Opening Hope and Family Coping

on that moment when your kid has knocked over the TV in a rage or crumpled in their bed having crippling OCD fears that are absolutely disabilitating and you're like, what am I going to do?

How am I ever going to get my kid out of the house? How am I going to get my kid to the doctor to even get help? How am I going to find a doctor? Just keep holding on to hope.

We know that kids can get better. If they're not 100% better, they're much better and will take much. I do everything in increments of 5% frankly, but.

Just keep holding onto hope. Keep trying to find one thing a day that you're grateful for. It gives you a little bit of a thing to hold onto, a tether of normalcy.

And know it's okay when you're in it. You don't have to live up to what the neighbor's doing. It may not be what our expectations were as a parent when we were pregnant or giving birth or getting married and thinking about our future.

We didn't envision this, no. And we're gonna have to shift our thinking, and that's okay. Shift it. You're not on anybody else's timeline. Forget everybody else's timeline.

Meet your kid where they're at every single day. And be gentle with yourself. Go to therapy yourself. Put your siblings in therapy too. We all need it.

This is a family diagnosis.

Introducing Gabriella True and ASPIRE

It's not just the kiddo. We have to take care of ourselves to some degree. I know it's harder during other times than sometimes, but just do something and just keep holding on top because it's out there and you can find it.

This is Doctor Talks, real talk from real doctors on the issues that matter to you most. Hi everybody. It's Dr. Nancy O'Hara, and I'm really honored to welcome Gabriella True to the podcast.

She's the president of ASPIRE, which stands for Alliance to Solve PANS and Immune-related Encephalopathies. And it's a national nonprofit dedicated to raising awareness, education, and support for PANS Pandas.

And I know firsthand that under her leadership, ASPIRE has developed very impactful programs for families, for schools, for healthcare providers, for legislators, and there's been over 150 professional development lectures for educators, school nurses, and ASPIRE offers ongoing resources such as toolkits, a library of educational webinars, peer-led chit chat support groups that connect families navigating this devastating but treatable disease.

She's got decades of experience in PANS and the autism communities, including 15 years of volunteer work for the autism community in action, which is TACA.

She's a founding member of the Connecticut PANS Pandas Partnership and former president of New England PANS. And then of course, together we served on Connecticut's PANS Pandas Advisory Council.

She's the mother of two children with PANS, one of whom also has autism. She brings so much professional

expertise, personal insight to her work. And I'm just thrilled to welcome Gabriella to the podcast.

Thanks for being here. Thank you so much for having me. It's such an honor. And I always love to spend time with Dr. O'Hara. She's been a guiding force and revered mentor of mine for many years.

And so I'm thrilled to be here today and talking to everybody listening. Yeah, well, thank you. And the feeling is mutual. But tell everybody how you got here, how you got to this position.

well you know i got here like a lot of people do confused a little freaked out or a lot freaked out and just like what what's happening where's my kid why is he so different um i think that's a common theme with all of us parents um we had a kid no matter of their neuro functioning for us it was Well, it was both kids, but we really knew it about Timmy.

And Timmy is the one that also has autism. And he was a really chill autism kid. I mean, he didn't have OCD.

Timmyu2019s Sudden PANS Symptoms

He just had severe stimming, severe communication problems. And those were, you know, his really big autism, you know, criteria. but with some intellectual disability in there for real, not just because we're missing it.

Anyway, so, and one day he just wasn't any of that. He was screaming, crying, shaking. We'd send him to school. My boys went to different districts and this is how the morning would go.

I would get him on the bus. I'd come upstairs, get Xander on the bus, go back upstairs, put proper clothes on, brush my hair. grab a coffee and start to walk downstairs because at that moment the Timmy school would call and say he's inconsolable, he's crying so hard he just threw up.

And this was this routine out of nowhere and nobody had anybody idea what was happening. Luckily we were already with a MAPS doctor or maybe in between one.

I had already started volunteering with Taka. So Pandas was already on the table of something that we knew about even back in 2009-ish, which is pretty early.

Yeah. And so A lot of people with in the autism world, when they could as pans, everything gets addressed. So it's just autism. It's just autism. But because we were talking, we sort of had the opposite.

It was like, well, if there's something wrong, what's going on? Like, there's a medical issue here. So we were lucky, really, really lucky by proximity that we're living in Southern California, where they're based.

And I remember talking to a couple of the friends and they're like, well, this isn't Timothy. He's totally different. And he was having a severe separation anxiety, very rigid in school, couldn't switch on his car seats, you know, on the sides without going bananas.

he was peeing more, he was still in diapers, but the amount of diapers we were going through was like a lot. He didn't know how to, we didn't even know about handwriting changes and some of the symptoms back then, but it's a little hard to figure out OCD in a non-verbal low-functioning kit.

So there was a little bit of a learning curve on that with this, but luckily we were able to see, you know, MAPS doctor and We flew to Florida to see Dr.

Rosignol, and he doesn't diagnose a lot of kids with autism that have PANS. He's very cautious, but he was just like, okay. This story is pretty different.

And so I remember him writing a prescription, turning it to my mom. He goes, go pick that up. It was for my son. Oh, and he had a tick that we didn't know if it was a tick or a GI thing that he was stretching his neck.

So there's a lot going on and a lot of good questioning, which is what you should do with pants. Like you've got to keep questioning. You don't want to just assume.

And I know you do the same thing, Dr. Herr, with like peeling back the layers of the president or the president or the onion or whichever metaphor you want to use.

We did a bunch of blood work and the zithromycin stopped certain things within about three days. We went to Disney World. Disney World, yeah, that's the one in Florida.

And so at that point, he was just like, it really looks like pans, but let's finish out the course of the zithromycin, which wasn't a particularly long one.

And within a day and a half of being off of that, he started ticking again and being just not comfortable in his own skin, not lone OCD look that we could tell, but more rigidity, all these things.

And we went back on it and it went away. And so we went down that path for a long time and then we moved to Connecticut and then we started seeing Dr.

Hara. And after that, my other son, We should have been diagnosed way earlier, but like us, so many other people, you don't recognize the signs of OCD.

You don't understand what it looks like. It takes 10 to 15 years for an adult to get diagnosed with OCD. Pediatricians don't understand it. Therapists don't understand it.

They do not see it. They see anxiety, the aggression, and all those. They don't see where there's a mental compulsion, especially if we have compulsion.

So he went under- Right, especially the intrusive thoughts. Right. Yeah. And so that was our biggest hindrance to care, because we just didn't even put those pieces together.

And he was the one bringing in strep. He was the one with the repeated strep infection. So we were just pretty clueless. until about late middle school when there was a big crisis.

That was really scary. And thank God we had help from you. And he got diagnosed pretty much right away from all of our historical knowledge with all the classic symptoms in the past and all those.

Xanderu2019s Later Diagnosis and Treatment

And he did a lot better on, you know, antibiotics and other supplements and everything like that, you know, a lot of anti-inflammatories. But in that path of getting, before Xander getting diagnosed, you know, when we moved to Connecticut, another fellow patient, now one of my best friends, he called up because, so we got this.

We want to put on a conference with New England Pans Pandas, but I don't know if anybody's actually been to a conference. And I was like, I don't have time.

I'm running to talk a chapter, Connecticut chapter. And he's like, come on. And so I ended up running that conference and Dr. Harris, one of the speakers, it was 2015 and it was a great success.

We had about 200 people. And from there, I became president of New England Pans Pandas. And that, you know, really Developing a lot of programs that because every, you know, this advocacy world was so much in its infancy that everything you created was basically new.

You know, it didn't this before, like basic posters, basic hand, one page flyers to even just hand to anybody. They weren't tailored for anybody. They were just basic information about what hands and pandas are.

And then from there, talking with school nurses, going to some lectures with you, Dr. Hara and me. I remember it was, you know, we definitely had a good dog and pony show for a little while.

It was so fun. And so Dr. Hara do most or all of the lecture, or sometimes I would do the school part. And then from there, we develop, I developed the school lecture part working with Patty Dorn, who wrote one of the Pan's Panda School books, which is one of the best books out there still, and a few other educators, and creating this great program that we've now developed into Aspire.

And then we created Aspire because at that point, in the infancy of this advocacy world, it just seems silly for every organization to write their own, what I call, roast chicken recipe, okay?

Why? Why do we need everybody to have to really wordsmith everything to sound a little different from the other so nobody's plagiarizing and having to design it?

And my biggest thing was, well, how many people have a treasurer that really wants to be treasurer on their nonprofit and no one raised their hand? And I said, well, if we come together, then we only need one person that's going to suck it up to do this hard job.

And, and, and that took a really long time, way longer than it should have, but it, you know, there's a time and place for everything and we met with Dr.

Sweto and we went through a plan, you know, I had a pretty good vision of what it could be. If you build it with your, they will come, you might not. fill an entire stadium the first night, but you build some foundations and you keep growing and growing and growing and growing as you go along, keeping in mind that everybody's a volunteer with sick kids.

So you have to work to your strengths and your volunteer strengths. And Dr. Suido said, please, please found this organization today. I will help you and we'll get it going.

And from there, we did. And that's where we are today. And so that's sort of in a nutshell. Well, it is such a great organization and so many resources for so many families.

And a couple of things I want to unpack from everything you just said. I mean, first of all, you've been through so much with both of your boys, with your family.

And I'm always looking for silver linings. And the silver lining for the rest of us is it brought you to this disease and to found this organization and to help so many more families.

You also mentioned MAPS, which for those who do not know is the Medical Academy of Pediatrics and Special Needs that's been around for a while, but has reactivated itself in a very good way in the last couple of years and is now a very strong organization for training physicians and all clinicians.

in taking care of children with special needs, which includes PANS Pandas, as well as autism and other groups. And then getting to ASPIRE. ASPIRE has been one of those great organizations that does exactly what it says to help solve PANS and immune-related encephalopathies in so many ways.

Building Conferences and ASPIRE

So let's talk about, first of all, the family support from the ASPIRE programs. What does that involve? Um, you know, that's really sort of where our heart is, is you come into this, you know, we were all parents sitting around this table, working in this field for many years, talking to families, living as a family.

And, and it's overwhelming. It's scary. It's dark. It's lonely. Very isolating and and how do you go from the depths of hell. And not having any concept of what to do next or that you can think that you can.

And we can't be in your living room doing that with you physically, but we want you to and we can't ourselves cure your kid or put your kiddo into lasting remission or adult into lasting remission.

But what we try to do is to empower families along the way so that they understand the disorder, they can speak to this disorder, to whomever, in a well-thought-out, educated way, where they understand the materials, you know?

And then also, at the same time, create a sense of community, because I would be lost without my parents, parents, friends. lost. And so, you know, we really strive to do that two pronged thing in different ways through education and family support.

So tremendous amount of materials, webinars on on the site. And what about the the chit chat groups? So with the chit chat groups, you know, it Working with talk and everything we had done you know coffee talks and pair to parent, and it's really about creating that community and saying, being able to look to someone say, Oh, you're in the same boat as me sinking boat that it may be with a fire on the back of the bow.

You know, when I'm my kids raging at 4 a.m. I can sit at the top of the stairs and say, I'm not alone. I'm not alone. I'm not alone. And how do you do that?

So we have an aspire Facebook group, which was an easy thing to set up. And it's not really busy all the time, which is kind of nice because it's not as overwhelming as some of the bigger ones.

And we have. What we call chit chat groups, which are mostly on zoom, but in person in some places and in persons week if you're living in that area and want to lead one please call me I can we can talk and go over the rules and how it works and set them up because those are easy, but really they're just.

Me talking, I don't come in, I'm in most of the Zooms because I have to set them up and I like talking to parents. So, but we have state leads or regional leads that are or actually topic.

experts so this week or next week we have a restricted eating topic one another topic is parents of adults with pans because sometimes this isn't clearing up it magically at 18 with the tincture of time and it's a kind of a different deal when your kid is 25 or 35 and still suffering and how we adjust as parents and what do we do and how do we manage those expectations.

We have an adult chat for adult patients so that they can talk and we have South Carolina, North Carolina regionals and mostly we go around the room and talk about because we often have a pretty big crowd so we sort of say a little introduction about ourselves and whatever people are comfortable sharing.

Family Support and Chit Chat Groups

if they're comfortable sharing and say one thing that they want to work on and I know there's a lot of things you could work on but within a limit to one for this and say one thing you're grateful for because even when your kid is suicidal in a psychiatric ward not getting medical treatment and you're totally freaking out at least when you stubbed your toe you didn't break both toes only one and and that was one of mine one day and so This disorder is so hard and so sometimes you just hope is so important and having one glimmer of something that's like.

A touchstone out of this disorder that I find to be very helpful and then with all the things that we work on. Sometimes it's the leader really helping that.

And sometimes it's really the group talking it through, you know, more of a small crowd source situation. A lot of those situations that, you know, you might not have listed that I need more help and getting more help on my IEP.

You didn't say that one, but mom five did. And so you end up covering a whole range of topics and symptoms and the solutions and. Really, sometimes there's just education.

A lot of the parents don't actually know what all the symptoms are. And so we're like, no, no, that is a symptom.

And then I show them, let me share the screen for a second, like a little four minute lecture or whatever, try to keep it at the minimum.

And I think these are so important. In several of the podcast interviews I've done, I've talked to people, social workers, parents, practitioners, just about the PTSD of being a caregiver.

in this disease and you know I think that being there to support each other to get appropriate information but also you know to not forget the one small step that you may make as well as that saying that one thing you're grateful for, no matter, you know, if it's just, I broke one toe rather than two, you know, it's something.

And it's good for a laugh from the rest of us that reminds us, okay, yeah, I didn't even stub one toe today, I'm okay. yeah i'm okay so it's great it's really good and then you know we put up links to our toolkits or our some of our webinars or to our pad you know i could link something to one of your podcasts or something that another organization put up um and then we also use them to sort of get people involved legislatively boots on the ground within their state so they can be really you know None of them are ever the same.

Right. And I never can predict how a meeting is going to be or what we're going to talk about that day, which is sort of the beauty of it. But it's been a great resource, and we would like to expand it when we can in sensible ways.

So people can find out about that on aspire.care. Also on Instagram, Facebook, you're often posting about when they are, the ones that are by Zoom, the ones that are regional, etc.

So people can find it. Yeah. Yeah. And we just message people back and try to set up a meeting and talk about different things. So it's great depending on our schedule when we can get those meetings and going.

But yeah. And then you also do a lot of aspire with school education. And you mentioned how you and I were the dog and pony show in Connecticut years ago.

And that was a lot of fun. But you're still doing it and and aspire has a large library of supportive materials in services for teachers, school nurses, can you talk a little bit about that.

Yeah, absolutely. So, in that build it they will come in this programs really. You started off small and then we keep adding to our resource libraries.

We do have a lot of articles that are, of course, are very pan specific, but we also have some really easy to understand articles on just what's the difference between a 504 and IP.

So when a parent is there without having to Google it and find it, you know, there's a lot of great resources out there too for that. So. But just being able to sort of keep it in house with a few example letters but we don't have a ton of those.

And then we have our school in service program which is a very robust program and we give lectures to Small school teams all the way up to districts on Pans and Pandas.

They're generally an hour or an hour and a half in length, the hour ones I don't love because I know what's missing, but they're still good. It depends on what the school can do.

And then we have a school nurse version, which goes a little bit more into the medical and some of the school nursing programs that they can work on. And then Those are done live via Zoom so we can have a nice robust question and answer session after, or we're available after.

Sometimes they're a little overloaded because of so much information. They're like, what just happened to me? But now we have it available. If the school emails us, we can send them links to the Longard School Nurse lecture, a long school lecture, and a short school lecture.

And we're about to roll out a program on that so that we're emailing every educator that downloads our comprehensive education toolkit in addition to that for them.

So it's really just for them. And then we can set up a question and answer Zoom meeting after with individual IEP and 504 teams. So that's been great.

We have about three districts this March who are utilizing those videos so that the entire district can see them.

School Education and Resource Toolkits

So we have several districts in Maine doing that. Alabama and I can't actually remember the third state. But yeah, so they're accessing a whole bunch of different programs, which is really, really good so that we're trying to make it more accessible when they can do it because it can be hard to schedule a whole district at the same time you're not coming in.

And then there are times where I'll travel to do it to this month, is it March already? I'm going to New Jersey to speak to the school nurse conference in New Jersey.

I'm really excited about that. And then in November, it's actually not school nurses, it's a bigger school nurse audience than just school nurses. I'll be lecturing at that conference and then a couple others.

So in Iowa, so. That's great. And the other thing that I refer people to all the time is you have a great resource of of letters that families can send to schools, adapt for their individual child about a 504 or an IEP or accommodations that that particular child may need.

And I think that's also a very simple but effective resource for families to be able to even understand what they should be asking for. Yeah. So I think that's great.

And then what about the outreach program? I had a post recently where I talked about PANS-PANDAS as a controversial diagnosis and got a lot of backlash on that because people were saying it's not controversial anymore.

But in my medical community, the conventional medical community, It is controversial. It is very hard. It's not a household name. And when it is, it's papooed.

So what is Aspire doing to make Pans Pandas an effective household name and provide the education in that way? It's funny that you say household name because that's when we sat down in one of our first meetings, that's written right up front, make it a household.

Because if we think of like autism as a household name, it didn't used to be until there was outreach and education and just basic blanket awareness programs.

And so not everybody's going to know what the symptoms are of autism people actually even if you have a kid with autism, you don't actually know what the diagnostic criteria is, but people aren't like, oh, what the heck is that?

I've never even heard of that word before. And honestly, that's what some of our programs are, just like, so that people, there's name recognition of pandas.

So for that, we, We heavily rely on social media and people sharing things and then having people comment on different posts and it can be small like little really grassroots efforts on doing that.

For example, this year there was so much mycoplasm and pneumonia that all these you know, influencer pediatricians, for lack of a better term, were posting a lot about mycoplasma.

So I was like, everybody you see it, you go out and you comment about mycoplasma being a trigger for Pans-

Pandas, you see that for strep, you see it for COVID, you say, and we just, if there's a post about restricted eating and RFID, We have people making comments in the comment section, like, refer back to Aspire, or it doesn't even have to be us.

I don't care. Just keep talking about Pans Pandas wherever you can. That's one way. And then this year we joined up with many organizations across the globe to do Light Up for Pans, which was we enlisted monuments, bridges, buildings to light up green or red in certain areas.

We still do the original green. And it was beautiful. That was a wild project. It was great. The entire Paycore Stadium in Cincinnati lit up. And the video of it is so exciting.

I'd like to re-watch it because I'm like, it's all lit up in green. And then creating some press around it when we can. We did a little bit of that of press last year and hopefully this year we can expand that because of course you know you see something green and you walk by you're like no one knows why it's green you know unless you tell them why it's green.

We had this great family in Indianapolis who stood outside a building and handed out a lot of aspire. flyers to people on the street with their kids that have pans and we send everybody a big poster so they could stand out and have their group take a photo and again push it back out onto social media in their local areas.

So you know it's a really wonderful program. Lots of places all over the country we had and that's one way and then really you know keep reaching out to schools that's even if they haven't contacted us, we have reaching out to them, working on a program to reach out to more therapists, getting articles on different with different, different organizations that have, you know, one of our comorbid symptoms, like, so a restricted eating thing, having enlisting the restricted eating groups to try to push out something about pans and panas.

And that's a slow effort, but it's worth it. And we keep working and slogging away on that. And then there's education. And for a while we were doing a lot of grand rounds.

We haven't done any this year so far, but working on scheduling some of those so that we can educate medical doctors at the place that they work and being able to get that done, trying to show at different conferences where the budgets allow because conference tabling is exorbitantly expensive.

Awareness Campaigns and Outreach

And then we have to have the right volunteers to be able to talk about PANS in a constructive way and not go too far off script and understand who their audience is.

So being able to have a doctor or therapist or whoever that audience speaks to. So it can be a lot of coordination to get that going and fundraising, which is not my strong suit.

Because I'm helping families to fundraise but it just annoys me so much that I have to do that. And so, you know this weekend we are doing an online conference for IG NS which is an intro.

immunoglobulin focused conference, but so we'll just have a virtual booth, but you know, doing things like where we can when we can fit it in this schedule and coming down to the maps conference this weekend, or next week.

So I'm excited about that. Of course, everybody there under knows about parents pandas, but being able to say, you know, we're a resource for your patients, like, you know, you guys only have such limited times, like send them to our chat, send them to our website, and be able to have that sort of internal outreach where we're supporting the doctors who already on board or want to be further on board into this pan's world and saying, okay, we appreciate you guys and we know how busy you are.

Let's help us do this for you. And why, in your opinion, do you feel it's not yet a household name? It's not yet something that especially medical doctors will even consider let alone treat appropriately.

Why is there, I mean, Pandas has been around, well, Scott Antoine and I were talking about the Spanish flu in 1918 and the neuropsychiatric things that happened many, many years after that, that may well have been early pans, but, you know, Sue coined the phrase in the 1990s.

Why are we still where we are today with people not taking this disease seriously? How much time do you have? Just kidding. I'd like to, first of all, quote Harriet Washington's book, Infectious Madness.

She says, science moves glacially slow. Yeah. Let's just start there. I think Well, I don't think a lot of doctors read a lot of studies. That's, that's, you know, when I talked to, I was like, did you read the study?

They're like, yeah, no, I don't do that. Like, they just don't read them. So even though Sue coined it many years ago in a small paper, that's not necessarily going to hit the desk of your pediatrician.

And I remember in early MAPS days, Dr. Rajanil and Dr. Fry talking about creating a preponderance of evidence on cerebral folate disorder, which you know very well in its relationship to PANTS.

they were like, instead of having a lot of really big robust studies that cost tons of money, we can create a higher pile of smaller studies. And that's what we do.

And so sometimes it just takes some volume and it takes a while to get some volume. And PANS has so many moving parts that creating lots of volume in all those spaces that you need takes a lot.

So, you know, we may not have a lot of double blind studies on certain things. We don't have You know, every detail of every part of this disease mechanism, but a lot of disorders don't so there is a bit of a.

Bias, conflict of interest, a bunch of negative phrases in there by certain medical groups that I think want everything to be just in the brain, only be psych, only be neurological.

The brain is totally cut off from the rest of the body. God forbid we have a gut brain access. God forbid the brain can be leaky. not just from now we know from Dr.

Tan's work from repeated strep infections, but many things like this is a thing. And I think things like if we take a big picture and look at big, big picture.

So what is all of America looking at? So when they get go to the grocery store and they go to Time Magazine right there at the checkout aisle, and it says the decade of the brain, or the decade of sequencing the human genome, right?

So those are the two big ones. They're big wallops as pans is just emerging. So decade of the brain, the brain is totally on a pedestal outside of the body on some sort of like, with like maybe a little tether over there, but it's not attached to the body.

So God forbid. Then we have a hundred years of the DSM messing things up, in my opinion, to be blunt, where too much is talked about just symptoms, symptoms, symptoms, and not why, why, why, and to none of this will merge.

So merging the body and the body function to creating an impact on the functioning of our brain and how it works is a huge paradigm shift. And paradigm shifts are scary.

Yeah. And I think that while there are a lot of brilliant, brilliant scientists and doctors and thank God for them, and we rely on them every second of our day, not just for pans, but everything else, I think there's a whole host of doctors that are very, very in the box thinkers.

Yeah. and they'd like it to have a bow on it with the rules and they go to medical school where they're not taught about PANS necessarily. There's a few that are mentioning it in one page now, like it's one slide, but now it's getting added, which is fantastic.

And I'm thankful for that, but it's a page and PANS and PANDAS is much more than one slide.

Why PANS and PANDAS Remain Controversial

And so if they're not being taught it in medical school, then you have to reach out with the post grads and people have their specialties and they have their set in their ways and they're like, oh, I didn't learn about that in medical school.

So it's hard to break through that wall that's put up. That's what I found talking with pediatricians in particular that are like, well, I don't know about that.

So though it can exist, I'm just going to say there's something wrong with it because I don't even want to admit that I don't know about it and I don't have the energy to find out about it.

And I don't think that's a great attitude. And that certainly wouldn't have gotten me to graduate high school with that attitude. Yeah. And I think the other thing too is just that, that for our generation in the generations behind mine, we have become very test dependent.

And unless there's one test that proves X, Y, or Z, we don't believe in it. As opposed to my parents' generation, you know, my parents were both physicians.

They didn't have any of the tests. It was always, you know, like that old Norman Rockwell painting, sitting there listening to the patient, holding their hand.

you know, figuring it out like that. But in our quest for fast answers and test-driven society, Pandas doesn't easily fit into that. It's too complex and it may be proven by certain tests, but it is still, you know, the clinical acumen to see this child changed in these ways on February 15th.

And that's not Normal. Um, and, and it's, it's hard in our busy volume based practices when we didn't learn it in medical school, when we're, we're not able to see it in that way.

to believe in it. And then like you said, a lot of physicians are, well, if I don't know about it, it doesn't exist. Or if I don't understand it, I'm not gonna treat it, I'll refer them out.

And then where do they get referred? To psychiatrists, sometimes neurologists, that again, as you were saying, that brain is cut off from the rest of the body.

And we're not thinking about the infectious triggered immune response that is affecting the brain. But at the same time, there's no test for, there's no biomarker for autism.

There's no biomarker for ADHD. There's no biomarker for ODD and anorexia. I mean, obviously anorexia is a little easier to diagnose because they're literally not eating and why, but But we have plenty of disorders out there that are hard to diagnose, and they're seen as legitimate disorders.

I just I find that frustrating because I'm like, well, but there isn't one for XYZ. Yeah. So let's just move along from there. And there are certain times where I know PANS can be hard to diagnose.

But then there are certain parts where I'm like, well, I'm not a doctor and I'm not doing the medical test to rule out other disorders with this being a diagnosis of exclusion.

But like, come on. Yeah. I mean. Yeah. And we both know, as do many of our listeners and viewers, that the AAP came out with a report that acknowledged that pandas exists.

But as we both know, it was bereft of many of the more recent studies from 2017 that actually prove the pathophysiology and the immune dysregulation and intolerance that these children have.

And it was lukewarm at best, unhelpful in a lot of ways. And I wondered if there was any other way that you wanted to comment on that or help the families to understand that report.

I mean, I remember that report was supposed to come out before COVID. Yes. And at Aspire, we had drafted a best guess response to their statement on pants.

Knowing that it wouldn't be 100% favorable, they weren't gonna be like, go get IVIG and da da da. But we thought they would at least be responsible to say, enough to say, if a kid presents even with strapped throat and neuropsych issues, you still have to treat and test for the strap, right?

And unfortunately, we had COVID, so they had to do the COVID response, and then they had to do another response, their response on trans kids. And then after that, we knew we might be in line, but no one had any idea when it would be coming.

And honestly, the letter that we wrote in 2017 could mostly be used today. And partly is because they did not At that time, they did a full, they consider a full records review of studies.

They ignored a lot of the studies that they had. And then in that gap between before COVID to now, they did not add any additional studies in which there have been a plethora of really, really important, very good work from many, many, top experts in the field, from Harvard to Yale to Stanford and Columbia, and it's all just not in there.

So their report is a dollar late and a dollar short at minimum. So it was nice to say, have them go, yeah, it really exists. But this is what happens.

You go to the AAP conference, to which we've tabled at many, pediatricians know that this is a real disorder. The ones that do and the ones that pay attention to their patients and their families that they've probably known for many, many years.

Maybe they've gone through three kids and they've known this family for 15 years. And then suddenly there's a kid who's very, very different one day. They know there's no result of bad parenting in any of that baloney that's brought up from time to time.

They know this kid is different and they know that this kid had a medical issue of Strap, Mycoplasma, COVID, whatever it is. And they come and they're like, we'd love to have some guidance from the AAP, but they keep doing nothing.

And then they come up with this, which is the part about not even testing for Strap is wild to me, because it doesn't even make sense. It's not even in line to what their red book of infectious.

diseases would actually say about treating strep. It's very important to realize that this is not a guideline. Like, this is not a medical manifesto of what to do with pans and pandas.

Insurance companies should not be treated that way. It's written by doctors who know things, but their area of expertise is not in pans and pandas.

Responding to the AAP Report

People like PPM, the doctors that support that organization or all the doctors on PCR, PRC, Pandas Research Consortium, they are living this day in, day out.

They are studying it. They are the experts in this. They are not out to just willy-nilly give antibiotics and other immune-modulating drugs to every kid.

That is nobody's intention ever. And I find it shocking what they've written. There will be responses and other things being done on the road. It takes a long time to do that because we're being methodical about doing it.

It is taking a long time. But I think it was so shocking the depth of how many things that they were going through and saying, don't do, don't do, that there's a lot of, It's 50 pages that you have to respond to.

You don't want to just do a quick blanket one and go, we don't like that. Like, I mean, we did, but that's really not enough. Like you have to really do the work that they didn't do.

Right. Right. And I think, you know, you've mentioned so many great resources, you know, the Pandas Physician Network for the practitioners that are listening or viewing, go there.

The Pandas Research Consortium, go there. For families, go to aspire.care, and that's A-S-P-I-R-E dot C-A-R. And all the other parent organizations, there is so much good information out there.

And we need to be accessing it. And you also mentioned the book on school. And if you could repeat that one more time. It's written by Patricia Doren.

Right. And do you remember the name of it? I don't remember the top of my head. It could be two seconds. And then how do people find you, Gabriella? Go.

I would just let me get the name of the book pans and pan is in school settings. It's a suppose that pictures the right story and it's a great book. You can get there.

It's linked on our website in our book section under the resource section, but it's available on Amazon and all the other places. Really? If they just go to aspire.care and.

Hit the contact section, they can email us and contact us or they can message us through our Facebook page. Usually it pops up an automatic message. Can you email us at info at aspire.care and that will get us right there.

And any last words of wisdom, of hope, anything you want to share with the families that are listening and watching? Really two things. One, it is getting better.

I've noticed the difference since when we moved to Connecticut. Doctors, if you brought up, say, have you heard of PANS? Could it be? Not insisting, not being aggressive, saying, have you heard of it?

The 90 plus percent of those families would get a letter within the week from the pediatrician saying, sorry, we can no longer treat you, your child, or your entire family.

Please find another pediatrician. That was wild and scary. I didn't get a pediatrician. much to Dr. Herzogrin over those years. Did a lot of school forums through other ways.

But anyway, now we'll be in the chit chat meetings and in the groups, people will say, well, you know, my kid's been going through this for two months.

And I'm like, wait, the symptoms start two months ago, and there are pediatricians and other doctors that are diagnosing this and treating this at maybe sometimes the bare minimum, but they still are diagnosing, treating, writing a letter to school much more quickly, not all over the country, not all over every state.

There isn't necessarily a state that's better than another one. There's just pockets, but we didn't have those pockets before. So things are getting better.

So the work that we do at Aspire that all the other organizations do, what the doctors do with educating and what all the parents do by keep talking, talking, talking, talking, just keep talking, just keep talking and sharing.

You don't have to go on for too long. Just share and keep mentioning Pans and Pandas whenever you can, wherever you can. It makes a difference. And then the other part is hope.

on that moment when your kid has knocked over the TV in a rage or crumpled in their bed having crippling OCD fears that are absolutely disabilitating and you're like, what am I gonna do?

How am I ever gonna get my kid out of the house? How am I gonna get my kid to the doctor to even get help? How am I gonna find a doc? Just keep holding on to hope.

We know that kids can get better. If they're not 100% better, they're much better and will take much. I do everything in increments of 5% frankly, but.

Resources, Hope, and Closing Advice

Just keep holding on to hope. Keep trying to find one thing a day that you're grateful for. It gives you a little bit of a thing to hold onto, a tether of normalcy.

And know it's okay when you're in it. You don't have to live up to what the neighbor's doing. It may not be what our expectations were as a parent when we were pregnant or giving birth or getting married and thinking about our future.

We didn't envision this, no. And we're gonna have to shift our thinking, and that's okay. Shift it. You're not on anybody else's timeline. Forget everybody else's timeline.

Meet your kid where they're at every single day. And be gentle with yourself. Go to therapy yourself. Put your siblings in therapy too. We all need it.

This is a family diagnosis. It's not just the kiddo. We have to take care of ourselves to some degree. I know it's harder during other times than sometimes, but just do something and just keep holding on to hope because it's out there and you can find it.

I think those are great words of wisdom and hope is so important. And I have to say that even after just the first episode of this podcast dropped, I was amazed how many physicians reached out to me with questions.

And so they're listening, they're coming. We just, like you said, have to keep talking, keep hoping, and take care of ourselves in the meantime. Right.

Gabriella, thank you so much. It's so great to see you again and I'll see you soon. And thanks for all you're doing with Aspire, with your own family and with all the families out there.

Thanks for having us. We really appreciate having Aspire and being able to tell my story and the story of Aspire. It's been great. Thank you. Yeah. Thank you.

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