Rewiring the Brain: The Hidden Impact of Inflammation in Kids with PANS/PANDAS Transcript

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Introduction to PANS and the Podcast

and they're just like, oh my God. And they're talking about the money and the cost. And I just had a kid in here last week and basically the discussion was on strike.

You know, they were on strike. Now they go on strike in their settlements. It's not as disastrous is if they go on strike from a major A that's holding them out of the hospital.

Many of these meds I'm very frank about this are chemical restraints. So you're an aggressive, self inducing, abusive child to themselves and others. Does not end up in the hospital because if they start to self harm or harm you, we do not have a choice.

You and I, they have to be a safe place. Welcome to Demystifying Pans and Pandas. The podcast where we uncover the mysteries, breakthroughs and hope behind these life altering conditions.

I'm Doctor 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. Hi, everybody. It's Doctor Nancy O'Hare again, and I am thrilled to welcome a colleague of mine, Peggy Chapman.

Peggy Chapmanu2019s Background and the Pan Center

Peggy is a clinical nurse specialist, board certified in child and adolescent psychiatric nursing, and she received her Bachelor of Science in nursing at Creighton in 1976.

In 1982, she graduated from Boston University with a master of Science in Nursing, and was certified as a clinical nurse specialist in 1983. And Peggy has worked in various roles in psychiatry in the Omaha and Boston areas, including as a head nurse of child and adolescent and adult psychiatric units, a therapist for children, adolescents, and adults, and as a psychopharmacology specialist for all ages since 1998.

She's been active in supporting parents, co-leading the Asperger Association of New England parent support Group for 11 years and being a medical advisor for New England Pans Pandas Association for the last 11 years.

She treated her first pandas patient in 1999 and opened the Pan Center, which we are all thrilled about in June of 2025, which is dedicated to treating patients with Pans, training and educating other professionals about how to diagnose and treat Pans, and supporting research for Pans and Pandas.

So, Peggy, thanks so much for joining me today. Thank you so much for having me. I joined I opened the Pan center in 24. You said 25. We wouldn't be. 24, right? 20 of.

We're not even there yet. All anticipating. Right. But but that is an amazing thing that you did. And just tell people a little bit about the Pan Center just to get started.

So I was going to mention this, and Nancy asked me to constantly talk about challenges. And one of the challenges

is I thought I was going to retire about now, and, I was frustrated because I couldn't figure out how to do that with all this information I had in my head about pans and no one to give it to.

And there was an earlier effort to try and do that that didn't work, and my husband kindly sat me down and said, well, honey, you're not one step further than you used to be a year ago.

So what now? And I go, I guess I have to do it myself. And wisdom at my side. John. He's amazing. He's been in healthcare sciences for probably 40 years.

He's been in research at very macro levels on Medicare data. But he said to me, I'd like to see it from the inside. It said, Donnie, you're going to well, the day you said that.

So every day when he's yelling across the hall and I have to go, come down, or I'm yelling about some stupid prior authorization requirement. But otherwise he's doing amazing things, getting out of network benefits coverage, which is the first, I think, in and out of network, out of outpatient setting.

I don't think this has done very much in the past. Providers. So we're hoping to set a model that can, I know, not only train people, but also I can train people about how to perhaps do it as a billing practice.

That's amazing. That really is Peggy. And European Center is in Massachusetts in. Situation Weymouth South Boston Apartments which is near right street currently from the South Shore Hospital.

There's a probably a temporary home if I get my desire met, which is to continue to hire staff. I'd hired my first nurse practitioner a month ago. She's amazing.

And, but I intend to increase it if I can, hopefully including a medical NP to take on a more of the line mold. The ECG ordering question, fill in the blank.

And then and especially as a functional oriented person on that count, along with Tamara, who is my new nurse, I'm very interested in as well. And also maybe a physician in someday.

But, this business does not reward as well financially, and that becomes a very difficult proposition. So. And also, I really would like to extend to the whole New England area, because I don't mind if people train here and go elsewhere and open their own practices.

I have no proprietary need for anything about this business. This is our retirement plan. So we're giving it a go. Well, I'm so thrilled you're doing it.

And you've always been such a wonderful clinician. I mean, we've known each other probably since at least the early 2000. I was running. We were. Whenever you joined the dance, I was there like a third year.

It started so. My my first one was 1998. I was pregnant with my son. Okay. So I think I didn't get there till 1999. One year later. Yeah, they had, so happy to, to have you in this field.

And as you said, it really is a calling and a passion. And I'm just glad you share that and, and are doing all the work you're doing. So I think it really helps me to know other people like you are out there, since this is a very isolating, lonely position to be in.

A lot of times when you ask about challenges of this job, but it's really good to know, even if we don't talk, that there are others I can reach out to and come to.

And you've been great about it. Absolutely no. We we need to stick together and the community is important. You know, that's why I started my membership program.

Just, you know, we meet every month just to talk and and know that there are other like minded people out there.

And also, you know, for the families, and, you know, I do a lot in functional medicine, but you and I both know that that often these children do need medications, antibiotics, antifungals, but also psychiatric medications.

How does prescribing medications for these psychiatric symptoms of pans pans differ from treating other mental health disorders? Well, I'm going to first started talking about what happens in the brain to set the tone for that.

So the first thing is we all know that Pans creates psychiatric symptoms and behaviors secondary to the inflammation, both in the body and in the brain.

But like gut, GI, for example, is also a big issue. And so what happens in inflammation is something called cytokines, which are there to help protect and to damage the brain.

How PANS Affects the Brain and Symptoms

And the other parts of the immune system are activated with inflammation. But excess cytokine, which really does reflect a lot of people where there might not just be one strep throat and but then you get strep three times in a row and then you got mycoplasma Covid added in, or then you have a food allergy or an asthma problem.

Is this often a layering of insults to immune system? And it starts to change the circuits, meaning the tracks and then pathways of dopamine, serotonin, norepinephrine and other chemicals.

But particularly I'm going to focus on those three, which those are. Three are the ones most psychiatric mints are designed to manipulate. So this would be like someone sneaking into the roadway system and changing all the directional signs in a large expanse of major and minor highways in your brain.

So now when you treat with medication, it's not clear which pathway and how it's going to work. It's not the same. But before I get just back to that, I want to also mention, very importantly, something I've been always struggling with through the years.

And I finally, I think, kind of better understanding of this. And believe me, it's not because I haven't tried that. I probably didn't know the language to query the data really well.

But the basal ganglia, which we talk about a lot, Nancy is one of a book about basal. The answer basal ganglia and satellite is behind her on the shelves.

I think when I'm looking at her, produces changes, particularly in this midbrain area. So if I took a pencil and poked it through my ears and through the nose bridge, I would hit the basal ganglia kind of frontal midbrain.

And it is like Grand Central for all the dopamine tracts, which control multiple functions, which I'm going to review about how come your symptoms show up.

So first of all, dopamine is the center. And there's a large section in the basal ganglia called the striatum area that is very heavily dopaminergic. And it's the area of what promotes rewards pleasure, all motor movements and social interaction.

So when this is upset and agitated or the wrong pathway is running, you are now losing ability to have fun. You don't have as much pleasure. You see a lot of these kids drop their sports partly because they can't do it, but probably because you just don't have any energy or enthusiasm anymore.

Yeah, they stopped while and they stopped piano. They stopped seeing their friends. So then they're left with numb and flatness reducing motivation. They have and then they have motor tics and disrupted circuits from those motor in the same region.

They have tics, vocal motor, and they have stuttering, which people don't. I don't see very often. But when I say this very distinct that there's a dopaminergic, disconnect and pathway that's not working.

Right. The second thing is dopamine. This one I didn't know I knew was always there. We always talked about it, but I didn't understand it. Again, decreased and confused.

Dopamine increases sensitivity to aversive stimuli. So aversive stimuli light smells sounds you know people chewing is a big one right now. I'm one of those people in my office today that they can't stand.

Only mom's chewing. Not everybody else in the family. I hear you. Yeah. Lights, textures, the clothing. Sometimes they can't even get dressed. They often drop out of soccer or ballet because they can't put the tights or the socks on anymore. Right.

So this is also due to this dopamine change. And a couple more is the activity that this also activates anxiety fear alarm bells going off. So you're in this hyper vigilant state in the amygdala, which is a tiny little level below the basal ganglia size of an almond amygdala.

And this now becomes a fight, flight or freeze patterns that people exhibit. So let me give an example. This light, they run away. They try to jump out of moving cars.

We know those triggers freezing, not talking, unable to respond, curled up in a ball, whimpering on the floor are fighting. Oppositional, aggressive, loud, just out of their mind.

I one time had a family tell me that, their five year old was on the mother in the kitchen beating her up. Now you wonder, how can that happen when you have adrenaline background?

You are strong and you were able to beat up a lot of people, and she was just horrified, but also knew she couldn't fight back. The last piece on this is the damage to the hippocampus, which is the seat of working memory.

One of the worst things you hear about is these kids over and over again. I just can't remember. I can't do my work. I can't do my homework. I can't listen in class because I don't remember anything.

I don't remember the sentence I just read. I can't go back and keep doing that. So this is all about the circuits that are lost. And this is now why medications are going to be very differently administered.

So for example, medications like depression, anxiety, you would know it's Prozac or Zoloft. They are supposed to be given for these neurotransmitters as particularly norepinephrine and dopamine I mean those serotonin with dopamine in the background right.

Dosing when you approach it backfires most of the time. So the goal is to go low and slow. And so for example, if I have a 12 year old who in normal depression anxiety would tolerate 25 to 50mg, I can start them on 12.5 and I can barely get past 25.

But there is a small group who can tolerate typical doses, and in order not to miss that group and miss appropriate, my attitude to say no, you shouldn't have that.

I do generally triangle up at least one time to make sure they're not in that group. Interesting. Other thing is, once you're treated and their inflammation is really in check and I'm doing follow ups with them, they may still have underlying ADHD or anxiety disorders that now can actually restart a single and are now can actually approach a normal dose structure for a typical antidepressant or anti-anxiety medication.

Yeah. Yeah, absolutely. So much to unpack there. I mean, I love your analogy with being on the highway and all the signs are messed up. I mean, that's so is is is what you feel when when you're with these kids that that's such a great analogy and also exactly what you're saying that many of these children do better on very low dose and titrating up slowly, but there are some that that need higher doses.

And I know you and I have said, I've been told and I even try it sometimes they. But not that Prozac for a really long time. I don't think it's doing anything.

And I go, well, before you just take it off, let's just go have a dose, which may be a really tiny dose, or just do it in isolation of any other change you make.

And then we have to watch and wait because it surprises me how much the little dose of Zoloft is doing for their anxiety that I never knew. They often came to me on that dose, so I've never seen them without it.

But I also, when you're first treating people, you don't count on that being the major player, right? So you might put it in place, but it's not going to be a major player in this whole treatment.

Right? Right. And absolutely I mean, often I'm I'm telling parents to shave off part of it or compound it. This is where, where I will compound it and, and just take it down by literally drops.

And and I'm really, really picky about like liquid Prozac tastes pretty bad. So I don't use it much if I think I'm going liquid. But Zoloft is a wonderful one.

Lexapro might be in the background. Zoloft though. Just an interesting point. Genetically is not impaired by what you and I know as to these six enzymes, which can work matter and matter a lot as to how the Prozac or, let's say Lexapro or being digested in the liver and how it spread in the blood.

And just statistically, you have a better shot at the left than you do of the other ones. Yep. Yep. I agree, I agree and some clinical. Location that just came out today from Salk Institute that was sent to me by a parent who said which says gee in mouse Prozac is an anti upset septic and any anti sepsis and anti inflammatory.

Now I know it probably has to do with all of these things that have never been tested, and that's maybe why their depression is getting better when they're taking these meds.

Right? Right. Because you and I both agree that inflammation and immune support, you know, in the gut, in the body, in the brain is is very important in pans pandas certainly.

But but in all of mental health, in all of health. Right. That's all totally coming together with that and publications. Now we'll, we'll we'll fingers crossed where I, you know, and and what about I mean, you mentioned SSRI.

Do you use any medications more specifically for dopamine. Yeah. I do actually. I'm often an off label use at this point now. So I'll mention things that I want to say that, stimulants for example, if you have ADHD hyperactive they are a disaster.

Generally speaking, even on them, they don't work that way. So as a mild a moderate form, amantadine is one, you know, and it's also antiviral biochemistry, but you have to be very gingerly with it.

People. Then to aggressive with it. It's it normally comes in 100 twice a day, but I order a tablet. Then I cut them down to half of that in the morning and a quarter of that in the morning.

Only test dosing it, and then only till I get assured that that is not activating and causing insomnia, and that if you read the package insert, it's got all the same side effects as a stimulant.

Yeah. And then I might gingerly at a tiny dose in the late afternoon. It's not any good if you give it a bedtime really. And then see if it interferes with sleep or activates.

But it's not a it's a hit. Yeah. Less than it's a miss. And yeah, with very activated pans people with bad symptoms. The other one I have really grown to love is memantine.

Now in Mantiene as an Alzheimer's medication, you might say, what the heck? What do people struggle with? With Alzheimer's? They struggle with short term working memory.

It also turns out new publications are talking about it as an OCD med. Same dose. It's talking about it as an anti

NMDA help. And that I won't go into the boringness of that chemistry.

But basically this is part of the excitatory, derailed system in the brain with inflammation called glutamate and glutamate enzymes. NMDA is a glutamate enzyme.

So when it's activated in a negative way, memantine is one of the meds that kind of helps calm it down. What is Alzheimer's? They feel it's a it's an illness of inflammation.

There's something going wrong that's layering their brains with tao and and tangles. Right. So it's pretty much thought there's a lot of inflammation in that process.

So to me, always looking for new varieties of how to use meds in that other than normal way. Right, right. Absolutely. And memantine is one that has some good studies in, in autism.

Oh, it's not the autism. Yeah. I mean yeah, years for ADHD. There's a whole ADHD and a whole set of autism spectrum articles about that. And I've used it for years with spectrum kids because it improves their social reciprocity abilities.

They remember now to hear what you just said. Yeah. And and I've seen it. Go ahead. One mother said to me, well, I know it's working because we stopped having dinosaur discussions all the time at the dinner table.

Yeah. And and I've also seen the big one is the social anxiety, you know, and some of that may be the, the help with working memory and, and word finding and things like that.

Medication Strategies: SSRIs, Dopamine, and Newer Options

But, but a lot of the kids are more able to engage at the not just the dinner table with mom and dad, but but more outside the home, too. There's also, I should tell you, I was not going to say this, but there's a brand new antidepressant.

Well, two years old now that I find I would like to put it in everybody's water. My treat is called a novelty. And although all of you're going to go crazy and go ask your provider, you're not going to get them to probably provide it.

It's for 18 and above. But with some work I'm doing now to see how, how far I can go with pushing drug companies to cover it and trying it with a sample ahead of time.

Yeah, it's actually, so in the brain, when you have axis inflammation, your glutamate NMDA get really excited and run amok, right? The downstream effect of that is to impair what we know.

We called BDS. Took me four years to say this word brain arrived neurotrophic factor. But a simple person said to me that brilliant person, Doctor Stephen Stahl said to me, people, it's brain fertilizer.

That's right. And in fact, it is why ketamine works. It gives a huge dose of BD and support, but it also has some major side effects. It's not available for most patients. And there's two potent.

This is like somebody said a ketamine light. So I have seen some unbelievable very rapid responses to positive diminishment of obsessions of self-harm, ideation, of agitation.

They're conversational, they're happier. But there are some dissociative episodes that can occur with it. One child had trouble peeing all of a sudden.

I still haven't figured that one out, but is there? And I'm really excited that there's all these other new meds coming on board in psychiatry who's finally recognized.

We got to go way outside. What we call Nano means that's dopamine and serotonin and find other ways. Yes. Of of intervening here. Yeah, absolutely. And you know, we both work in, in this world.

But you do a lot more with the psychiatric medications. And, you know, with functional medicine, we use a lot of nutraceuticals. Right. What should our families, other practitioners know about the interaction of the psychiatric meds and the the over-the-counter or other supplements?

Right. Well, the first rule of thumb is don't get too excited. Just go get a supplement because you heard about it and give it to your child without consulting your provider unless you don't have one.

But even if you don't or do have one, you are not sure what you're doing. And in fact, IRBs do matter. IRBs do have drug drug interactions, and you can inadvertently really put things in a tablespoon.

So, for example, curcumin is when we use a lot as anti-inflammatory. It is also a drug that has some interactions, especially with blood thinning. Also I don't find it right now literature.

But I know when I was studying genetics a lot and Zoloft when I mentioned earlier, certainly it raises in the serum relative to curcumin. So when somebody came to me on bulls and I was trying to figure out a proper dose, and then it dawned on me and it was enhancing the levels, I had to take them off of curcumin before I could actually see what the dose was doing for the child before I increased it.

So, for example, also, I've seen people get really excited about homoeopathy, and usually most homoeopathy. People do carefully warn you about herbs, events, how to do one at a time.

But again, if you're doing that, when I just prescribed Abilify, I don't know what's up or down or sideways. My my rule or my rule for my patients, which is not always followed, is you must not introduce something until you talk to me because you don't know.

I don't know what you're doing, but I truly appreciate the enthusiasm. So, for example, I'm at a pants conference in Columbia about eight years ago, and I'm in a lunchroom area, which was almost happened to be they would just be rolling randomly, said, go to this room, and I happened to be one with parents and stay in line.

I hear two things F and NAC the entire time I'm traveling through the parent group and I think, okay, all right, here we are. And Paul Hardy, our colleague, used to say, hey, this is like a whale.

Watch everything run. So that's the boat. You're right. There's the boat. But they might collapse the boat if we're not careful. So there's a drug that I just saw that someone posted.

I got sent to me late last week on a very. The most potent antipsychotic out there. Not easily to be given, and certainly not young children called classroom.

Now, I'm expecting that I'm going to be brought that information some time in the next month with great enthusiasm about trying this med. Similarly, things can happen with things.

So if you're hearing about NHC alert, great, but NHC actually disturbs a lot of kids stomachs and methyl folate. Probably. Okay, but you got to make your choices about how you're going to spend your money.

And there's a lot of math also laid out there that's useless in terms of mood. It's one milligram or a half of a gram. The psychiatric data and research is it's 15mg, and there's very few products that give you that much mental solely.

It is also prescribed, you know, through the form we can use it. But again, people are just desperate. They want to help their child. They've heard from another parent.

It's great. It may not be great. And back to Syd Baker, who you know and I know and love especially you have a great relationship. Them it's an end of one. Your child is the only one.

That's the science experiments right now and you have to respect that. So my rule is always please talk to me and run it by me. Even if that doesn't happen, the rule is never put more than one in place.

Four days closer. Unless I tell you, you know. Exactly. Yeah, yeah. I mean things. One at a time. So many things. Then you have some problem and you got to take off.

My other warning for people is supplement fatigue and and going on strike so many years. Over the years when you and I were treating kids and dams and similar still with autism, any treatment they have.

So many supplements they send me pictures of them aligned across their kitchen counter and they're just like, oh my God. And they're talking about the money and the cost.

And I just had a kid in here last week and basically the discussion was on strike. You know, they were on strike. Now they go on strike in their settlements.

It's not as disastrous is if they go on strike from a major A that's holding them out of the hospital. Many of these meds I'm very frank about this are chemical restraints.

So you're an aggressive, self inducing, abusive child to themselves and others. Does not end up in the hospital because if they start to self harm or harm you, we do not have a choice.

You and I, they have to be a safe place. But if you just suddenly make your kid go on strike, you really risk a really bad problem and including withdrawal from things.

You know, like if you've been on Zoloft for a long time, or even an adamant dose which you need for anxiety and you suddenly stop it, you're going to have such bad rebound.

It's not. Absolutely. So that's probably not sad about that. Yeah. Well, and I think, you know, a couple of things along those lines in my monthly teaching, just last week in our membership program, I provided a, a big long list that Jill, Krista had put together and that I had amended of the interactions between these medications and the herbals, botanicals, supplements.

So you have access to that, Peggy? So, I. Will have to go in and see that I. It because there are interactions and they need to be known about the other one with curcumin and tumeric.

Is it decreases your iron. So if you're taking too much of it, you know, that may be another effect. And I don't like to call them side effects because all of these are effects of the medication.

They may be good, they may be bad, they may be ones we don't anticipate. But another one actually people inadvertently end up with, too much vitamin D.

They have this supplement with vitamin D and that's a calcium, magnesium, vitamin D, vitamin D and or they because they have a 5000 unit in their house, they're going to give it to their child.

Vitamin D is an A. You know it's a it's a fat soluble vitamin. And you and I know we talk about A and D are toxic. If they're absorbed too high in our body and it's stored in the fat and the sweet spot is 40 to 60, there's a lot of data in geriatrics that about 80, you might be even risking more fractures in your body, but it's not clear that any more than 60 is helpful.

Now there. I know there's some practitioners in functional that like to push it towards 80, but I want it to be comfortable. I don't and I don't, and you have to count it.

A lot of people are not counting because it's in these healthy herbal vitamin supplement minerals packages that nobody's counting up the amount that you're taking.

So if you have a child, you're giving a lot of time. Someone's to pull them out and count up how much vitamin D you're giving them. Right. And also, every supplement is different.

I recently had a family where I had said one drop of vitamin D is all this child needs, because in that one drop or 2000 units, your father was giving one dropper.

Oh, and the, the vitamin D level was 235. I've never seen one. I hadn't either. I hadn't either. And and you know, so I think as parents and practitioners, you know, one brand is important.

And you said this about methyl folate. I mean, it's not only the dose, but one of the things that I've learned with methyl folate is it matters which side that methyl group is on.

And not all methyl folate supplements are made the same. So the brand is important, the dosage is important. And then, you know, the other thing we've seen a lot I don't know if you've seen this this week on social media is Doctor Frye's interview on Foley receptor antibodies and the use of locavore and and for linick acid for auto.

I did see it was I kind is I got it sent to me as if this was new. And I said, actually, Doctor Frye has been talking about this for years. Exactly.

Supplements, Interactions, and Safety Concerns

And Doctor Wells and I published an article this summer that we're also seeing it in kids with Pans and pandas, small study, you know, etc. but it's not the be all, end all.

I think, in this world where we're looking for that quick fix. Oh, look over and there's this simple medication can fix my child's issues. Well, if your child has cerebral folate deficiency and it's supervised by your practitioner, absolutely.

That may help. But it's not going to, you know, cure autism or help every child with pans pandas. And so we need to to look at these things not in a vacuum but in the whole picture of everything we're doing.

Right, right. Yeah. And, and that's one of the challenges, I think. And, and, you know, working with families and, and caregivers and patients, you know, but there are a lot of them.

So what are the challenges and the strategies that you use to help the, the decision making with these, these patients and parents and caregivers? Right. Thank you for that question.

I, I know that I mean, I suggest we talk about this because I do feel like some of the masses are forgetting what it's like to be on the ground and what we are living.

And also parents and families, I feel like join us all the time and they should be informed of this as well. So yeah, I you're asking, so when I open the doors in, June, I had a waitlist carried over from a, a business.

And also then, you know, by the time I opened up intakes in August, I had 80 more than 80 people on that list. And many people who are relatively new, many people who had been treated and wandering and still treating them their children for ten, 15 years and, so in order to try and match insurance, I structured the interviews and the whole intake packet for labs for the parent.

Do you know that story? Yeah, filling in lots and lots of forms and also formalized questionnaires so that I'm not being questioned by insurance about the validity of what I'm measuring.

And these are very important. So a demonstrate rates and actual validity of the illness. The second thing is that, it takes five intake for the five intake meetings to do an intake because it's broken into the family history, the medical history, the psychiatric history of family and child, and then the interview, both medical and psychiatric with the child.

And then when I needed a treatment plan meeting. So all this can be come together with the results in hand. So this has come from a lot of years of trial and error about what didn't didn't work.

The second thing is, I really want to know a lot about your story. You know, you and I know that it's a clinical diagnosis. It's not a lab diagnosis, but in order to get the clinical diagnosis, it takes careful peeling away different layers and asking different questions.

And us and our minds trying to make sense of this. Right. I sometimes feel like my mind is playing Tetris, trying to set the block into the right space.

Yes. And, so I have to you ask about older kids. I was going to tell them she's a good example. I had a 24 year old who came in, was introduced me by a therapist, begged me to take her new to her.

That realized pretty quickly this was probably Lyme tick pans and the story was that she I got as far back as a normal child to up to about sixth grade.

She told me she was the best athlete in her middle school. She was a really good friend. She had a lot of friends, and then all of a sudden she came into school, was mute, literally couldn't read selective mutism diagnosis.

She just wouldn't talk. And at other times she was super anxious. She started therapy. Now, I read in one of the things she said later on, because I keep going back and review and trying to make sense of the story, she says. 24 you know, how do we get here?

And she had already told me that she had a tick bite in June. July of 2022, had meningitis from it in the ER, treated her for a month. The Doxy. Great.

And then the entire slide started happening where in her entire college career came to a halt, etc. I found out she had a sport she was really good in, which requires, pitching a ball a certain way.

And she know, I said, how could you not make that team as a freshman in high school? She goes, I don't know. I just couldn't hit that ball anymore. Like I needed to hit it or I couldn't.

My swing was just off and I thought, there is the evidence. That is it. In addition to all the urine issues, all, you know, all the anxiety, the OCD is about the time she got to me, that was probably that one unchecked box.

Her diagnosis list is enormous. Because by the time I got Ahold of her, she was actually extremely compromised in her room, in her home, barely could drive to phobic to disabled, couldn't.

Oh, couldn't work because her verbal tics were really bad. So she would be making all sorts of inappropriate noises to the rest of the people in her life in a work setting.

So she was really just limited, extremely. But it was not until I had to just keep probing and pulling the data end that she gave me, but it took some interviewing to kind of collect the rest of the story.

So I really do work with a hypothesis. I build a story in my head, and then I order lab work to know and to check and verify or detour me to a totally different subset of things I need to pay attention to.

Like, oh my gosh, you know, she's got three. And, Lyme tick borne illnesses right now, maybe to and and then maybe no mold or maybe no Bartonella. But she has autoimmune thyroiditis, right.

You know, maybe really great deficiencies in nutrients, but there's usually something else. So this is the problem because this takes a lot of time. And I always struggle with having enough time, you know, and also because parents need and want and the person or the patient want action, want some solution.

I'm always not ready to give that at that time period. I try and have something concrete to move to after the lab

work is done, and certainly and plan in hand.

I'm sure you go through this all the time, but it can't all be solved. So that gets me to my noticing as a strategy. More recently, last 5 or 6 years, I've started to say to parents, caregivers and the patient, especially children, adolescent.

Right. What are the goals that I've already gotten, what the goal of the parent is and the intake packet? But now I say the child, if you could tell me three things you want me to work on, I would really appreciate it because there's so much stuff here that I want to know.

Interestingly, here's a good example. The parent. This child had really bad OCD. They really focus on that. The child said, I have these tics and it's really difficult in school to have these tics. I need you to fix that now.

It was also very, very, you know, suspicious of me and any meds I might offer. So and this is very true most of the time, not all the time, but I thought, okay, let's try on some medication for your tics, because knowing if I can even diminish the amount of tics he is feeling so embarrassed by, it was a grunting or a doe clearing and a facial a really bad fashion tic.

That's immediately noticeable. I knew then he might trust me to try other things or more, taking care of what the parent knows to be very developed into the parent.

And the parents, of course, are really desperate to prove to us because they've run into so many naysayers that this is real, right? And so but I don't want them to discuss this in front of the child, because, you know, I know I've had pictures, you know, pictures and videos like, oh, put those away because these children internally are very shamed, embarrassed and lost as to what has happened to them.

And they cannot control it there. And they've often been to psychiatry, which has endlessly told them, as well as their primary care, as well as a GI, that that stomachache they've had for ten years is, in fact just their anxiety.

And so just go to treat it with anxiety, despite all the treatment besides all the therapy. So they're not trusting push. Why should they trust me any more than the last person?

Right story. Right? Right. That's what I see is really the challenge. And so the strategy is to join with the families and to join with the child and try and meet them where they're at.

Yeah. I also try and provide the parents some realistic about what this medication or intervention, whatever I'm doing of any type is. What am I looking for?

What am I goals? What am I expectations? My expectation usually with the first doses, let's see if I get any side effects. Let's great tolerate this medication right mentioned.

You know you want me to resolve their OCD and there are really high aggression. You want to be able take them to Disney in three weeks. But yeah, I mean not if you want to take them to Disney and have a terrible reaction to something. Right.

So, that's a bit of it. The other thing is I have had to really learn about freeze as part of anxiety. I never used to understand why parents would come in crying and desperate for a medication, or a child or a patient.

I give them medication and supplements and supplements and they never try. And they come back in and say, oh, we never did that. And I go rewind, kind of, can you explain for me, right is right.

I would be dumbstruck. I would literally just not even know what to say. Like, why are you in my office if you're telling me this, right, you're back.

And yet you didn't use what I gave you. Please. But they couldn't explain it to me. They kind of just look at me like. I

don't know either. They do, I don't know.

And then I was working with Sheila Gauss a lot lately. One of my colleagues and I consulted her school, and she's the warrior mom of Massachusetts who helped get the Ivy League and advisory panel past advisory council panels, for panels.

And she said, Peggy, it's freeze. It's freeze. They get to the point they just can't move. And I went, this is what it is. And now I see kids doing too, but particularly parents who are administering these meds.

Yeah, they all, like, beg you for something. And, actually, medical personnel are some of the worst of this, but they don't want to give the kids medications nurses out.

They actually are more informed, which I think is why they're more hesitant. But freeze factor is a real problem. And I have learned to appreciate it.

It tells me a lot about trauma that I'm paying a lot more attention to, etc. and the last thing I want to say about caregivers and how I manage this, because this is very hard work, very complex work is very isolating because almost everybody I'm running into knows either nothing about it or thanks for the pediatrics around me.

Think I'm kind of crazy, I guess. Yeah, I know, so they're kind of getting informed and trained along the way. But I think about this in an old, psychiatric concept called folding.

Winnicott was a famous psychiatrist in England shortly after the war, and he studied babies of mothers about the concept of nurturing and holding their pain and their misery and their personhood.

Building a Clinical Picture and Working With Families

And over the years, because I've dealt with tremendously ill psychiatric patients and adult units to run a locked intensive care unit, if you can imagine what that would be in an adult world.

And also many child psych units I've been involved with. And the issue is witnessing and holding the suffering and pain, along with the family that I'm working and watch, walking with them alongside them.

Then I don't feel so alone and isolated. They need someone and I sit and and by doing this over the years as a provider, and I think this is a necessary element, you have to be able to tolerate a lot of people's pain and a lot of really risky business around suicidal intent.

But over the years, many people come back to me and send me messages, or I just run into them at some event and they go, oh, you treated my son, or you answered a phone call for me 15 years ago.

I went and got a strip swab and the Allen panties. They treated it, I know I did, but they remember in are grateful. And that's what still nourishes me, right?

Right. And so much resonates with me of what you've said. I mean, I often say the best instrument in my office is a tissue box because the trauma, the disbelief, the the actual shame that these patients, as well as their families go through is incredible.

And but also as caregivers, we have to take and we're caregivers too. We have to take care of ourselves. Yeah. We have to make sure that we're setting the boundaries.

And I think it's it's good as an example for the parents, too, because the other thing I see is that as the kids are going through this, sometimes as parents, well-meaning and loving, they're feeding the beast of the disease.

They're they're coddling the child to the point where the the secondary effects are outweighing the inflammatory, infectious or other components of this disease.

And I think it's so important to, to support. But I'm not very good at self-care. I'm working on it, actually. I did really well with this practice, and it kind of went backwards because we're still really in the building process.

We're almost to the end of really create an amazing and take note that mostly will be imported and pre, you know, everything the patient writes will be actually directly important in the note.

I know I used to do this a lot, but in psychiatry that's really hard to do. In insurance you got to have all these rules met in a note right. But anyway, so yeah, so self-care is hard.

But I also found that just telling a mother and this was a pen, a girl with pens. But we were this is after she had pretty much recovered and we were talking about the moms for about her bedroom.

I looked and I said, just close the door. She's 17. Just close the door. I was furious at me because she her OCD require that eight pens in the house that were made and I just said, this kid's going off to college in a year and a half.

You better let them know what it is to live and figure out how to do things on their own, you know, or people when I say they need to be on birth control or I said, why are you giving the birth control?

They're 17. They have going to college in August. You said something about giving her the birth control. I said, she's not managing it well, no, she might get pregnant.

And I said, better to find out now than when they're in college. After you've paid for 40,000 50,000 hours of tuition, they can manage their birth control.

So yeah, I, I do try, but I think especially in the beginning, especially for an OCD, you're especially restrictive eating when you're going to be in the hospital.

If you don't feed your child, they do have they do break all boundaries, all training of OCD. You know, I'm sticking the parent from the child. You know, they just there's no other choice.

I think in the beginning for some of the meat. Right. And I think, you know. But later on you got to kind of pull them away. Right. And that's where the therapy for the parent support is really helpful.

The training. So important. And I talk to parents about that all the time, even if the child can't access it at the time either because they have autism together with their pans pandas, or they're so deep in a flare, or they're a teenager and refusing, or whatever it may be, it can be very helpful for the parents.

Yeah. And if your parents out there and like in Massachusetts, if you know a good therapist who you have to happen to find because this happens a lot, please let their providers know, because we keep a list of these.

Oh, absolutely. Very valuable to know. Our pediatrician who's really very helpful. And that's another really valuable thing to know, although we try not to publish their names because they would be absolute overwhelmed. Right.

So that happened some time ago. Not me, but somebody else would like spread the word. And I thought, oh geez, that person may be out of it right away because their practices, they just can't do their thing unless they're individual practitioners.

Yeah. But I also think something else you mentioned is really important. And that's the detail which with you drill down, you know, we're really being detectives.

It really takes and all of these questionnaires, even though the parents may think, oh my God, this is just overwhelming. Well, this disease is overwhelming.

And and filling out those questionnaires, my parents have found at least that that often helps them. Oh my gosh, I

didn't realize that was a trigger. Oh, I forgot about that water damage, you know, the month before this happened or, you know, and then when you were mentioning that kid that that got the doxy cycling for, for a decent amount of time, you know, now we both know that, that most of the ticks carry, you know, multiple, spiral kids.

And you know, and living in a basement that she was living in the basement at that time that had been flooded. It had mold on the walls. And in fact, she has Bart now, I think.

And like, maybe not like the two out of the 3 or 4 to a, I think two definite tick borne illnesses. Yeah. Yeah. So it, it takes the detective work and then the last thing is, you know, I often use the analogy with my families of being their GPS, you know, and I'm going to give you what I think is the best route to go down.

But you're still driving the car, and I need you to to tell me this works. This doesn't work, but also what else you may be doing, because when we're not being transparent with each other, that's where things really fall apart.

Right? And therefore, please keep your provider informed. There's the gene all the time. And I will say, great. Thank you for telling me or willing to talk about this, you know.

Yeah. Yeah. Mentioned something else because you asked me why is this diagnosis so hard and so controversial? Yeah, that was what I was just going to ask you again.

A hard so far. Part of the thing is for the clinician who's a psychiatric person, there's so much of this presentation that actually does match traditional diagnostic criteria, but with a twist.

Yeah. So for depression, anxiety, anxiety, especially eating disorders, it's not body image problems. But now that you have a name called our friend so they can diagnose you with a restrictive eating disorder without ever bothering to wonder why that would be the name for it now.

Right? So, but, the timing and the severity of the symptoms are what really differentiates the traditional anxiety disorder, separation anxiety disorder, or even OCD.

It's not so fast and furious in most cases. It's not a no overdose, not an overnight. It often is a period of several months, I think, to really escalate.

And I call this the the treatment seeking and the experience of the family I call the suitcase effect, which is your trip. And you go on collecting more and more and more diagnoses.

Yeah. On the other hand, parents and kids have come to me and say, well, I pay you. I think you missed a diagnosis. And I go, well, when is that? It's usually autism and go, well, let's try not to put that on the record unless we really have evidence that's true because it could be true, and especially in a mild case, but especially as a girl, for example.

But, there's a lot of times I'm seen neuropsychologist diagnose autism and 15 year old girls who have never had abnormal peer relationships. They were peer leaders in fourth grade.

They had no problem communicating. They had no symptoms of what's required by the DSM to be met as early onset kind of rule bounds and particular interests and things.

But this is true that because they had really high sensory issues and the mom could fill out one of the forms, as you know them, that she was socially inept and shut down.

She met criteria for autism recorded that neuropsychologist and now in this in her record for the ever and I get so upset because you and I know it's great I mean there's no problem with having autism, but how you get treated in the emergency room and a doctor's office, if you have that disorder, you are discriminated against and it's bad enough with everything else you're struggling with to not then have the parent find out, well, they're autistic, of course, that's why they're doing this, right?

You and I know that's every excuse. We we think that an autism the parents have diarrhea up the back of the child five days a week. And the doctor would say, well, that's because they have autism.

Go away. Right. Don't worry about it. They have autism. Yeah. And I say this all the time, but Syd always used to say Doctor Baker, you know, it's name it, blame it, tame it.

Medicine. Well once you have the name autism, everything gets gets well, you know. Right. And parents and children and adults do seek out the right diagnosis.

That's there. That's good. But the desire is that if you know the right diagnosis, there's a right pill. Yeah. And that's where things hit the wall most of the time.

Right. So absolutely I just want to make that point. Yeah I get it I get it. And and how about the controversial part. You know, we we know that the AP just came out with a report that, you know, was limited in the amount of research that it was showing.

And, and we know that there are a lot of practitioners that either since that or long before that, don't believe in pans. Pandas. How do you address that?

What do you think is behind that? What are your thoughts? Well, I, I know what's behind it is if you ask people when they trained, what did they learned about pans pandas it's usually they might learn about pandas.

It's still stuck back in 2000, in 1998 to Sweden. Yeah, that really changed in 2012 that no one got the message. Or it's not mentioned at all. My new, nurse practitioner just graduated from master's, you know, NP psych, and I don't think it was mentioned in all her training, but remembering that they have to learn a lot in a short period of time.

And I continually, you know, I, I interact with providers, especially when somebody is hospitalized who are trainees from major mental health programs, you know, Harvard related, for example.

And they keep telling me it's controversial. It's not real. And what happened is a little be known that but, Doctor Dan Geller taught me this one time in a psych pharm conference.

I sat next to me in the back and I said, why is it that for ten years or so, I. There's this long period of time where there was no new publications on pans pandas? And I kept checking.

Yeah, I got an internet right. Dial up. And, the reason he said was the head of NIH at that time did not believe in pandas. And then Tom Insel took over who did believe in pandas and in fact, published one of the beautiful MRI pictures, which I still backed himself, and of an enlarged basal ganglia and a normalized after IBD.

And then the publication started again. But what would happen is it would just cough up the old. Somebody must have had to write a paper to get tenure or something, or meet their educational claims, because they would just read, format and restate everything that had been stated the prior eight years.

I had drawers full of these articles and so nothing advanced for so long. Then the second thing is only until I think Covid, we finally got a golden ticket to kind of talk more rigorously about viruses and illness and migraines, not short illness.

Why PANS Is Controversial and How to Advocate

And, it's kind of like the groundswell, I think I and one thing that sustains me, actually, is the work with autism for so long that we, you and I, were at the beginning of the revolution of people being.

I mean, remember when we started, people were still being told they were refrigerator mothers. Oh, yes. And for their diagnosis and since then, eating disorder parents have been told that's a controlling mother.

And now, you know, with cancer being told it's Munchausen by proxy, by the mother. Right. And kids are being taken away at times by the courts Thursday.

So, I, I have a very long view and something just bland who, you know, in functional medicine said years ago. He said from the time it's on the bench in science laboratories, it's ten years before it even begins to hit clinical practice.

So you and I heard about MTF probably around night 2005 maybe. Yeah, yeah. From there he was talking about he was traveling. If I just look back in astonishment, he was going around with a little suitcase and meeting with those in little hotel rooms.

Yeah, I mean dinners, right? Yeah. We talked about to Jeff, and I remember that evening so well, I thought, oh my gosh, this is interesting. You know, 15 years later, the general population might be talking about it, right?

Not even now, you know. But I am really encouraged. I have an adult therapy client who has really bad, autoimmune disorder and her world's expert to bring women's in Boston.

Said to her, one of the first things he said to her is get off dairy, meat and gluten. Wow. And he said, this is lupus. I said, he said, what? They told me.

I go, I'm just gobsmacked. I said, that's fantastic news. Now, she didn't listen to him for about eight years. Know I was like, so was that it finally is up.

Oh trading and I'm sorry. Yes, so many people have been ill by text. It's hard to know a family that it has not been impacted by it. Right. And you know, and debilitated by it.

And so I'm hopeful even with the A report as onslaught as it was, it allowed a parent to say you're wrong. If you tell me it doesn't exist, it says it exist right here.

Now write the rest of the article was it the Esther? Which of course, really the phone and my email were blowing up the day that thing came out with all the upset, despairing people.

But if it allows 15 out of a hundred more parents not to be denigrated by their pediatrician, that is a blessing. That's number of parents who are forced to leave their beloved pediatrician.

One of them, way back, had had a liver transplant at Children's Hospital, one of the first of daughters that sadly also had a patient. And when that mother went to that institution to say, my child has plans, and they said, oh, you're so stupid, you're so wrong, go away.

She was devastated. This is the institution that saved her daughter's life. And then she had to make a choice. This is happening to parents all the time.

Yeah, so I have these, but at least I can say. Well, here's the article, doctor so-and-so. Beyond that, it's a problem, of course, because. Because you have to have an active strep that's look like strep test is not like strapping us to swab strep.

And by the way, you can only give ten days of antibiotic. And that's all you can do. Bye bye. Yeah. We're still stuck in 2012. But it was one little step and I, I experienced the same with autism.

It was chippy in a way. It was parents who drove the agenda. Eventually you and I did not change. It was parents. And I believe that's still what's happening to this day.

Parents who show up, the legislator, parents who talk educate, who support each other, who whisper in people's ears, go get your child. Check for strep.

Yeah. Look at your, you know, go check for x, y, z. So I am hopeful in the face of despair. Yeah. No, I hear you. And I think the the silver lining approach the the looking for the good in everything.

You know, like you said with Covid recognizing that there are infectious triggered, virally triggered issues, recognizing that just the app saying this exists, I think those are really important.

And, and I think we have to remember that the good every little nugget and that's true in our kids, too. I mean, what we're doing is trying to, you know, people always use the onion analogy and peeling off the layers of the onion or the the gift analogy that this is again wrapped in nine layers of wrapping paper.

And our job is to unwrap each layer. But it's still a gift. And that's the thing that I try to impart to my parents too, that no matter how thing difficult things are, your child, even this disease may well be a gift.

I mean, you know, I got into Pans Pandas because of my own family, because of my child and, you know, how many kids would we not have helped if we hadn't suffered?

And I just think that the there are always nuggets of hope, that we need to share. Yeah, it's funny, I have never understood why I was so drawn to this because I don't have a child with pandas.

I have a child to have some anxiety and stuff, but I then realized years and years later that my mother and dad had a child born with, my mother's second child.

She was the child was in labor in the birth control and not oxygenated. And a covering for this is post-World War two. She was having a birth without scopolamine.

And no in a state in which was unheard of. She was having a natural childbirth, one of the first in Saint Louis. And the doctor on call boarded the nurse to hold my mother's legs together.

And my sister came out with severe cerebral palsy head to toe. And my parents were fully advised that the treatment of choice was to institutionalize her and put her away and forget about her.

And thousands of parents did this. Thousands. My parents refused, and my mother was a love science. She was a chemistry major. As a college person. She worked, you know, she was a she taught for 45 years until she died in 87.

But I think somewhere in my neurons early on, the challenge of not status quote was given to me. And my mother was actually quite traditional about defending medicine.

But, I just think there was I think that's the connection for me. I never understood it until many years later. But, something wrong about what good medicine was telling people, and I did.

Yeah. I mean. Yeah. And for me, you know, I used to read all those Nancy Drew mysteries as a little kid, and. I always. Loved being a detective. I'm scared to death to walking into a dark building.

So I couldn't be an actual detective. But but that part of of nurturing, doctoring, figuring things out, I, you know, that drives me also. And, you know, it's really funny because I do really get excited with the new intake as much as new work.

It's like, oh, a new is mystery to solve. I really do get excited. And I go, oh, this is cool, you know? And then I start to see it. I go down, there it is, there it is.

Yeah, exactly. Exactly. When the lab reports come back confirming what you thought. Yeah. We don't follow ups when they come in and not only is it, of course, the one thing they're supposed to be here, but then we hear about all these other things that are happening that are like, oh my goodness, I got to pull back the line back and get a bigger picture of what it is we're actually talking about now.

Yeah, not just why that medicine didn't work, except that you were just been in a flare for a month, and four members of your family had an A virus. And that's the other thing that's really struggling is to get parents to recall that everybody got sick, and now they're in a school.

Yeah. I can't tell you the endless times I gotta go. They come in, they're majorly depressed. This antidepressant is no longer working. Okay, let's talk about who's been sick in the family.

Yeah. Eight weeks. Oh, well, people were had Covid over Christmas. It's now July, January 15th. They had Covid over Christmas. Yeah. All the family members got it.

I go who was the last member and went yeah. Oh around January said I go okay two weeks is at least two weeks.

Closing Thoughts and Resources for Families

You know not it's not. Oh okay. Well this is flare. And yeah, the most educated people who've actually lectured on PMS in the middle of the trauma of their child going down.

Right. They cannot not recall that most of the time. And I've learned to just live with it, because it's just amazing how that gets wiped out in their brain.

Yeah. And I think. We have to remember if it's just a little sniffle, Peggy, I go a little sniffle is not a little sign to your child's system at. All. Exactly.

But but it still reminds me that that these families, these parents, as intelligent and wonderful as they may be, are struggling and and and not of their full ability when it comes to their own child.

It's that old shoemaker's kids have no shoes. So yeah, right. And there. Anyway, it was my turn. Peggy, I could talk to you for another seven hours, but we've we've gone over and first.

I know you're incredibly busy, but how can people find you if they want to? Pam centered.org paziente r.org. And there, if you want to inquire about, admission or is an intake, there is a form there and I am going to be very honest.

I'm not doing an order of what people do because I do have to train people. So different ages matter, different presentations matter. And also I am committed to trying to get new cases who were just diagnosed into the office.

They have a lot less history, especially if they're young. And also they're very quickly respond to. And then I don't have much more to do for them. Many, many, many a probably a half come with long histories of treatment already of Evangeline mold or maybe no mold or tick borne illness because they've only been treated to major medical center people, and they've got a lot of IVIg and a lot of treatment, but they're not better.

And, you know, and I know that they have to be checks for mold and Lyme and proceed from there. But I, I'm just a really small resource and I can't do everybody it all the time.

So I do kind of try and prioritize and also committee on training needs. I have to do that. Yeah. No. I so appreciate your honesty. And Peggy, I so appreciate everything you're doing and being in this world with you.

And and thank you for all of that. Any last words of wisdom or pearls you want to leave everybody with. Parent support is out there. You need it whether you have a provider or not.

So please get online. There's multiple, you know, parents, parents groups. I'm hearing about them all the time. I do not go on them. But, yeah. Please get yourself support.

You're up at three in the morning worrying and trying to figure out what the heck's going on in your life. That's a great time to just look, knowing that some of the more severe cases we talked about.

But you will find a place and support. Please ask for help. Parents are always saying, I want to give this forward. I always want to help, but they don't know you're out there.

Yeah. Yeah, absolutely. Well, we know you're out there and we so appreciate it. And thanks for everything. Peggy. Good to see you again. Thank That's it for today's episode of Demystifying Pandas.

Pandas. I hope you're walking away with insights, tools, and hope to help you and your child on this journey. If you found today's conversation valuable, be sure to subscribe so you never miss an episode!

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Also, for more information, training and community, check out our website D. R. ohara.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 Gans. Pandas.