The Hidden Signs of Pans and Pandas - And Why It Looks Like ADHD and Anxiety or Even Autism Transcript

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Introduction to PANS and PANDAS

So parents know something's wrong, but all those tests and professionals say it's normal. Dr. O'Hara, I am so grateful that you are here. This is truly a privilege.

You are beyond a legend and a pioneer and trailblazer in the world of autism and pand pandas. constantly coming off in Facebook groups and people are emailing me about is what are the signs of pans and pandas?

And what is the overlap between pans, pandAS and things like autism and anxiety and OCD? So welcome. I'm so glad you're here. Thank you, Roseanne, and right back at you at all those accolades.

And it's a privilege and an honor to be here. I think there are many things. First of all, by definition, the symptoms that a child has to B pans or pandas need to have abrupt onset at some point in time.

That could be when they're 15 months old or two years and that abrupt on set is speech loss or OCD or dramatic increase in OECD. So if that were abrupt at that time and they were diagnosed with autism, in fact, it could have been pans and pandas then, and there could've been an infectious or metabolic trigger that triggered the immune system to attack the brain and cause inflammation in the brains that led to those symptoms, OCD, anxiety, a restrictive eating disorder, et cetera.

But for this moniker, this Pan's Pandas monicker, there needs to be an abrupt onset at some point in time. That's the thing that sets it apart now. If you're talking about vector-borne diseases like Borrelia, Bartonella, Babesia.

If your talking mold, if you miss the abrupt onset, can it be subacute? Absolutely. But we need to use different terms. If we have no abrupt onset, we to call it autoimmune encephalitis of the basal ganglia associated with blah, blah blah.

Like strep or mycoplasma or Borrelia, just so that more practitioners can get on board with understanding this. And then I think the other thing is the OCD is part of it, but often we miss O CD.

because it's not the checking over and over again or the going in inside and out a door or doing things a certain way. Sometimes it is just intrusive thoughts and the child either doesn't understand it or is ashamed or embarrassed from those intusive thought, so shuts down.

or gets anxious over everything and you don't even see it as OCD, but that's what it is. And then I think the last thing I like to say about all of that is if anything happens in that neuropsych realm, the OCT, The anxiety that ticks to any of our children with any underlying diagnosis and with that comes any somatic symptoms.

like urinary frequency, urinery urgency, bedwetting, sleep disturbances, where all of a sudden they become a restless sleeper, then that's this disease and find somebody who's gonna listen.

Yeah, and so many pearls in what you said and I want to go back and unpack them. But for people that are new to Pans and Pandas, because people find this podcast, they find the YouTube channel all over the world and want you to lean into this and learn about Pants and Pandas because we don't have an army of providers who are the frontline workers really helping parents to understand it.

Defining abrupt onset and hidden symptoms

And most parents are discovering this on their own when they're like, what happened to my kid? Can you really

talk, can you just briefly explain what pans and pandas is and how it affects the brain?

Pandas was first. given that acronym in the 1990s by Sue Sweeto and others. And it stands for pediatric autoimmune neuropsychiatric disorders associated with strep.

So a child gets exposed to streps. They don't even have to have the strept symptoms themselves. they can just have behavioral changes or they get a strepinfection.

and within days to weeks to even up to three months, they then developed an abrupt onset of symptoms that includes OCD, restrictive eating disorder, and then two of other things like anxiety, tics, handwriting deterioration is pathognomonic, sensory overload, motor changes, baby talk, behavioral regression, then those somatic symptoms like urinary or sleep I just mentioned.

But what's happening in those kids that are genetically susceptible So again, it doesn't happen to everybody. It's genetics loads the gun, environment pulls the trigger.

So when they're genetically susceptible, those antibodies are proteins from the immune system that are supposed to be attacking the strep in the throat.

Instead, cross the blood-brain barrier at the criboform plate and etc. and cause inflammation in the basal ganglia. So those antibodies or proteins are supposed to be attacking the throat, getting rid of the strep infection.

They're not there. There's molecular mimicry or a misdirected immune response to the brain and that part of brain that then gets inflamed and causes these symptoms.

Well, this was all very controversial because- It sure was, Nancy. I always tell the story at one of the AAP, the American Academy of Pediatric Events, Sue Sweeto was asked to present for 18 minutes on pandas.

Did a lovely job showing all the research, everything that was going on. And then another gentleman was to rebut that. He showed pictures of pandAS, The Animal, for eighteen minutes.

Now, how do you come back to that? And there was no recrimination. There was, no, this is not okay from the AAP. So in- And that's where the doubt was where it's festered and really came to, it still there.

And people always ask me how that happened. It was a wonderful movie called My Kid Isn't Crazy that actually does a beautiful job showing, literally showing what happened and so it is important to talk about that because we want to empower the parents to push back when a provider says, this isn't fair.

Nancy, I have my last, probably last intern I'm ever going to have, and her name is Kat. And she's in a master's and social work program. So she brought it up, hands in pandas, because she has been working with me for many years.

Her professor said that doesn't exist and don't ever bring it in this class ever again. So Kat's trained by me, so she went to the head of the program and was basically told, don't bring it up with that professor.

And Kat was deeply concerned that we are not sharing this with frontline workers, which are mental health workers. That's the kind of, God, I don' want to use potty words, but the idiocy that happens and these opinions that form, anybody that's ever seen a child with PANS will never deny it.

Right, right. And just use the word pans. I just want to follow that up with in 2012, 30 clinicians, researchers got together to try to make this less controversial and made a bigger umbrella of pediatric acute onset neuropsychiatric syndrome, which was then to include Lyme, should be called vector borne diseases now because Lyne is just Borrelia burgdorffii and as you as I Both though there are hundreds of species, but I was to include that include mycoplasma, which can also cause very similar effects, viruses, metabolic changes like anesthesia, pesticides, mold, etc.

and it was supposed to make it less controversial. Well, three of the 30 wrote their own paper and called it cans. And it made it more controversial because I think it opened it up too much to then everything can be pans.

Because as we know, especially since COVID, any infection can induce an immune system reaction. and cause autoimmune encephalitis. And if it happens in the basal ganglia where the anxiety centers are and all of that, then it's gonna be these symptoms.

But I think we have to be clear in our definitions so that we can help more practitioners to see it. Oh, by the way, years ago, Aspire.care and their head Gabriella True and I I went to schools to talk to school nurses because they're on the front lines and we wanted them to understand it.

We sent a survey out to all clinicians in the state of Connecticut and many groups, including the psychiatrists, pediatricians, neurologists would not even fill out the survey.

because they said this doesn't exist.

How PANDAS affects the brain

So I think we need to get the word out as much as possible, but we to use the words correctly, appropriately, and maybe as Sue Sweeto said on my podcast, I wish I had never called it that.

I wished we still called an autoimmune encephalitis of the basal ganglia associated with streptococcal infection, because that's not a mouthful. And I'd wish she had called the Sweetoe disease, to do that and so I think we're left with a moniker that's gotten a very bad rap.

It really has. The disease is real, the symptoms are real and as my mentor always said, follow those who seek the truth but flee from those that have found it.

So anybody that says it doesn't exist, go find somebody who knows that it does. And there's so much more and all these are my first person I worked with with tick-borne illness was 1997 probably somewhere in there we're in the 90s where we started and and we had these patients we couldn't make sense of symptoms And we then started searching like this doesn't seem to fit anything.

What do you think in your clinical experience of all these decades, these years and thousands of patients, what do think are some of the hidden signs that really get ignored, even by parents and certainly by practitioners?

The hidden signs that get ignored, I think first are the somatic symptoms because one, the parents may not even realize it. The child does go to bed, but they're up for hours or they are restless and they don't see that as associated or the urinary symptoms.

I'd think that you need to ask for those. And then the one that I mentioned quickly, they handwriting deterioration. That's so classic. Like, like you have to see it and I mention the OCD, I think that gets missed because of the intrusive thoughts.

And I thing one of information, I mean the triggers that really gets miss a lot, especially in our area, is mold. Mold can be the grass, the weeds that are really the background.

Or the fact that I was saying, it's no longer Lyme. It should be called vector-borne diseases, not even tick-born. Because everybody will say, oh, I've never picked a tick off.

Well, number one is you and I both know that ticks are the size of poppy seeds. Two, It's not just ticks. Its fleas, its mosquitoes. Bartonella is cats, cat scratches.

it can even be dogs that have been infected by cats. And it's much, much more than that. And I also think that one of the big things is as doctors, especially, we're so dependent on lab tests.

And I have to say again and again, this is a clinical diagnosis. Lab tests may be totally normal because 40% of these children at least will have immune deficiency.

All of them have a immune dysregulation, meaning the immune system's not working right. But some of the will will be have frank deficiency, 40%, of though.

And they can't mount an immune response that you'll see in blood work. so that ASO and anti-DNAs be the doctors get. And they say, well, that's normal.

It can't be strep. No, it still can be. Or they don't test for the trigger that it is, like a virus we don' even have a test fo or COVID, which has been a huge post-infectious syndrome that causes, you know, That's what long COVID is.

Except in our kids it can come out looking like anxiety, OCD, brain fog. That' another one. I mean, I could go on and on, but slow processing. Yes, slowed processing, brain fog, all these symptoms.

And I think, Nancy, when you're getting people, you are like me, people come from all over the world. Please know that Dr. O'Hara is going to be retiring from clinical care so she can focus on training other people so that we have appropriately trained providers all around the World.

We need an army because this isn't a rare condition. People make it sound like it is. But when people are coming to you and they're looking back and making sense out of all of the symptoms, what I have seen a real change, particularly since COVID, is that there's this slow waxing and waning that they start to see a little anxiety or they look like they are ADD all the sudden.

They see cognitive brain symptoms, psychiatric symptoms that start at a lower level. And we're definitely going to get back to OCD before I see physical things.

Now, I used to see a lot more physical problems that would start with people coordination or different things that, constant infections and those kinds of things.

Why the diagnosis remains controversial

Not that I don't see that but now I'm seeing a lot more of those early signs which can really overlap and make you feel like you have OCD and anxiety and all these other things, not to say they're not part of this.

So my question is when you're with your people and you are looking back, are you seeing it's starting to kindle on the mental health side or more in the physical side, or you just seeing both?

I see both, but it does tell me something. So if they've got that slow roll, like you're talking about, I really am digging in to mold. I'm not taking it at face value that no, we don't have any mold in our house.

Well, what's your shower look like? Well did you have a leak under the sink? What about the basement or the attic? Oh yeah, well my husband took care of that by himself.

There's a big red flag right there. Not that we do not trust you dads out there, I also think about tick-borne diseases in those cases, particularly Bartonella and Borrelia.

And if there's more dysautonomia, dysregulation of the autonomic or automatic nervous system, like the temperature control problems, the nausea, those sort of slow roll kind of things, I'm thinking about Babesia and then as you've talked about COVID, since COVID Yes, I've seen a lot more of that because I think that that has reactivated other dormant infections that may be coming out.

Think about dorman infections like a cold sore. If you have a herpes cold sores, It may not be there 90% of the time, 70% percent of time. But when you get stressed, when get another infection, then it pops out.

That's a dormant infection that is re-triggered or reactivated by some other stressor. And we're seeing that a lot with COVID, with reactiving other viruses, EBV, CMV herpes, reactivating tick-borne diseases or something else.

And those kids are showing themselves much more with slow processing, brain fog, that ADD, ADHD kind of thing. When you dig, you find the triggers. Yeah, so fascinating and you gave away so much value in there because these are the questions that I know we're constantly getting.

And when we are talking about OCD, because I really want to talk about that because agree with you completely, I feel that it's missed. And everyone thinks, because of TV and people talking about their OCD, that you need an outward compulsion, like checking or hand washing.

And people always say, well, I don't hand wash. That means I do have OECD. The way that it works in the brain is an intrusive thought that gets stuck on, and you're avoiding a fearful thing, a bad thing from happening.

You're 100% right. What makes people not talk about it? First of all, sometimes, that fear is always there. And the child or now the adult doesn't even know that they shouldn't have it.

Exactly. But they also are afraid to talk about it because intrusive thoughts are often dark, disturbing, they can be sexual, and it's embarrassing. Right.

They also wax and wane, depending on different stressors. So it is something that is absolutely there now. When we talk Because you said this, and this is so important, because everybody always says, what test should I take to determine?

And there isn't a single test, as you've said, it is a clinical diagnosis. So if a parent is listening and they're like, holy cow, I'm thinking my kid might have PANS, there was a sudden onset, they haven't been the same ever since.

They were a happy kid, now they have X, Y, and Z, plus they had constant illnesses. I notice a difference. When they get an illness, the decline. There's so many things around that that we could go on and on.

But if they're suspecting it, what steps should they take? So I think, one, I just want to say that even if you're listening and that acute onset was 10 years ago, three years, ago they can still get better.

Don't give up. You can find help. But none of this is a quick fix. It's a marathon. especially if it's been going on as many of the people on my very long waiting list can attest to, it has been on for a long time.

But I think number one, you go to somebody who has known your child, maybe your pediatrician, And say, look, I found this and take them something. It can be research articles.

The 2017 journal of adolescent and psychopharmacology has the whole section in February around pans pandas. There are many great books. I wrote a book, demystifying pans panda.

Scott Antoine wrote. Comprehensive guide, um, to the management of pans. Pandas there are. Groups aspire.care. Pan's Pandas Network, Look Foundation, go to them, talk to, them get resources.

They all have chat groups, talked to other moms, get emboldened to understand this. And then if you're a pediatrician or somebody you know hasn't looked at it, look for another practitioner.

It doesn't have to be a doctor. Doesn't it have be an MD or DO.

Common missed signs and triggers

It could be a health coach, a naturopath, the social worker, or a psychologist, just somebody that understands and will listen and your child get started on that journey.

There are in my book as well as Scott's books, regular lab, conventional lab blood work that we do consider because even though the streptiters can be negative, It may not have been strep.

You want to check for tha markers that are positive a sedrate, an ESR, you know, those can give you information. So there are regular labs you can ask your pediatrician to do, but again, find somebody that listens.

That's really what you need. So critical, truly, Nancy, because you go to somebody and they say, well, this doesn't exist or your kid doesn' meet this criteria.

And that's what we see a lot. They're told your kids don't meet these criteria because they're not educated. So you do have to go somebody, you know, look at the math doctors list.

Go to Aspire.care. These are providers that have some level of training to at least have an educated discussion. Maybe they're not your treating provider, but they could guide you in that direction.

I think that's so critical. And so much can be done without medications, too. Yeah. But I want to remind people there are tremendous nutraceuticals, botanicals herbals that, especially if it's chronic, may be more helpful than the prescription antibiotics or other medications.

And say that, that is so important because people are looking for the fix. Right. Now. It's not a quick fix. It is not. And the other thing I wanted to say along those lines, I've talked to many psychologists on my podcast and in my career, and there's a type of therapy called space, which is a family centered therapy that's trying to get rid of the anxiety or the OCD.

Because one of things I, yes, we can, dampen that down. But while you're dealing with it, there are lots of ways to not feed the beast of the disease, to feed, the, anxiety to make it part of when my son was diagnosed with this disease.

One of things I always say is that I tried to help him see that he could take care of this. He could pick him up by his bootstraps. and do it. He still doesn't believe he ever had Pan's Pandas, so hopefully he's not watching this, but that's okay with me because I was able to do the things I needed to, do but also he was to figure out how to manage his anxiety or OCD when it does flare.

because it may flare for other infections or everything he's come across in his life. Borrelia and strep first, but then it was viruses and Bartonella and Babesia, and mold and COVID and girlfriends.

There are stressors all your life, exactly. So we need to give our kids tools to deal with this. And yes, it can be wonderful things like neurofeedback and nutraceuticals and herbals, And I often tell this story, and I'll tell it really quickly.

When my son was in college, you know, he had been through a lot. And he said to me the first day we were together for about four days, mom, I'm off, just off.

Four nights I was up all night long thinking, is it the Borrelia? Is it The Bartonella? is at the mold? It is COVID? What is, what am I missing? what does he need to do?

And all of this. At the end of four day and no sleep on my part, He said, Mom, it's about a girl. And it reminded me that I had so much PTSD and so many fear myself that i needed to go back and put my own oxygen mask on.

So I get it. I understand what parents are going through and also what kids are doing through. And so hold space for yourself. that give yourself the room to breathe, the rooms to meditate, to walk, whatever it may be, and help your child to do that as you find the practitioners who will listen.

And that's so important because you talked about hope. And I feel that a lot of times in the Pans Pandas community, people lose that hope, they lose their faith.

And it's because they're not regulating themselves first. They're NOT putting that oxygen mask on. You're Not going to be capable of giving yourself space and grace and also logical reasoning when there's a little bit of a flare up, because a lot of times we know both as PAN's moms that when your kid is having a setback, we're thinking we are going back to ground zero.

That is not what's going to happen. When you are taking time, it can be small amounts of time. We're not talking about getting a massage every day, which would be lovely, but not realistic.

You can be that regulating source for your child, your young adult. I mean, this is all hard stuff. This is not easy stuff, nobody signs up for this. to give you a food train every day.

This is like, what the heck is this? And that kid looks crazy, really, truly, and people get scared. And so your support networks might not even be there.

So you really have to, it's an inside job. You have do things for yourself and keep yourself keep that hope alive, which I think is very hard. Very hard and, but very important.

One of the quotes I love, I've gotten through 100% of my horrible days. And you have and remind yourself of that or horrible hours or whatever. and also all of this is for you, But it's also modeling the behavior for your child.

When you lose it, which you're going to, you are not going be your best self every moment of every day.

OCD, anxiety, and clinical evaluation

None of us can and none of should. You know, we're all perfect and you're perfect. And give yourself grace for that too, as Rosanne and I both do. It's also modeling it and modeling when you do fail to your child saying, hey, you know what?

I yelled at you yesterday and, I'm really sorry. I know you weren't being yourself and it wasn't you. and i'm sorry I reacted that way, but mommy's not perfect either.

The other thing that I find helps families a lot is naming that part of that child that is going through the flare. Actually giving it another name, whether it be Cheeky or Gertrude or some Minecraft or Halo character, I don't care what it is, something that's either funny or that the child can get angry at that separates it from the wonderful human they are.

and that they were before this disease and they will be again. Because it helps them separate that piece that don't understand and gives them some space from it too.

It's a powerful technique. We do that very much in the mental health world, especially with OCD, where it feels like that part of your brain is it's a foreign thing and you don't want your child to think that is who you are and naming it can be really incredibly powerful in such a really simplistic way.

I love that. So a lot of times, you have such extensive experience in autism, that's where you started, and then you really started to see the overlap.

When you are seeing a child on that autism spectrum, when do you start to think this is pans? Or even, because now so many of the cases you're really are leading in pans and pandas, What does it look like this overlap?

Because I think both you and I see a lot of people who are on the spectrum and why is it so important to identify this because really it can lead to a Reduction in symptoms.

We're not saying you shouldn't be autistic, which is a very sensitive subject in the autism world We are saying, you have less of things that are holding you back.

Yeah And I always say it, we are just trying to help each person reach their fullest potential and their healthiest life. Being neurodivergent is not something we're trying to change.

It's not what we are trying make different, but we'd like you to be healthier and without constipation or sleeping well overnight or learning how to deal with things that intrude on you like OCD or anxiety or things like that.

So that's number one. Number two is I think if we get away from the monikers of pans pandas, in my opinion, almost every child with autism has inflammation in their brain, if not everyone.

So autoimmune encephalitis is just the immune system attacking the brain and causing inflammation there. Whether you call it pans Pandas or not, a lot of these nutraceuticals and herbals and therapies can still help because there's inflammation in the brain no matter what.

And then to answer your question directly, I think so much of the time the triggers of disease are being missed. Or there has been reading that it's gotta be this.

It's got to be the dairy now because of cerebral folate deficiency, or it has got be be vaccine because the MMR live virus vaccine. The thing to remember is it is never any one thing for everybody.

Your child is a unique individual. And what I'm trying to train practitioners to do is to look at the end of one in front of you. So you as parents can do that.

What was it that changed with my child? And how did it change? What were the things that happened in the few months before that change. Go back and look pictures, look videos, try to figure that out.

Get your medical records. and your house record. So much of the time, I'll have somebody come in with a 12-year-old with autism and I say, okay, we're going to go back to when this started at 15 months.

And they're gone back through the history and all of a sudden they remember, well, yeah, had to move out for a couple of months then because of leak in the attic.

I'm like, there you go. Let's go to that. Look for that in your child. So all of those are really important things to do in all our kids, but especially our children with other diagnoses.

It can be ASD, it can ODD, ADHD, ADD. There may well be triggers, or it may not be just genetic, because in my opinion, almost nothing in this world, including diabetes.

Yeah, there's a genetic predisposition, but it's virus that brings on the symptoms. Everything follows that model of genetic susceptibility and environmental trigger.

And we can impact the genetic susceptible by going around that defect or whatever, But we definitely treat and overcome the triggers. And that's such a powerful statement coming from a medical doctor.

And I think parents really need to go back and listen to that because we are led to believe that everything is genetic. Also, once it shows up, there's nothing you can do.

There's only psych meds. No.

What to do if you suspect PANS

What you do in your lifestyle, Every day has an impact and we and even if you think about this from your own lens like you decide to do a little diet because you want to lose five pounds and so you you go to a paleo type diet for for short amount of time you like.

Wow, my energy is better. My brain feels less foggy because those foods are giving you more nutrients. They're

helping detoxify. And that's just one small example of little tiny things.

That's not a little, tiny thing. Food is a huge thing and it's food is medicine. By the way, one of the things I always preach to practitioners and talk to parents about is don't talk about restricting.

Don't take about taking away before you put in something good. So for example, you were just talking about the paleo diet, the protein. What do most of our kids have in the morning in our sad, standard American diets?

Yep. Bagels, cereal, pancakes, muffins. There's no protein there. They need protein in My kid's not going to eat eggs. I can't make bacon or nitrate free and all that stuff.

Well, you could add a little bit of protein powder. You could use that leftover chicken from the night before, the steak from that night and give them that.

Get a protein bar as they're walking out the door to get on the bus, whatever it is. adding that one thing, that healthy thing. And that's the part of the modeling too.

When parents are trying to get their kids to do it, they better be doing it themselves. Oh, it's such a big deal. Plus, I try to tell my parents what you're doing in your 30s, 40s and 50s is actually going to determine your quality of life.

in your 60s, 70s and 80s. And beyond. So why wouldn't you want to just do this for yourself? Why wouldn' you have that self-love? Exactly. Your palate really changes when you eat differently.

You might think, well, I'm really going to miss this or I am really gonna miss that. No, you're not. Because you are actually going create healthy foods and things like that and it's just part of what you wanna do.

People always say, what can I do to help my child heal faster. Well, you can bring these things into your home. Know that some kids are restrictive and you once you start, regulating the nervous system, You start putting those nutrients in.

You get those buggies and infections and all these. Things you get them back under control. It will be easier. overnight. Exactly. And as you've talked about, like magnesium, that you have a great product that, you talk about that little change, not allowing your child to be as constipated or helping the brain fog a little bit with that make a huge difference.

Zinc. So many of our kids are deficient in zinc and that makes everything taste like starch shirts. You get their zinc levels back up, their palate expands.

You know, there are so many little things that can make such a difference. We just need to listen and figure out what they are. As a kid, I always used to read those Nancy Drew books.

Partly my name, partly I loved all that detective work, but I was scared to death of the dark. So my detective now is as a doctor. And I think being a detective and a teacher is really what practice of medicine, the clinical practice, of what you do, what I do.

What we all should do is rewarding, it's challenging, but that's what we need to do to help our families. And parents need understand that every little thing that you talked about, like, oh, we had to leave our house for a couple months when they worked on a leak, or oh they had a difficult birth.

Every little piece matters. Even when another physician or provider has told you it doesn't, please consider that you want to give details. I love, I ask for, and not everybody gives it to me, actually a running record of a timeline of issues because when you're going to a good detective, they're gonna look at it through a different lens, through clinical experience.

And so just because something's been dismissed by somebody else doesn't mean that that is the truth. Right. You

wanna make sure your person has a lens of experience to look what this is, because again, it's not very likely to lead to a magic wand.

Oh, you absolutely must have IVIG. you need to be on antibiotics six months. Maybe it does. But most likely it's going to lead to a lot of little things that you can integrate into your lifestyle, which food is a hard thing for people, but it could mean a of things like essential oil might help or an air filter and lifestyle components really do make a difference.

And I just want to emphasize that to people because they get very overwhelmed and uncertain if they're making a different. And I would say, I totally agree with you.

And when you leave this podcast or any that you listen to, take one thing, one next step. Don't get overwhelmed by doing it all. Pick one think that's you've heard that, you think could help your child.

Maybe practicing breathing, maybe starting a garden box, Maybe getting out for walks more. maybe adding protein in the morning, may be adding the magnesium or the zinc.

Treatment, lifestyle support, and family coping

One thing. that can help you move in the right direction. And also, don't give up on it too fast. So much of the time I hear, oh, I started it and it didn't work in a week, and I stopped it.

As one of my other mentors, Maura McDonald, always said, you got to take them through a door, not the window. And so much of the time, by the times I've seen them, the parents are saying, I did that, well, how long did you do it?

What brand did use? When were you doing it. There's so many, you're trying to put an antimicrobial in when the kid's totally constipated, it's not going to work.

The kid is going get worse. You're going a die off reaction. All of those things matter. So even if you've been in this game, it's not a game I know, but working and struggling through this for a decade, go back, look again, think about something you may have tried years ago that now resonates a little bit differently that you want to try again.

And they might have done it out of order. So like you mentioned, like, so you're adding anti-microbials, but you are constipated. We have to say what are the systems in the body that will allow for healing?

So the nervous system, detoxification, elimination, I say this all the time, I'm in shock at how much constipation and how long people go without pooping and long they live with it, whether it's them as an adult or their kids.

If you are not eliminating, those toxins are just going back and recirculating and not going to allow anything to happen. But I feel that people sometimes keep looking for the big thing without looking at the systems and making sure that we're really saying, okay, these things have to be working.

And so when you talk about something that didn't work before, it is often because of that. Right. Yeah, for sure. So when we talk diagnosis, because again, that's just one of the biggest, biggest things that really struggle with?

What do you think in all these thousands of people you work with, what do feel like is the greatest mistake they make in terms or, or not even they may make, What is greatest hurdle or actual mistake a parent makes to prevent them from getting a diagnosis, proper help?

I think it is very depending on the family. So I don't think there's one answer that fits everybody, but the things I see most are one giving up too soon.

especially if the tick-borne disease, vector-born disease was congenital or happened very early in life, it can take many, many months, sometimes years to recover from it, depending on how long you've had it.

So giving up too soon. Second is starting everything at once, throwing the kitchen sink at the kid and thinking it's going to get better. You've got to start things one at a time.

and increase start low and increased slowly. That is also a big mistake people make. And third is sticking with somebody and trying to convince them that this is what needs to be done.

Or if it doesn't trust your gut, you know your child better than any practitioner and you will always know you child. We're here to help you. I always use the GPS analogy.

Let me tell you what route to go down. It may be a pushy GPS, but you're still driving the car. And so you have to feed back to me, you know what, that isn't working for me.

But if the practitioner is not listening to that, then go to medmaps.org, go aspire.care, to the Look Foundation, Go to ILADS, which is the Lyme Associated Diseases Society.

Find a practitioner who will listen, who you fit with. I mean, it's not going to be me necessarily, but there are so many good practitioners out there.

And one may be a great fit for you, and it wouldn't be good fit me. But find one that is a good for fit you. Also, join these groups, not just online chat groups.

I think you need to join a coffee group online, someplace where you can interact with people. The isolation. The thinking that you've got to do it on your own also keeps you as a parent and your child from getting better.

There is a village. So true. And I think some of this because these kids have mental health issues. There's there's an embarrassment, there is a stigma.

My first chapter in my book is called The Bitches on the Bus Stop for a reason, because it's really about that isolated journey that we all take. when our kid is outwardly dysregulated and people don't know what to make of it.

So they often just avoid you and that's their own stuff in it and it is very painful and this is scary because you're trying to navigate it I would also add that who you are following online Be careful.

Make sure you're following a credentialed person. Join, like Nancy, she has education groups.

Autism overlap, healing, and hope

Be in a place where you know you are getting qualified information because there is a lot of misinformation, especially in the Facebook groups and people are can be incredibly helpful, but they also are very fearful.

Is this a good book? Should I get it? And I was like, everybody should have this book. Because again, it's about getting the right information so you can educate yourself properly, not just for the care of your child, so that you feel empowered when you're talking to providers.

It's such a big deal. But for parents, what's the message of hope you would like to give parents who feel dismissed or overwhelmed or just stuck because so many people are dealing with this for years?

Or more. You are constantly, you're always really creating a container for the people you work with and teaching that compassion to practitioners. What would you like to leave off with parents who are really feeling very stuck?

Have compassion for yourself. Have compassion for your practitioner who may not get it every time. And have compassion your child. Model that. Know that this will get better.

Read Roseanne's book too because it gives you a lot of great advice, by the way. My book is now available on audio and it has five new chapters that are not in the paper book.

on Borrelia, Bartonella, Babesia COVID and Mold. So the audio book has even more information than this one. We'll have that link up, Nancy. I think so many of us, I love an audio box.

Oh, absolutely. The audio and the print. And I that it's really so incredibly helpful. You have an amazing podcast as well. Everything I do is demystifying Pan's Pandas.

That's the podcast and it's really, you know, I had a lovely little boy on recently who is 10. and almost on the other side of Pan's Pandas, but still dealing with it and gives great analogies, all the things you talk about in your book about the bus stop stuff and all of that and the way that that he feels about it.

And the. Way he deals with. It and and. All of these little things, whether they be a podcast, my membership, which there's an upcoming 50% off coming.

Watch for that on Instagram. Ways to learn and connect are so important. But as Rosanne said, do it with people that you can trust that are getting the information out there and are not just complaining about how bad things are.

That negative energy brings all of us down. Go forth with compassion, kindness, and hope, because this can get better. If you start the day that way, it'll be a little bit better today.

Oh, such important words. And truly, you are an inspiration for so many practitioners and families. You are a godsend. Thank you for leading us and educating us.

The idea that compassion is the thing we need more than anything else, it is very powerful. I don't think people talk enough about that. And thank you for all you are doing.

It's amazing. Thank you. Amazing. And make sure to check out the notes and this won't be our final discussion. We'll be talking more about this.