that, but also then, you know, and I think naturally, we want to find reasons, right?

Because, you know, as intelligent people, we don't, like, I just don't understand, like, how do things happen to good people, right? Like, that's just one of those things that I'm like, all right, like, what's what's happening?

So I'm like, well, it must be something we did, right? So it must be my fault, you know, and then you go down the rabbit hole, like, okay did this this but did I miss this did I not do this like what else could I have done and the thing is and especially with Jake's pregnancy I did everything right like literally like I ate spectacular and I didn't stress I did yoga like three times a week I mean with my daughter who by the way is completely neurotypical and she was born four years later when I was 41 um I had Jake at 37 which is still considered old I guess but I was older with her and she's fine, but I didn't even do as much with her with him.

I missed my first pregnancy. I sat on the couch, my husband rubbed my feet. I took all the things. Not to mention the 10, 12 years of work that you had done to be the healthiest possible and all the things you were doing dietarily, so many things.

Yeah, keep going. Yeah, no, so it was, you know, and I think that sometimes, well, not sometimes, I think, most of the time for parents, it's just one of those things like, like, what, like, what did I do wrong, you know, and the one thing and I know, obviously, that Hashimoto's is that big predictor.

Of course, it could be any other, you know, other things too, but I really had that under control. So then I was like, okay, well, it's my age, right, because I am older, but you know, that's just, life.

There's not, you know, and I wanted the reason we waited so long is because I wanted to correct all of these things and plus I wasn't ready, you know.

So it's just, it's an interesting place to be and interesting kind of feelings to sit with. And over the years, you know, I had to do a lot of healing because for me that under, well, not even the understanding, it's the not understanding of how did this happen, right?

That was very much like, okay, like, But why? And the not understanding really made me feel, well, it just wasn't, I wasn't at ease, right? Because, and a lot of it too was, well, there's something wrong with my child, right?

And so over time, I mean, yes, of course we're constantly working on things and I'm excited to share about some of these things and we've made such progress, but I think the mental aspect that I had to shift is that there's not necessarily anything wrong with my child.

My child is the way my child is and we can support him. And it's that shift that helped because there was so much anger behind all of that, you know? That is such an important point.

And it's one of the things I talk about a lot. You know, we talk about when we're treating our kids, pulling back the layers, peeling back the layers of an onion.

And that never set right with me because, you know, onions make me cry and all of that. And I rather think of it as a gift wrapped in many layers of wrapping paper.

And that simple thing shifts me to say, you know, this child, your child, my child, all children are gifts. They are who they are. We may help them reach their fullest potential, but we're not seeing them as broken, as bad.

You know, that shift is so important. Yeah. And it's hard. Very hard. That shift isn't really, especially when, you know, your child is yelling and screaming at you and telling you that they're going to do something bad.

or whatever it may be. And it's a shift day to day, moment to moment sometimes. You know, it's taking that extra breath. Yeah, definitely. And the other thing that's really helped me is instead of asking why me, I often ask why not me.

you know, whenever it comes up, whether it be my child or something else that happens, and try to turn things around, you know, your son is incredibly fortunate to have you as his mom, because of all you know, because of all you've gone through.

And, you know, where might he be if born to a different mom? Oh, I think about that all the time now, once I got over some of the anger and all of the things that came to it, because yeah, I mean, who knows where he would be if he would be eating gluten and doing all the things and sugar and But as you said, he's a really high-functioning young man, even though he carries those labels and has all the things that he has.

Might he be one of our much more affected children that wasn't speaking, that wasn't able to have a fulfilling life? So anyway. We don't have that crystal ball.

But tell me, I just want to know so many things about what you think, for instance, about autoimmunity in our kids in general. You know, you did everything to try to avoid that in your son.

What's your thoughts on it, and what do you recommend families do? Absolutely. Well, so I think that what you do pre-conception and pregnancy really, really matters.

And, you know, when I look back, even though I did all the things, you know, back then I also didn't understand thyroid the way that I do now, 10 years later, specializing in it.

And, you know, I think that that's such a big part. So for me, I did have my levels much better, but I was coming off a flare when I got pregnant with him and my levels were better, but that still weren't 100%. My TSH was a little bit higher.

And even though my thyroid hormones were okay. I don't think I was on enough thyroid medicine, and I very, very much believe that thyroid medicine isn't like medicine.

You know, some people, I think, knowing that we're more holistic, say, well, why would you recommend medicine? Aren't you someone who does natural things?

And when it comes to thyroid medicine, it's really just replacing an essential hormone your body needs. I don't even think of it as medicine the way, say, cholesterol medicine or other medicines are.

Preconception, pregnancy, and thyroid optimization

And so I sort of had this idea. Well, first, even before, I thought, well, medicine is bad. I'm not even going to do it. Once I learned, I'm like, oh, wait, I need this.

But then it was the idea of the lowest amounts needed because we don't want to make the thyroid lazy or whatnot. But that also isn't necessarily the most correct way to think about it.

It's not the lowest amount needed. the most optimal amount needed to get levels of where they need to be. And, you know, especially before and in pregnancy, you want TSH below two, and you want thyroid hormones to both T4 and T3 to be really in that middle optimal range.

And I think for me, they were there once I was, I think, at maybe six weeks pregnant with him. Initially, my TSH did jump and I didn't raise my medicine.

So it was probably, it was like a three something. And so much happens in those first three weeks of gestation. And so I think that as much as there's so many different environmental factors too, which we'll talk about in a second, but I think really getting your thyroid optimized is so important before getting pregnant and in pregnancy, you know, just to make sure to support everything, you know, and then of course, And just on that for one minute, it is such a balance between what we use in functional medicine and what we use in conventional medicine.

And one of the things that I think both of us agree is marrying those to the optimal is really important. And you're saying, I agree with you, thyroid medicine is different than cholesterol medicine or even some of the medicines we use for neuropsychiatric illness.

But also, I know you use a lot of, you know, like myonocytol, and you also have something called thyroid love. Thyrolove, yeah. Do you mind just mentioning that real quick, and then I'll let you get back to all the environmental stuff and everything?

Yeah, yeah. So this is something we just recently launched. I've been working on this for almost two years, and it's essentially a multi-nutrient formula made specifically for people who have Hashimoto's and hypothyroidism.

I mean, I don't even like to call it a multivitamin because it's so much more than that, but it's essentially like a multi-nutrient vitamin, but it has the inositol in it, which is so good for thyroid antibodies and to help sensitize TSH.

But it also has higher levels of zinc and selenium than typical multis. It has CoQ10. It has all the minerals that we need when we have autoimmunity, especially for thyroid.

And it's in want because I think that what often happens is that to get all those things you have to take five or six pills you know and then it's like oh my gosh all that and I also wanted something that was really beautiful because I find that when people see vitamins and they're like oh I have to take this and it's a chore and a lot of times you know bottles that aren't very pretty and not to say that that's everything but you know it's just like oh it's more that so I just wanted people to open something that feels really beautiful and nourishing so then it feels less like a chore and more like you're doing something good for yourself because, you know, so much of how we see and think about things affects what happens, right?

And if we like take something and we're like, I'm so excited to take it. It's going to be so good for me. You know, that's going to help your results to some degree, at least.

Yeah, it's like what we were talking about, resolving the way we think about our kids and the issues they go through. It's the energetic, the karmic, the spiritual feel of something.

And also in the name, it's not just the bottle, the name, you know? So that's great. I just wanted to mention that, so go ahead now. Besides that, you were talking about autoimmunity in our children and things we can do.

Yeah, and so, you know, I think, again, just environment. And I know we can't control everything, but we have so much control over so many things, right?

The water we drink and the type of filtering that we do, the air that we breathe, maybe not outside, but inside with filtration that we could do there.

And that doesn't cost a ton of money, doesn't require a lot of effort, because I know one of the things that I hear a lot, as I'm sure you do, is, but I'm so busy, I don't have time to do 100 things.

I get it, right? But if there's a hundred things we could do, but if there's three that are going to give you the biggest bang for your time and your buck, then we work on that.

And then the body is going to be able to take over with the rest. So I think a clean environment, because we always hear, oh, the body knows how to heal.

And I think most of us are kind of like, okay, whatever. But really, and then I think the reason why people think, okay, whatever is because they're not seeing the healing necessarily, but they're not putting in the environment, right?

Like if you have a fish in a dirty fish tank, you know, the fish isn't going to thrive or even survive, right? So if we can help our body to heal by giving it the right nutrients and giving it clean water, clean air in the right environment.

And ideally also in our minds, right, that environment where it's okay to rest, where we're not lazy because we're resting, where, you know, we put in these breaks, so it's not work, work, work, unless rest only when work is done, because hey, we all know work is never done, right?

Like, so once we have that, then the body can take over some of that. You know, one of the big things that I talk about, and this isn't just with Hashimoto's, but really any autoimmunity, is that we have these triggers, right, that are going to trigger the immune system.

Because with autoimmunity, you know, and I think a lot of people think, oh, well, if it's thyroid autoimmunity, then it's the thyroid, or if it's this, it's that.

It's not the thyroid's fault it's being attacked, just like it's not your joints fault that it's being attacked, right? And arthritis, it's not your brain's fault.

Or your brain's fault. Exactly. So it's the immune system that essentially got confused, right? So why does the immune system get confused? Well, it gets confused because it's literally overworking.

Environmental factors and reducing triggers

And it is tired and it's almost like a soldier who goes to war and then comes back with PTSD. I mean, it's sort of the same thing. If the immune system is constantly trying to fight, say, you know, Epstein-Barr that's underlying or Candida, which is a type of fungus that's underlying or parasites or, you know, mercury or other toxins, like it's trying to deal with all of these things and it can't.

It just gets tired out and confused and becomes hypervigilant and essentially saying, I'm going to shoot first and ask, I don't know who you are, but you must be bad.

Right. And so, you know, as parents, it's so helpful if we look at. and support our triggers, right? Because the less triggers that we have, the less we pass on to our kids.

And ideally that's preconception if we can, right? And in pregnancy, but then also obviously when the child is here, you know, they may be carrying some of the triggers that we had.

And, you know, obviously, if you have a baby, you're not going to cleanse a baby, but it's just making sure that we're giving them good nutrients, you know, and even things like, you know, don't heat up milk in a plastic bottle, right?

Like, there's things that, so then we're not getting those PCBs and chemicals like that that can be really disruptive. Right. And there are so many simple things, but it is also about modeling for our children, you know, showing that it's okay to take those breaks, like you say, it's okay It's good to eat well.

It's good to get outside, get fresh air. And there are simple things that help us to feel better and be able to deal with

the rages and everything else that we go through, but also show our children that that is something that helps us to feel and be better.

It seeks into their DNA, so to speak, even if they not be seeing it, no matter how old, how young, it seeps into their thought processes too. Of course, and we know that most of everything we learn is before the age of seven.

because we are in more of a theta brainwave state. And so, which is kind of crazy if you think like you don't even have a logical minds until after seven.

So how is it that 90% of what we learn happens before a logic kicks in? Well, it's because It just gets accepted in. And like you said, for children, it's really like, it's not even that something is told, but it's the mannerisms that we have.

It's the things we do, right? If we see our parent do something over and over again, they never say, oh, this is bad, right? Like kids pick up on that.

And then they think that's the right thing. And what's very interesting is that as kids get older, you know, eight, nine, 10, and the logic online does kick in, especially as they get, you know, into adulthood too, then that's where there's this disconnect because this learning they picked up, right, before seven saying, oh, you know, mommy never rested, so rest is bad.

You know, and then they hear, you know, on meditation app, oh, you should take time to meditate. And then their brains, the subconscious and the conscious mind are like, No, no, no, that's lame.

Don't rest. You know what I mean? And it's just like back and forth. So, you know, even if things are not said, they do pick that up. And for the positive, of course, as well.

Yeah. You know, I think a lot of that we can use for the positive with food. You know, as I'm sure so many people listening know, you know, what we eat, of course, affects our kids and has such a big effect on pans and pandas.

all the things right whether that's gluten or dairy or any food really I mean it's not just those things I mean kids can be sensitive to a lot of stuff sometimes it's temporary um sometimes it's longer term I mean of course we ideally don't want to restrict everything for too long because there's negatives of that but you know to get the inflammation down it is helpful to at least take some of the big triggers out with food but it's hard with kids right so it's you know, ways to model it where, you know, like this food isn't as good for us, but why don't we eat this food and notice how you feel, right?

And then when you eat this food, how you feel, I do this with Jake a lot. He actually knows like how many grams of sugar things have. And he's like, oh, this is too many grams of sugar.

This is that. But I always go back to, okay, like it's good to do the math. But like when you eat this, like what happens, you know, and it's a practice because, you know, especially for a little kid, you know, they may not understand at first, but I, I has been asking him this ever since he was little, like, oh, where, like he'll say something, but where do you feel that?

And he kind of was like, I don't know. And I'm like, okay, what color is it? And he's really good with that. And so sometimes like, even if he's angry, like, what color is it?

And he's like, oh, it's yellow. I'm like, okay, cool. Like, let's see if we can vacuum out the yellow and replace it with purple, which is his favorite color, you know, so we can kind of do different things, you know, because I think As with anything, it has to seem like their idea for them to really get behind it.

And be fun, or interesting, or make sense. You can't just say, you've got to eat this because it's good for you. And I love the colors. And also, when you're talking about that, I think about one of the things for me was always the hangry piece.

you know, and helping my son to see that when he didn't eat, that that affected, you know, how he was feeling. And even now as an adult, he'll say to me, you know, he'll be angry about something and he'll go, mom, I ate, it's okay.

You know, so, but it got in that, you know, eating and eating good foods helped me to feel better. And so I think that's really important. Even when they're not able to do it, like you're making the changes, the child might not be on board, just saying why you're doing it or how it makes you feel may help them eventually to see it, even if it's not in the moment.

We talk about protein a lot just for that hangry piece and how important it is. And, you know, just like sometimes like, and it's funny, I mean, as a nutritionist, I think I love hearing that, but sometimes he'd be like, oh, mom, I didn't have a carb in this meal.

Where's my carb? I'm like, something's getting in there. Yep. We always have a protein and a vegetable and a carb and it's simple, but they know what it is.

My daughter, it's funny, she's four and we obviously talk about this as a family. And she goes and she doesn't always like to eat her meat. And she's like, mom, I so wish that ice cream had meat in it.

Food, family routines, and supporting regulation

Then I would have protein, and we'll do a protein plan. She'd be like, Mom, I made you this ice cream. Don't worry. It has 100 meats in it. That's great.

But I'm like, however it could get in. Exactly. But that's important. And they'll remember that forever, and hopefully in a very positive way. Versus, don't do that.

That's bad. And bringing your daughter in reminds me that if we do this as a family, and we get the kids involved, all the kids involved, in getting their hands in the dirt, maybe in a garden or a window box, in helping them to be part of the cooking, whether in play or really helps them to, it nourishes them in many different ways than just as the food nourishes them.

Yeah, yeah, absolutely. So anything else in the autoimmunity of children? I mean, I think those are kind of the biggies with that. I mean, obviously there could be very specific things for each child.

But again, I think that if we look at the low hanging fruit, it's amazing like how much there is that people discount or don't think about or, you know, don't realize.

So it really makes a big difference. Yeah. And they're little things that aren't that expensive. Exactly. You know? Exactly. Absolutely. Now, even though you do so many things wonderfully, obviously your son, as many of our kids do, does have flares.

How do you manage that as a mom? Yeah. Or as a professional? It's really hard. I'm just going to come out and say it. It's really hard. You know, because I think people look at me, and obviously I'm sure they do the same with you.

And they say, well, you're a professional. You know this. Like, it should be so easy for you. And it's not, you know, and I think it's just really important to kind of get it out there because I think that it's hard for everyone, right?

We're all human and, you know, these flares come from what seems like out of nowhere. And I find it so hard to know, is it a flare or is it just a bad day or is it this or that?

And, you know, my mind being very analytical always goes to, okay, what's going on? Who is sick? Who had this? You know, to try to figure it out. And sometimes I can't figure it, but sometimes I can't.

And that was a really hard thing for me because my whole thing is like, find your cause, get things done. Like it irks

me if I can't figure something out and just had to be okay with that.

Right. Because as professionals, we're detectives, you know, and we, when we don't have the answer that really rubs us the wrong way, but also as moms, we want to know, we want to, you know, because we don't want it to happen again.

So we think if we figure it out, then we'll solve it. And it's just when the flares come and come again and come again, it's really, really hard. So, you know, what we do, I mean, it's probably fairly typical, but the Advil, when we do 200, Jake is eight and a half.

So for his weight, he gets about 200, 225 milligrams. We do that three times a day for a couple of days. I find adding Benadryl helps too. It doesn't make him super sleepy.

I do five milligrams of Benadryl and I'll do that at the same time. doesn't seem to affect him too much in terms of like the sleepiness of it. Um, so we'll do that.

Um, I've also had a lot of success with vitamin A. That's something that you and I have talked about, um, doing, um, 200,000 of vitamin A and then for two days, and then we do a hundred thousand, then 50,000, then 25. So sort of like a five day with that.

Um, I would say that's probably something that I saw the quickest shift like within 12 hours. Yeah. And just a piece on that, because I think there's a lot of information out there with regard to measles encephalitis and other things.

That is actually a very well-researched intervention, and there is a lot of good research out there that supports doing it. I certainly feel as a professional that I'd like to follow vitamin A levels and make sure we first do no harm.

But I absolutely agree with you. There's good evidence that it's a good antiviral. And many of the triggers of these flares are, if they're not sick with a virus, it's exposure to that virus.

So the anti-inflammatory, absolutely. The antihistamine, absolutely. the mast cell activation that happens for these kids. And Benadryl is great. And I've never tried the five milligrams.

That's very interesting. I maybe have to think about dosing it even lower in kids I recommend it to. But I have found that other antihistamines work too in other children.

So if Benadryl doesn't work for your individual child, there are other antihistamines that may. So try them. So those are all great suggestions. Do you usually dose the Benadryl higher?

I do, I do. And not too high, but still, I don't really think at an age where your son is, I've recommended trying five milligrams. Another pearl, I'll take away.

Yeah. Well, also because we do it during the day at school, so I don't want him to fall asleep. No, no, no. And then along with that, I usually do some GABA and some theanine just for extra calming.

We do that ungoingly, but I find with both of those, it's something that works for a little bit and then doesn't, so then we take a break. And I'm not exactly sure why it sort of has this up and down, but I find that we do it for a few weeks and then when it has their diminishing returns, then we break and then a few weeks later we try again and then we see more positive with that.

And I think that's also a really important point is that often when we're doing things all the time, and some things need to be done that way, but like what you're talking with the GABA and theanine, using it in a flare, when it has less returns, taking it away, having it to use again, that sort of holiday discussion of it can be very helpful in a lot of our kids and something to consider that a lot of our moms don't think about.

And dads don't want to leave them out. Yeah. Well, and I think with flares too, like you said, it's kind of trying to

figure out, which again, it's not always easy, where the flare came from.

With Jake, everything started with him having strap. I always go there and knock on wood, you know, he had strep for one year, like five times in a row and then he hasn't since.

So not that you grow out of it, but you know, his body might have developed more immunity towards it. And, you know, it's a little bit easier, but I always test that first.

Then I have the home kits. Of course, I still go into a culture, but I like having the home kits just to get that initial. And, you know, again, pretty good at.

getting in there and he's pretty good. He's pretty good with it. He doesn't love it, but he's pretty good with it. So I always test that first. And I test my daughter too, because sometimes you never know.

But what we have found this year was that the flu was a big trigger, both the regular flu and the stomach bug, the stomach flu. He had two big flares post that and I knew it was viral because my daughter had that and he was never sick, but it happened a few days after.

So that was an easy one to figure out. So with that, you know, we did the, the flare up protocol, but then I also did the magnesium and extra zinc and lysine and a lot of the things that are antiviral.

Managing flares and viral triggers

But sometimes it's hard to know what it is. I mean, right now, As we're recording this, it's April and it's allergy season. Jake does not seem to be affected by allergies.

Like, I feel it. He does not. I mean, he has no symptoms. But I wonder, right, could it still be causing neurological inflammation even without those symptoms because he doesn't get as many symptoms from other things too.

So, you know, it's thinking about them. And again, we have evidence of that in research that allergies can cause neurobehavioral flares without any allergy symptoms.

I mean, I remember a very small but eloquent study by Dr. Boris decades ago that didn't show any allergies when they injected pollen into these children on the autism spectrum, but their neurobehavioral symptoms went through the roof.

And so, yeah, they don't have to have a runny nose and watery eyes. and all the typical allergy symptoms. And, you know, I was talking to Tanya Dempsey about this, who's one of our mast cell mavens, and she was saying yes, you know, and Jill Christa in mold.

Each person can show the symptoms of the allergy or the susceptibility neuropsychiatrically, you know, respiratory-wise, skin-wise, but they're all still symptoms.

We just don't think of the flares and the neuropsych symptoms in the same way that we see the ones that are much easier to see, like on the skin and in the nose and things like that.

Yeah. Yeah. And I think it's just so important for people to realize that because we can drive ourselves crazy if I don't see anything, what is happening?

And it does make it more difficult because it makes it harder to know, but at least it still gives you some other options. Like it could be this and then, you know, it's process of elimination really.

Yeah. Yeah. Absolutely. And I think the other thing in a flare is what we were talking about of modeling our own behavior. Because if we react to a flare by flaring back, which is very typical by getting angry or just getting tight ourselves, that will exacerbate the flare in a lot of ways.

If we can take that deep breath, put our oxygen mask on first, you know, that can help also. Do you agree? It really does. I agree 100% now. Do I always follow that as a whole other story?

I mean, especially when the flares come, you know, sometimes, you know, we're lucky and it's a flare and then a month or two later, it's another flare.

But sometimes it's like, we just get over a flare, we have two good days and it's another flare. And when it's one after the other, you know, because again, it's like someone's sick, then it's allergies, then someone else gets the stomach bug, and you know, they go to school, they have siblings, right?

It makes it hard, but that's even more of a reminder for me and everyone that like, we just have to make sure that we're able to self-regulate, because that is how our children learn.

You know, and I find for, you know, it's so important to do the self-regulation techniques on a daily basis, you know, on a regular basis for us, right?

Because I think as parents, we talk so much about, okay, we're going to give our children this vitamin, we're going to have them do this, we're going to do this medication, we're going to go to this therapy, right?

And then we're just surviving in the background, trying to keep everything together and trying to seem like we are okay, which honestly on the inside, I think most of us are not, right?

You know, doing all of the things, but it's, you know, and of course, like we could do certain self care, but I think it's not even just like, oh, it's a nice, pleasant thing to go get a pedicure or whatnot.

Like it's actually a necessity that we do some sort of regulation techniques specifically just to for this. I mean, everything else even aside, but obviously if we have autoimmunity ourselves or other.

things ourselves, we have to do it for that. But I'm also thinking like just being a parent of a child with special needs, like there should be like an allotment of techniques that are done.

Right. And also the more we practice it in non-crisis moments, the more it gets into our routine. It's like practicing anything. Yeah. And so practicing it by taking care of ourselves when we can and making that a priority is really important.

Yeah, definitely. Now we talked, just I mentioned, about getting vitamin A levels and things like that. As a parent and as a professional, you know, with children with PANS-PANDAS, what about lab work in these kids?

What's your thoughts on that? Well, I think lab work is really important. I am someone who does drag my feet a little bit. I get my own lab work all the time.

I test my thyroid every three months, and you know, I think it's really important. Jake is better now, but you know, there was a time where it was a struggle, right?

So again, we do what we can, but I think it is so important to look at things. I mean, in an ideal, If I had her on my way, it would be every three months, right?

Especially because a lot of these children do have the thyroid stuff that can come up. That's one thing that Jake had, but I see it so much more. Once I saw it in Jake, I don't see a ton of kids, but the kids that I do see, I saw it in so many others where their thyroid hormones are normal, but their TSH is a little bit high and that's just signaling that there's something happening in the gut and there's some inflammation which is affected by this.

checking that staying on top of that vitamin D is so important as is vitamin A. So checking those, you know, but also just seeing, you know, if there's anything else from other triggers that are coming up.

So, I mean, I know sometimes every three months is hard, but you know, at least every six months, but I think that lab work is important. So we make sure that all those levels are optimum.

And we're not talking about specialty lab work. We're talking about conventional labs for the thyroid, for the liver, for the vitamin and mineral levels.

You know, it is so common for our kids to have really low levels of vitamin D, vitamin A, zinc. And that is the foundation of so much of what we do. And I think knowing where those are, because as they get sick and they get one infection after another, those will get used up.

So knowing where they are, I agree with you. And again, just like we're trying to reframe other things, like eating good food and breathing and all that for our kids, we can in a lot of ways reframe the blood work.

Absolutely. I actually take my kids with me when I get mine. And I, my kids, I mean, being children of a practitioner, they've been taking vitamins since they were like four months old.

Like if I forget a vitamin, sometimes I'm like, mom, you forgot my fish.

Lab work, minerals, and hair testing

I mean, in my four year old, she's like, you forgot my magnesium today and where's my probiotic? Like she's on top, she gets it all out. She's on top of that.

And so the way I tell them is like, you know, you're taking all these vitamins and then we're going to check to make sure that the vitamins are actually in your blood and they're doing what they're supposed to be doing.

And then maybe We need more or less, you know, and they like some of their chewable. So I'm like, oh, this may show us we need more instead of one. Maybe you'll get two.

And so, you know, that's a way that I try to reframe that for them. Another thing that I also do with my kids is I do hair testing because that is very painless and easy.

And a hair test isn't going to be an end all be all for everything. I mean, it's a way to look at metals. It doesn't really show you everything because some people may not excrete.

So no metals on a hair test doesn't mean that they have no metals. But if metals come up, then something is going on. But it's also a really good way to look at minerals, especially zinc.

You know, I find so many are zinc deficient and they may have higher copper. And copper, while essential, can really kind of be more act as a toxin in the body when there's too much of it and you know we can get those through if we're drinking water that goes through copper pipes I mean there's and also I think as you know I see I do hair testing a lot on people that I work with and so many have high copper and so in pregnancy right through breastfeeding that passes through which is how kids have it even if they're not drinking water you know tap water So in those situations, the extra zinc is even more important, and it's just a very easy, painless way to keep track of that every six to 12 months.

And I think that's a great point. And I am coming around a little bit. You know me and hair tests. But I think that if you use them regularly and not just one point in time and say, well, this child has no problems with metals because there's nothing in their hair.

That is a very false statement, you know, because as you said, you know, and there are studies that show that children who cannot detoxify may have very high levels of metals in their body, but they can't detoxify them so you don't see them in the hair.

But if you're using in a serial way in looking at minerals particularly, It may be a very effective and non-invasive way

of looking at these things in our kids.

So I'll get there. Anyway. But one of the things I've also heard you talk about, and when I think about getting a blood test on a kid, I think of it as a traumatic experience.

As much as we try to make it not, it can be traumatic. But you do talk about trauma as a trigger. And I think we've talked about it around things. this morning today.

But do you want to say anything more about that? Because I think that's a trigger in us as well as our kids. Absolutely. So, you know, when I think about triggers in the buckets, right, we have the food bucket, we have the infection bucket, the toxin bucket, and then the stress bucket.

And the stress bucket is really anything that affects our nervous system. And, you know, it's one of those, it's a simple thing in terms of nervous system, but I think a lot of people also don't see it the same way or they underestimate it.

But the nervous system is in control of everything. Yeah. So, I mean, that's like, there's nothing else even to say about like more than that, but it's like, you know, our immune system gets confused, but what's in control of the immune system, the nervous system, right?

So that's at the top here of everything else. And so when our nervous system is upregulated, it's going to affect every single thing in our body. And, you know, that could be emotional or physical stress, right?

Physical stress could be blood sugar dysregulation. It could be some of these infections and things like that. And then the emotional stress is things that maybe are happening right now, right?

Like for kids, maybe it's a friend at school and for us as adults, you know, it could be work stress, money stress, you know, any of those things. But then our past trauma, right?

And I think what's really important to realize about trauma is trauma isn't always like these terrible things that we can hear that unfortunately happens to some people, right?

There is big T trauma, which is those really big things, but there's also little T trauma and even tiny t-trauma, right? So there's three. And so, you know, you may not have this big t-trauma with something really, really awful and horrible, but little t-trauma could be things like, I mean, even simple, and I mean, this, I think everyone can remember this, you know, you're a child and a grownup is towering over you.

right? Saying, you're not being a good girl. Shame on you, right? That's two things, right? That's trauma of like, you're not safe now because you're little and this person is like, you're yelling at you, right?

They're telling you're not good, right? So if we think about what happens from like a bigger picture, right? If someone is telling you're not good, right?

You interpret that as I am bad. Well, if you're bad, then you can't be loved. And if you can't be loved, then you're going to be rejected. And if you think back to like old times, right, if you're rejected out of the tribe, what's going to happen?

Well, you're going to get eaten by a bear or a tiger and you're going to be dead, right? So this kind of line, right, of you're not being a good girl, literally takes you back to I'm going to die.

It means like, I'm not gonna be loved, my needs are not gonna be met, and I'm not gonna survive. That is quite a stress, right? But it's not, we don't think of it in that way in the moment, but that's what, there's a loop that goes on in our brain.

Trauma, nervous system regulation, and inner child work

And so there's all of these things that could have happened to us that are always going. So they're on the surface, but it's constantly triggering and increasing our cortisol level.

And, you know, there's of course lots of different ways to support that. One of my favorites is actually doing inner child work. I do this a lot with myself and I actually do it a little bit with my kids, but kind of in real time, you know, because they are children.

Yeah. but I do a lot with myself. And, you know, there's not, I mean, there's, of course, different ways, but I find there's not really a wrong way to do it.

But sometimes if I feel something, and a lot of times, like, I can be triggered, or maybe someone looks at me a certain way, or says something negative, right?

And I'll feel like, oh, you know, and it makes me feel less than or whatever it is, right? It actually, and I do this a lot when I'm walking, because when I'm walking, like, it's almost this meditative suite.

And I literally like out loud talk to my little girl. I'm like, Hey, like, what are you feeling? What's happening? You know, and she'll say like, this person yelled at me.

I just feel like I just want to crawl in a hole and I don't know what to do. Right. And I literally just say, okay, like I'm going to hold you. We're okay.

Like, I know this person did this, but. look at like how much control we have over that. And I explained to her and I sometimes even like take her and say, hey, come with me into our life now and see that we're grown up now, right?

We don't have to worry about this. We have control. You know, we have more power. And like just having that conversation, there's again, like no right or wrong, but it's being there, holding her or him, right?

And kind of walking like them through what's going on. Yeah, so, so vital. It brings me back to it used to be every time somebody took their glasses off and went like this, the hairs on the back of my neck would go up and I would always be in this stress response.

I had no idea why until finally I realized that was my inner child because my dad always used to do that. before he would say he was disappointed in us or yell at us or anything.

And just that awareness, I was able to say to my inner child, you know, you're OK. And you are loved. You were loved then. He, you know, there's so much to unpack in that.

But you're right, the little T traumas, it's a phrase that I always remember is it's just a little turd. But you take a bunch of little turds, it becomes a big pile of crap.

Um, you know, and we all have tons of turds and our kids have tons of turds and we're all just doing the best we can. But if we can be aware of these things in ourselves, we can help our children to be aware of them too.

That's such great advice. Yeah. And I think for kids, you know, one of the things I do, cause I mean, it's not going to be the same inner child work, but.

One of the things I tell them is that I love you no matter what and I'm going to be always here for your new needs are going to be met because that's one of the things that I find is the biggest thing that that makes them feel safe, right?

Because if the body's not safe, it literally can't do anything. You can't heal it. Nothing is going to happen if your body's not safe. And it's amazing what can make us feel unsafe, anything, you know?

Right. But it's back to our saber-toothed tiger days. You know, that's what they're feeling like. Yeah. Yeah. And so

that's one thing I say to my little girl.

Sometimes, like, if I know she's feeling something, I don't even know what to say. I'll just say, whatever it is, you might be feeling alone, but I'm always here for you.

Your needs are always going to be met. And I'm going to love you unconditionally no matter what. And that instantly just calms me. And so then I say the same thing to my kids.

I mean, even if Jake is acting out or, you know, doing something, you know, and I'll say, listen, like, I know this, there's a lot happening, but I just want you to know I love you no matter what and your needs are always going to be met.

And it really helps. Yeah. Such great advice. So first of all, tell people how they can find you, how they could find the Thyrolove. Absolutely. So for Thyrolove, just go to Thyrolove.com.

Super easy. And then for everything else, it's enatoppler.com. And I have all of the different Thyword programs and support, podcasts, and lots of free information.

Well, that's great. And any last words of hope or advice you want to give to the families, the parents, the kids, the doctors, anybody that may be listening.

Yeah, well, you know, I think the biggest thing I would say is that there is hope. I mean, that's one of the things I talk about all the time that as much as I know it's so hard, like I really know it's hard, like I'm in it with you, like I know it's so hard, but there's always things that could be done.

Sometimes it's not a linear road and there is a little bit of. down and up and down and sideways and all different ways, but there's always something to do.

And if there's one road you're going down and it doesn't seem to be working, that's okay, right?

Hope, resources, and closing remarks

Like there is a hundred other roads and there's just so many different things and you just want to keep going. It's one foot in front of the other. And, you know, it's hard.

It is hard, but you got this. And, you know, there's so much support, like providers like you, Nancy, and all of the work that you do, you know, your book and, you know, there's just so much information in this podcast.

And so just keep on going. There's always hope. Well, such great advice. And there is. And it's not false hope. There is hope. And today may be a bad day.

But we're glad you're listening. And tomorrow will be better, especially if you listen to some of Ina's advice. So thanks so much for being here. I really appreciate it.

Thank you. That's it for today's episode of Demystifying Pan's Pandas. I hope you're walking away with insights, tools, and hope to help you and your child on this journey.

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And if you have a moment, leaving a review helps us reach even more families who deserve answers. Also, for more information, training, and community, check out our website, drohara.com, and join our annual membership.

And remember, every step forward, no matter how small, brings us closer to healing and understanding. Until next time, be present, be hopeful, and we look forward to seeing you next time on Demystifying Pan's Pandas.