Inside a PANS Flare: A Child Explains What It Feels Like Transcript

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Opening on parental self-care

For self-care for parents, I think for a while I was kind of resistant to it because I was like all the time, all the money, all the effort needs to go for Aiden's care.

And my husband's like, you need to get help so you can be well. I would start going, I go for acupuncture weekly and I get the treatments I need because I have to reset every day.

Every day I have to be like, okay, I'm resetting now. Yep. And Aidan, let me, one of the things your mom's saying is that old adage, put your oxygen mask on first.

You know, moms and dads can't help their kids unless they're helping themselves. It took me a long while to accept that, though. And it was hard to hear, because even when friends would say that, I'd be like, but you don't know what's going on here.

Like, you're not understanding. And it's, I think you have to, you come to a certain point where you realize the engine's totally empty. Welcome to Demystifying Pans and Pandas.

The podcast where we uncover the mysteries, breakthroughs, and hope behind these life-altering conditions. I'm Dr.

Podcast introduction and Aiden's story

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. I'm Dr. Nancy O'Hara, and I am so excited to welcome to our podcast Demystifying Pans Pandas, Aiden Newman Brown.

Aiden is 10 years old, and he suffered with PANS for years without getting the correct diagnosis. But right now, he's in a research study that's conducted by LSU and Stanford through Dr.

Melamed's practice that started a few months ago, and he's receiving IVIG infusions. And he was the first person participating in the study, and they're planning on including 10 kids with the hopes of receiving more funding for additional participants.

So that's exciting. What's also exciting is that Aiden loves playing and watching baseball. He's not a Pittsburgh Pirates fan, probably, or he wouldn't love it as much.

Who's your team, Aiden? Well, you've much better record. I gotcha. He collects Pokemon cards and going to arcades. And what's also really cool is Aiden is the founder of Bottle Caps Are Cool.

And he sells NFC enabled nostalgic or custom logo bottle cap charms that are called Tap Caps that can be programmed to any digital content you choose, like websites, social media, video, photos, apps, your phone.

I think that's so cool. So Aiden, before we get started talking about all the Pan's Pandas stuff, can you tell me a little

bit about that Bottle Caps Are Cool?

Yes, so when I make my bar caps, a portion of my money goes to the homeless and I make food and give them to them when I drive around Denver. And yeah.

Wow. And how did you come up with this idea? How did you, how did it? Well, in 2023, when I went to France, they had many areas had bar caps and at first I just wanted to collect them for the fun of it.

Bottle Caps Are Cool business

And then when I brought them home, I had the idea of making a business out of them. And at first I had no idea what to do, but then I looked it up and I found out that the NFC would be the best thing to do with it.

Wow. And what does NFC stand for? Near Field Communication. Wow. That is so cool. And by the way, I want to tell all our listeners and viewers that you guys reached out to me, that you were interested in talking about this.

And I think that is so cool. You know, I talk to so many kids who are not willing to talk about their Panzer Pandas. because they're worried about what people would think.

So first of all, I just want to say thank you. And I want to say what respect and admiration I have for you, just talking on this podcast. So I really appreciate it.

Thank you. Go ahead. You go, Mom. For National Pans Awareness Day, I had asked Aidan what he would like to do to commemorate the day. And that's how he came up with this idea.

It's such a great idea. And I am so honored that you picked me to talk to you on this. So I really, really appreciate it. But let me ask you, my first question is, can you remember back when things started to feel different for you?

And what did it feel like in your body or your mind then? Well, I would say that's kind of at the beginning of 2023, when I started going to France, I started feeling like I couldn't exactly control myself in certain things.

It wasn't that bad, but I felt it and it was different for me. So I called them, I talked to my parents saying they're like problems and we talked about them.

And then at first we thought, then when we got home, we thought it was OCD and then we found, and then Now, many years later, like now, I found out those plans and then…

Yeah, but back then, people didn't… I mean, even just a few years ago, people didn't know what to think, right? Yeah. And Mom, was it very abrupt? Did it just come out of the blue from your perspective?

Yes. We had noticed little signs that did look a little bit characteristic of OCD. And we had OCD in the family, so it didn't seem too far-fetched. But it wasn't interfering with daily life or school.

First signs of PANS and OCD confusion

Yeah. And then later on, that's when it started interfering with other things. At first, they were just small things. And then once I came back, it got a little bit worse.

OCD is not just being destructive. That's not OCD, unless it was a repetition of something that you did before, but it just came out of nowhere. So then we still thought it was that, because it didn't exactly have nothing that it could have possibly been that we thought it was.

we finally figured it out. It was a very interesting conversation I had with Aidan. We were trying to find our apartment in Paris and we were a little disoriented.

And he started, during this long walk, he started talking to me that he felt a change in him. He felt that he had several problems. And he said, you compare, you want to explain it?

For example, like that have like like, I would say, like, prom, and then, like, each night, like, before I went to bed, I'd expand on it, like, saying, like, oh, like, I have, like, these folders, like, A to Z, and then, like, each letter would mean, like, a different, like, thing, you know?

For example, like, A for, like, my name, things about, like, me, then, like, something about, like, D about, like, a repetition with a dog or something like that, or different things that went to it.

And then, like, each night, I, like, add something to it, and then, like, I still do that now, but less commonly, because less… bad symptoms since I'm getting help now.

Was it scary for you back then, Aiden? Not exactly scary. I just didn't understand what it was. So it was kind of confusing, mostly. Got it. OK. And then once we came back and I started going to school, I kind of made a thing of a car, for example.

In the trunk was me. Then in the back seat, it was focus. Then it was repetition in the passenger seat and anger in the front seat. I do a drawing of that kind of saying what was the worst and what was It's like, you know, like I was in the back of the car, so I couldn't control anything at that point.

Then slowly I got to control the focus and to the repetition, but then, yeah. Wow, that's a really good analogy, buddy. Did you come up with that? Were you thinking about that yourself?

Wow. So let me just re-articulate that. So at the time, before you were getting help, you were a car, but you yourself were in the back. You couldn't control your thoughts or what was going on in the driver's seat.

Like I was in the car. I was not in the car. Right, you were in the car. Yeah, but in the trunk. You can't drive the car from the trunk. Exactly, but then slowly I got to the backseat and then I stayed in the backseat for a very long time and I'm still trying to get into the passenger seat, but way easier now.

Okay, so right now you're in the passenger seat, you're not quite driving yet? I guess, yeah. OK, all right. But also, now that I'm getting treatment, like, anger is not really there anymore.

It's more like the repetition. Kind of like, once I got my help, like, the anger got, like, removed, kind of. It wasn't even there anymore. And then that's why the repetition is now in the driver's seat.

So technically, like, if you think about it, I'm in the passenger seat. Got it. Got it. So you still have… Go ahead, buddy. If I was in full control, then I wouldn't…

If I was in the driver's seat, that'd mean I'm in full control. That means I wouldn't need help right now. Right. Right. Got it. That makes sense. That makes sense.

That's a really great analogy, buddy. I like… I'm big into analogies. So I like that one. during this walk in Paris and explaining this to me and explaining how he was feeling anger and he was afraid it would turn into rage.

And he said, if I don't, this is, he just turned 10, he was eight when he said this. And he said, mommy, if we don't get help now, I don't want to be like this when I'm an adult.

And if I don't get help now, it's, I mean, I felt like I was talking to this old soul. Yeah. As a mother, it was wild, you know, because he's a little boy, but it was just a wild conversation.

Right. And you must not have known what to do, what to think, what was going on.

Car and trunk analogy for symptoms

I didn't, because beforehand when we noticed little symptoms of OCD, we had called the pediatrician who's phenomenal, and he recommended one of the best acupuncturists I've ever been to.

Her name is Molly Dyer. She helped Aidan with congestion and all sorts of other things. And we thought it could help. The pediatrician thought it could help with some of what could be OCD.

It wasn't diagnosed yet. Oh, did you want to say something? Go ahead. And that I wasn't diagnosed with OCD. She wasn't 100% sure that it was PAN, but she thought it was PAN.

She was the first person to suspect it. She said she couldn't diagnose it, but she suspected it. And when we asked the psychiatrist, it was kind of brushed under the rug.

And they had put him on two different SSRIs that we tried that really made things way worse. We weren't sleeping. We had all sorts of side effects that were not typical of the prescription.

And I felt convinced. This didn't seem like classic OCD to me. It didn't seem anxiety driven. There seemed like a different flavor. Right. As we dug deeper and deeper, I started to realize I really think Molly might be on to something.

And we went to a neuro-immunologist at Children's Hospital and she's like, no, this is pans. And she felt when we went to France, Aidan had a little irritation on his tush and she thinks it was strep.

at that time. And we had called a doctor, but we couldn't get an appointment before we left. And, you know, they thought it just could be, you know, nothing major, don't worry about it.

But things got worse and worse. And what was most surprising is Aidan is one of the most empathic, sweet people. I know he's not a mean or a violent person.

And when we saw this anger, it really took us aback. You know, the doctors asked, did something happen? Like at some point, like then at some point it got like worse that they would have like violence at home, but not at school.

So it was interfering with some of my life, but not all of it, you know? Yeah. like throwing big objects, like knocking down doors, like things that are very violent.

Totally uncharacteristic. Then one day at school out of nowhere, I had one at school. Well, this is what happened. Everything would be fine at school.

And I'd ask the teachers, they must have thought I was nuts because I said, are you sure everything's okay? They must have thought I was like paranoid because at home it would all fall apart.

And at school they'd say, oh it's one everything's great he even went on a two night overnight trip it was great everything's fine and then started fourth and things started to get difficult sure like what they were for example what they were doing was that they were like saying like at the end of school he was like throwing cushions at the wall like not like towards anything just like getting my anger out towards an object or something or like when someone said oh it's this class like i I say I have to go to the bath and I never come back till the class is done like things I wouldn't normally do, you know, like that.

Were you trying to hold it together, Aiden? Like was that what was going on inside of you at school? Like you didn't want to show that at school and then at home you felt freer to release this anger that you were feeling?

look, I could stop at one place and I mean, at school better than at home, you know, to stop it. So at some point you got, I mean, since I wasn't getting the right medication, you just kept getting worse and worse and worse.

And at some point it's not like I was getting better, better, better. So since it was getting worse. That's how that happened. I also sent him to school unknowingly with strep and I didn't know because this is before we realized

Pans was in the picture and it was diagnosed as OCD.

Did you know I had strep then? I didn't. No, I would never have sent you to school. Aiden, when he gets sick, he doesn't present like a typical sick child.

He's also not a complainer. So there was a day or two where he's saying, I didn't want to go to school, but we had a few days of school refusal. And I was told by the therapist, get to school.

Like you can't get into that place where this starts to snowball. So I was like, all right, bud, we're going to school. And he came home early, two days, and then I spoke to the principal.

I was like, keep him there. He's fine. And then I got a call saying, you really need to come to school. And I said, what's going on? For example, I saw like one day, I just do like, so it was like, almost, Oh, it was like the time of like, it was like after recess or something, we came in and like, instead, like I tried to run out of the classroom.

So like they called a teacher, but I was already out of the classroom, you know. So then I just, I ran out of the school all the way to another building.

And then like, I didn't, and then I went to one building and then. and then I went to… It was like a scared… It was almost like a scared squirrel, because I got to school.

And then every time someone was surrounding me, I'd find a way to get out, and I wasn't trying to attack anything, I was just trying to get away. No, it wasn't harming anyone or anything like that.

It really felt like people trying to trap a little squirrel and that squirrel wanting to not be trapped. And I was taken aback because I get there and I'm surrounded by 12 adults, all trying to get a child, some of these adults crying, panicking.

It was overwhelming. And I got there and I was by myself and I was like, okay, we just need to extricate ourselves from this situation. I called my husband, come, I need you.

So at some point, then I got into the middle school building and I was stuck in these doors. So someone was blocking both doors. So I was able to get him.

But then we went right to the pediatrician. And because I was really worried, I didn't understand what happened. And they did a strep test. And it was positive.

Yeah. And so I realized I had sent him to school for three days with raging strep, having no idea. Right. And that is such a typical history that I hear from so many families that, you know, the kids weren't complainers.

They didn't complain about things.

Strep, school struggles, and diagnosis

It was a behavioral manifestation, not a sore throat, not a fever. They were exposed to strep and had behavioral changes. Or you get to the pediatrician, the throat looks pristine, but they've had these behavioral changes and it ends up being strapped.

And that's so classic of so many kids. So from your perspective, Aiden, what's something people get wrong about what it's like to have pans or pandas?

What's something people don't understand? What's something they get wrong? I don't know, like, how you can, like, technically, like, when you're there, like, you can't control yourself.

They just think, like, you're not trying, but, like, even if you're trying to control your thing, it's like, like, your body

controls, your brain doesn't, your brain controls your body, but technically, just because your body's bigger doesn't mean your small brain can control, like, it doesn't matter if you're big or small, it can still control a bigger thing, or a small thing can control a big thing, you know?

So it's like, if that gets bigger than your brain, I mean, then, hard, you know? If it's sinking differently as your brain but at the same rate, it'd be like two things the same size fighting against each other and it never ends, you know?

It just keeps like one person gets punched, one person gets punched, it just keeps happening and happening and I could get better than worse and better than worse and then it just keeps alternating.

Well, his teacher told me that Aidan had confided in her that he just wanted to be out of his body, that he didn't feel control of his body, that he wished he could just be out of it.

Yeah. And that's so typical. And back to your car analogy, you know, it's not you. You're back in the trunk. You're not driving this car. And some of my patients call what's going on for them some other name because it's so not them.

It's so not who they know themselves as. So that's something a lot of people get wrong. And also that the behavior, the trying to get away from everybody, like that trapped squirrel, that's not you.

That's this disease driving your brain, right? Yeah, exactly. Like, for example, I'm like, well, we're just eating, like, flight, flight, it hasn't existed.

Oh, fight, flight, or freeze? Yeah, fight, fight, or freeze. I normally fight or flight. I don't normally freeze. When I have trouble with something and I can't control myself, I'll just freeze.

That's not like me. He would run away. Luckily, we live in a one-story house, but he would leave through the window, just run down the block. It was terrifying because this was so atypical.

This is a child who at school would confess to me if he took a sip from the water fountain without permission. I'm like, I think it's okay. Don't worry about it.

And he would confess to me. And then all of a sudden to have trouble at school was really, it really took us aback because it was not something we had ever, ever had an experience with.

Yeah. Well, for you, Aiden, how does having Pan's Pandas make school or hanging out with friends feel different for you? Well, what do you mean by that?

Well, like, do you feel different at school or back then when this was going on? Did having this, hanging out with friends, feel bad or feel worse or feel different in any way?

I guess different because before they were sometimes mean to me, but not a lot. Sometimes my parents would do something annoying that I didn't do purposely.

I'd do something that someone doesn't like normally. I'd do something that they don't like and they think it's just my fault. They already would react extremely even if I did it purposely, but I wasn't doing anything purposely in the first place.

It was just my parents. So when I say annoying, it's not like I purposely annoyed them. Yeah. Can you, do you try to explain it at all to your friends or other people in your life?

What's going on in your brain or body? Yes, for example, I did a presentation. Before I thought I had a parent, I did a presentation about OCD, and we watched a video on something about it.

And then for that one day, everyone was nice to me. And then after that, they were like, oh, he didn't have it that

day anymore, just for that one day.

Teachers were watching that one day specifically. But then after that, it was like a normal day again. It kind of like a special, crazy note. They're nice to me in another case, and they're not.

It also kind of depends because… It's tough sometimes because it looks behavioral and people have less sympathy for that than you would if you walked into school with a broken leg.

Exactly. When it involves the brain, it's very hard for people to understand that it's inflammation in your brain, just like arthritis would be inflammation in your knee.

They can see that though. see bad behavior and think you're a mean kid. And we know that's not true. And I think that was really true. For example, my teachers in the other grade knew I wasn't that person and they saw something was wrong.

But since that started all fourth grade, my teachers in fourth grade thought that was actually who I was because they never saw me the other way. Because my other teachers, I was always nice the entire time.

Then in the fourth grade, since I was inflamed the entire year of fourth grade, they didn't know who I was. They thought I was that mean kid. Right. Right.

And how did you help them to understand? Were you able to talk to them about it or did your mom help talk to them? We did, but it was difficult because he had not been diagnosed with PANS yet.

So we were talking about it through a lens of OCD. We had him medicated on things that made him worse. The therapy we were bringing him to was not helping.

And it really came down to just needing this to be treated medically. Also, when I left school, I had a play date with another friend. They told me that many people were making a story saying, oh, he ran and got hit by a car on the road.

Understanding PANS behaviors and triggers

We're like, oh, he dropped a bomb. I mean, I think that was a funny story. Yeah, saying really outrageous things, even though he just ran out of the classroom.

Yeah, I mean, I ran into a building, because no one could exactly see out the window. All they saw was me running to one building that was near the road.

But that didn't mean I ran into the road. Yeah. when I were talking, like, it's not that our suffering is unique or special, but we were thinking, well, what makes this different?

It's the isolation. It's so isolating. And then we took a little time off. We've been doing, luckily I'm a curriculum developer for the last 20 something years.

So we decided to do one year of homeschool and then re-enroll in school. But what we realized is it's almost like we vanished. People didn't reach out.

And I think that was the hardest part because Aidan's like, does anyone remember me? And it felt like we were just erased. And that was, I think, the absolute toughest part.

And the one beautiful thing, wait, one beautiful thing was we go to a temple that is extraordinarily warm and loving. And they saw Aiden on his worst days.

And they said, you know what, we're going to find a way, even if it looks a little different, to make it work. And then

as he got better, you know, he participated in Hebrew school.

Kind of like the same thing. When I had been at school, my mom said it was just because of one thing, a strep, you know. And then I didn't have strep then a lot, you know.

Then I still went to Hebrew school the next, like, a few days later. Well, we didn't know it was pans, that we didn't realize exactly what was going on.

So I was taking medication for strep and all that. But then the exact same thing at Hebrew school technically happened worse, you know, because like at school, I only like…

But you ran out, yeah. But then like I went out of the building and then… But then mom and dad came and got you. So that was good. But it was a little…

It was scary because we thought that was a one-time incident. We thought that was just like, oh, maybe something happened at school. But then we realized this was more serious than we had fully understood.

Luckily, you know, we had Children's had put us on a 30-day antibiotic regime and steroids, and that helped briefly. But I think what helped even more was the functional medicine doctor who helped, you know, actually really analyzing what's going on in the blood, what he needs, where he's deficient.

And then we started seeing things really changing. Dr. Melamed thought that the IVIG could be really helpful. Aidan's case is also somewhat unique because when he was three years old, he had something called autoimmune hemolytic anemia.

So what happened is we, I remember like it was yesterday leaving Barnes and Noble and Aiden just saying, can you carry me mommy? And I was like, oh, you know, you're a big boy.

You should, you know, we're going to walk back to the car. And then he just kind of like wilted in the parking lot. So I scooped him up and you know, no fever, no vomiting, no diarrhea, you know, nothing really alarming, but he was in pre-K at the time and like everyone has sniffles and stuff.

And I said, okay, that's probably just, he's probably getting something. And I remember that evening, I was working with a client and my husband said, you know, he looks really pale and his urine had a little bit of a Coca Cola color to it.

And we didn't think it was blood. Of course, what does any 40 something year old woman do? They call their mother, who's not a medical doctor. My dad's like, you know, your mother's not a psychiatrist or a pediatrician.

So she said, call the emergency line. And I felt silly at first, because what am I saying? My child doesn't have a fever. They said, go to the emergency room.

We did. They said, this is quite serious. You need to get to children's. And before we knew it, we were in the hematology and oncology unit and they didn't know what was going on.

But he did have two blood transfusions as the red blood cells were bursting open pretty quickly. So that was like the first time where there was this major issue with the autoimmune system.

I think in the back of my mind, I always felt like, you know, my mom's like, don't borrow trouble. But I felt that there was something like unfinished business there.

And years later, when we did go to Molly for acupuncture, she said, I feel like there's this, you know, this is an Eastern medicine talk like this pathogen that just needs to get out.

And I didn't fully wrap my mind about that, but I kind of understood what she was getting at. And I think that's when

that huge flare happened. Right.

There's that huge flare. And, you know, although most of our children do not have to go through autoimmune hemolytic anemia, having autoimmune disease in the child or in the family is actually very common.

You know, at least 64, 65% of the kids have that in their family or in themselves. It isn't about strep or mycoplasma or viruses. It's about the way the immune system reacts to those and the inflammation that the immune system causes in the brain that brings about these behaviors and abnormal movements and all of those things.

It's interesting that you brought that up because that is something we noticed also. We would notice things that now I realize was a tick. It was hard for us to know, is that like a compulsion?

And then I spoke with my friend whose son was diagnosed with Tourette's and he said, that sounds like a tick to me. But there would be like, it started when he had some congestion and he would be, you know, but then I noticed it stayed for quite a while after.

Yeah. Yeah, that was like for a long while or certain like, you know, starting certain things. And I could see that it could happen when his body might be under stress or starting to.

Yeah, but like technically, like, not exactly about what you're saying again, but like, for example, like when when you when I'm in a flare, like, I can't exactly, I like use my strengths, not like my, I'll just think about things I do.

Like if, second I think about a thing, I do it like immediately, you know? Yeah, there's no space between his thought and then the action in a flare. And then also like, let's say I can't do something, I'll put like all my strengths into something.

Like let's say, like I wanted to like break down the door and I was like, I can't do this. And then I found a way like, oh, I have no idea. Like let's just put the chair into the door, you know?

And then destroy it. Normally, you'd think about that thing that would break the chair and the door. I wasn't even thinking. I said, break the door in the first place.

But then at some point, you can't control yourself at all. Yeah, that was shocking to us because that was not something you ever experienced. Like still now, I can't control myself 100%. But you don't have those major outbursts anymore.

But then like, but like doing it out, but it's like, if someone says like, like, like, whatever you say, like, oh, I'll give you video game time, I'll give you money or whatever.

It's not something you can bribe away. That's for sure. You can't hold a pirate and hope that you'll snap them out of it or have a punishment lined up and snap out of it.

And it does feel like you're a bit on a roller coaster. For example, like now a punishment would say, oh, you know, it's not worth it, you know, fine.

But like, Well, because now you're more emotionally regulated. But then it was like it was like the roller coaster started for the nervous system. And then we'd know we're in this for at least 90 minutes, maybe up to three hours, but we're in it.

So we just have to strap in Try to stay calm ourselves. When it starts happening, what you do, you close it. Well, we try to get ourselves in a safe place to make sure there's nothing around that could be unsafe.

Treatment, family support, and recovery

Yeah, exactly. You wouldn't have anything unsafe. Yeah, like you would put things in a room and lock it. For

example, they put the utensils in a room and locked it because they didn't want me throwing utensils.

But I didn't break down the door for no reason. I broke it down to get them, you know? Yeah. During an outburst, I still have reasons to do things. It's a bad reason normally, but let's say I wouldn't just break down the door for no reason.

Your nervous system feels like it's in danger. You feel like you're in danger when that's happening. That's the fight part of the fight flight. One of his outbursts, I remember him sitting down.

You were sitting in that little red room in the basement and you're like, what just happened? It was almost like, But he remembers it, not like his memory has been totally wiped.

He remembers what happened, but he's just like, well, why would I do that? Right. And I think, again, there's so many important things you're saying that I want to emphasize a little bit more.

One, that it's a roller coaster, that this is episodic. You can look absolutely feel fine one minute, and the next minute you're breaking down doors or you're ticking out the yin-yang.

That's the first thing. Yeah. And then the second thing is that as moms and dads, you know, we really have to try to stay calm in that moment ourselves, because sometimes us getting upset doesn't help.

And my husband's masterful at that. He's very calm. Also, it's not like when it was very severe like that, it would just happen out of nowhere. For example, I'd be like, why would I do that?

It could happen, then it stops, and then five minutes later it happens again, you know? And then at first it's like, oh, I'm in this thing, I still remember it, but then all of a sudden I'm like, oh, I'm back to normal, you know?

That's the interesting thing because you don't see the… what instigated it. But then now that still happens, but since the things are so less severe, it's kind of like it's not super visible, you know?

Like it might be like, I know where I do a repetition thing, but then it stops, you know? But it's not like a super extreme thing, you know? So it's not super visible.

It's not like a thing like, oh no, he's doing the outputs now. It's not like it's a very small thing that's like, oh, he does this a few little time. That's a good point, Aiden, because we've had gone on vacation where we had to kind of just like, by noon, we're going back to wherever we're staying and we're just going to be in the room and calm because it's too much, too much stimulation for that day.

And we had just recently went away and it was an incredible vacation. And there'd be like little bouts of maybe two to five minutes of dysregulation, but not out of control, just like, okay, we're having five minutes of dysregulation.

Yeah, like saying, like, oh, I want to order this meal. And you're like, no, I don't want that. That's fine. You know, but like, for example, like, last, last time, like, last time we went to, this time we went to Costa Rica and it was a very nice vacation, as he said.

But then last time we went to Belize, for example, and then the poor, like, chased people and like, and like, like say, like, we're playing tag. And then all of a sudden they're getting chased and they're like trying to.

and my husband would have to extricate him from the situation. So the hard thing is like the vigilance all the time. When that happens, it ruins the vacation for me and it ruins the vacation for us and other people, you know?

Right, right. But then like if it's one thing that's like a tiny argument like about like if I can order something or not, that's like barely, the only people it's going to affect is us for like one minute, you know?

It's not a big thing, you know? But it's interesting in your vacations, you're sort of, that's a microcosm of what a lot of

our kids deal with is that, you know, parents and we all want it to get better immediately.

That's not the way this disease works. It's up and down and you're getting better. But like you said, there's still some things it's not as bad, but there's still things that you get stuck with.

Well, travel can be very difficult. Just the stress on the body from even getting from point A to point B. And we've learned as a family that we try to keep things very low key.

We don't get too committed to plans. We say, this is the hope. We're not going to over schedule ourselves. And Aiden actually really knows himself. He'll say, mommy, you know, when we went to France, we did three activities and that's too much.

We're doing, let's do one or maybe two. And then like when he has more agency in the planning and he feels more in control of what's happening, that works a lot better.

Yeah. So like what you're saying before, when it goes up and down, like you can't like completely heal parents or OCD any of them. Like it'll keep like going up and down.

But then at some point, if it goes up, it'll be like literally like 1% was, you'd barely be visible. It'd be like a normal day. It would still go up and down.

Like, even at the peak, it'd be like nothing. It'd be like, oh, you touch one thing that's not normal, you know? But like, once you're, like, fully charged, it's never, like, 100%. It'll still go up and down, but the ups and downs will not be visible at all.

It's more manageable. It'll be, like, still not visible at all, you know? Yeah. And then, like, also what you were saying in trance and all that, like, the first time, like, three things is not a lot.

But, like, for example, like, once we went there for, like, Like three things in a week is a lot, you know? But like three things in like a month is nothing, you know?

But like let's say you go there for like a week and you have like every single day book something. It's like you never ever think also like it also depends where you go, you know?

Like let's say you had a hotel that has a pool. You know what it is? It affects your endurance. And I think that it takes a toll on the mind and the body.

So like we know when we make a plan the next day, we're going to just you know, maybe we'll go to the park, maybe we'll just go to the beach, maybe we'll just relax.

It's not going to be a very scheduled time. And I think sometimes, you know, if you do the school day, that's awesome. Yeah. But trying to do the school day and then an extra, you know, and trying to stack that, you know, you can only ride that so long before then there's like the collapse.

Yeah, it's like in another analogy, Aiden, it's like a battery, you know, you're spending so much energy trying to control some of the things that are out of your control or trying to do the activities and your battery just runs dry.

And when you have pans or pandas, it runs dry faster. Go ahead, what are you going to say? like I use lots of my energy for like pans and the rest I use for like one big activity I have to do a day you know like let's say oh today we're going on going on a big hike and I save some of my energy for working and not being tired you know.

Or let's say today we're doing a hard test I'll put my energy towards that but like half my energy is going towards pans and the other half is going to one big thing.

That's a really important point because I can see when Aiden knows you know, for the bottle caps are cool. He won

a major competition in Colorado and he had to get up in over 400 people and make a speech at this gala.

And I also had to sell two hours. And sell two hours before. So he had to, he's like, I need to reserve my energy to be able to do that. And even- That's why that day I used 100% of my energy towards that.

Just to accomplish that. No, no, but like they're already speaking in front of other people is like half my energy So what I did is I used all my energy towards that and that means no energy was going towards pants That's why like after we left that a big problem at home.

It's hard to like yeah I had no energy towards pants to control it So it's just like it's kind of like if you if you're protecting your home and one and each day you put another gate down Then one day you don't put any gate and just have fun at home.

They're gonna destroy your house, you know I get it. I get it, buddy. And that's really good for parents and other kids to understand. And it's the same thing like if you had the flu, which is something else.

You couldn't go out and run a marathon. and take care of all your work and your schoolwork, you need to rest. And when you have pans and pandas and the inflammation and the autoimmune disease of it, you also need to reserve some of that energy, because so much of that energy is being expended in this disease.

So it's a really good group. For example, I would spend, as I said, I use half my energy towards pans each day, and then half it towards something hard.

But let's say I do something that's fun, it might give me a little more energy. Let's say I put half towards school, half towards pans, and then because I did school, I get to play video games, I might get a few percentage back, and then I can still control myself for the rest of the day.

Yeah, I get it. And one other point that your mom brought up a little bit ago I wanted to emphasize a little bit because I am a functional medicine physician and I come from a very classically conventional medicine background.

But in conventional medicine we're usually giving antibiotics and steroids and I think the functional medicine piece of it is so important because if you're also low in vitamin D or zinc or you're eating a lot of inflammatory foods or you're gut is upset because you're constipated or you don't have a good ecosystem in your body.

All of those things will drain your energy or also not make you heal as well. So I think that's a really good, important piece that you guys had mentioned also.

Yeah, and just dovetailing on that with the diet, you know, Aiden loves to eat and loves to cook and we do our best. We say, okay, we haven't cut gluten out completely or dairy out completely.

But what we say is, okay, if like when we were away, he said, I'm going to have gluten-free and dairy-free for like breakfast and lunch, and then I'll have some cheat at dinner.

And we figure out how can we at least cut back somewhat so it doesn't overwhelm. For breakfast, I'd have cereal. And then for lunch, I'd have a salad or something.

And then for dinner, I'd have a pizza or pasta or something that has cheese and gluten.

Diet, energy management, and fever effects

And then in the home, we try to keep it pretty gluten-free and limit the dairy. And that's helped a lot. It has helped a lot. Yeah. And for those that are listening that don't know, I mean, gluten and dairy are very inflammatory foods.

And they also block pathways of detoxification. And so removing them can be very helpful, but it can also be very

hard. Like you want your cheese and you want your pasta.

And do you know, Aiden, I don't know if I told you this before, but I have celiac. So I can't have any gluten. So I found lots of ways to find really good gluten-free pasta and pizza and all that kind of stuff.

But it's hard. Yeah, gluten-free pasta and pizza is good, but like, for example, at home, gluten-free pizza tastes the same, you know? Right. It tastes good, but then there's some things like, for example, you don't want gluten-free, gluten-free, and dairy-free is different.

Having no gluten is easier than having no dairy, because you can always find gluten-free bread or things like that. We already have that. You don't like the fake dairy so much.

Fake cheese doesn't exactly taste amazing. I agree with you there, buddy. But there are good alternatives to milk, you know, like almond milk and coconut milk.

Yeah, the cheese is the hardest. Yeah, we do have like the unsweetened pea milk, ripple pea milk, and we do have like unsweetened almond milk and all of that for sure.

You did say something just kind of jumping back regarding when he gets sick, sick, not strep. You've noticed when Aiden has like the flu or a high fever, He doesn't have the symptoms of PANS.

He actually is like very docile. Right. And there's good research that actually the fever is helping to treat the inflammation and that level of inflammation that always is there with the PANS pandas until you're fully recovered is dampened by the fever.

Go ahead, Aiden. In the beginning of this year, maybe like the end of last year, we also did homeschooling. So like the end of last year, I had like a 105 fever and I did like eight times the work.

He did so much homework in his bed. I did like, normally I don't want to do any. And then I came in saying like, oh, I'll do something when it's bedtime.

I want to read more. I want to do all these things more. It's like normally when you have a fever, you're tired and all that. I mean, yes, most of the time I am, but like during like the day, I'm not tired, you know, but like…

Your brain didn't feel as overwhelmed for sure. It was really interesting to see that. And I was like, one, that can be tough. It's a blessing and also a challenge.

Aidan's a very logical, thoughtful person. I remember when we went to therapy, our therapist was like, have him tested. I think he's quite bright. And it turned out to be the case.

And when we told the pediatrician, he said, that's wonderful but it can also be challenging because there's so much it's like he can get very meta about things yeah and that in and of itself like if you could get a decent like score on something but i was also like on the on the test for example to see if i was if i was like in the iq thing i did i i had like an okay score but also that was because i didn't try you know like if you try it also depends like those things it also depends like what happened that morning what what's going to happen next.

You know, like if something bad happened in the morning, you might not be focused a lot or something. Yeah, how you score really depends on how you are that day.

That's for sure. And you brought your cat to sit with you. What is his or her name? Vinny, he's a boy. Oh, hi Vinny. Now let me ask you, well, a couple of questions.

One, what do you think really helped you? You know, you're not fully better yet, but do you think it's the IVIG? Do you think there are other things you've done like the diet that have really helped you feel better?

The thing we probably said was what made me feel better, you know? Was there one thing you think might have helped the most? That we didn't talk about?

Or out of all those things you think is most helpful? I know the things that help me and the things that help me are the things you said. So it's not like sometimes I'll say no.

I don't know when something helps me. When someone tells me something helps me, I believe you. So let me ask you a different question then. What do you wish adults knew about kids like you whose mood or behavior or whatever can suddenly change?

Although, like, you should always kind of, like, be calm. You shouldn't, like, overreact, like, the second something happened. Like, if you were sure you didn't have that, fine.

But, like, if someone has, like, parents all that, like, if something bad happened, you're, like, yelling at someone or telling them, like, I'm gonna take something the way you're doing in Elvis or anything.

That's not gonna do anything. You have to, like… You have to figure something out. You need to find a way to get someone to go to the emergency room or wherever you have to go.

Maybe some compassion. Yeah. Instead of just yelling at them, saying like, oh, you didn't do… If you keep behaving like this, I'll punch you with this and all that.

That's not how it works. Yeah, I think the typical response is like, oh, if you didn't do this, you have to stay in for recess or, oh, you know, like shaming statements in front of a group of students.

And I don't know that that helps for anybody, but it certainly isn't helpful for someone. that might encourage me to have a flare then you know if someone says like no recess or they say something in front of me I might get angry like someone might just get angry but if you have pan you get off and you don't have the correct treatment you could get if you don't have treatment or you don't have the correct treatment like and someone says something even if it's not super mean like the tiny thing kind of like a kind of like a glass if you if you like um if you if an opera singer sings a little too loud it breaks you know like you can't be like You can't, like, if you go too hard, then you're gonna make something that might be, not everything is super hard, but like, for some, like, for someone with a pan, like, you could say something that might not be super hard, but it could still make them be very angry and have a way harder response and just, like, saying, oh, that's not fair, you know?

Yeah. I think it's difficult. You have a class and you need to keep the class in order and it can be very difficult for the teacher and for the kid. I see it from both perspectives without question.

But I think that calmness and compassion for everyone. That goes for all of the adults, whether you're dealing with pans or pandas. And it's a struggle.

It's a struggle to be calm all the time. I'm really, really fortunate because my husband is an incredibly calm rock. He is, you know, I have to be like, okay.

I mean, at some point, it's enough, you know? Like if you keep… But daddy stays very calm and that's very anchoring. That's very anchoring. And I think that is absolutely the way to go.

Because I even see when my nervous system starts to vibrate at a higher frequency, everything starts to vibrate at a higher frequency. It just gets exponentially worse.

I think for parents, one thing, one thing, one thing, for self care for parents, I think for a while I was kind of resistant to it because I was like, oh, all the time, all the money, all the effort needs to go for Aiden's care.

And my husband's like, you need to get help to, so you can. be well. I would start going, I go for acupuncture weekly and I get the treatments I need because I have to reset every day.

Every day I have to be like, okay, I'm resetting now. And Aidan, let me, one of the things your mom's saying is that old adage, put your oxygen mask on first.

You know, moms and dads can't help their kids unless they're helping themselves. It took me a long while to accept that though and it was hard to hear because even when friends would say that I'd be like, but you don't know what's going on here.

Like you're not understanding. And it's, I think you have to, you come to a certain point where you realize the engine's totally empty.

Advice for parents and closing remarks

Like for example, let's say I don't want to wash my pillowcase. You shouldn't make a gigantic argument about it because then I'm going to get more, like let's say you say, no, we have to wash the pillowcase and I might get super angry and at some point it can become like screaming at top of our lungs.

So I think that's a really good point with Pansy. Thinking about which… Which things you can let go, how important is it? And you have to put, yeah, how important is it?

For example, like taking your pills or like brushing your teeth, things that like you need to do, like changing your clothing, it's not a very important thing, you know, like brushing your teeth to get bacteria in the mouth is different, you know.

There's like some things that like you can let go for like once, you know, like you don't need, it's not worth a gigantic argument to change your, I think that's something that I've had to accept as well because you're used to things marching in a certain order.

it feels like utter chaos and things really do start to smooth out if like the little things just, you have to kind of, that's not, who is the author about essentialism?

I think that's really like the heart of it. What is essential? What are we optimizing for here? And not getting lost on details that we might've originally thought were really critical.

I think has been really, really important. And in all of this, I would just say, I know we probably have to go, but one of the last things I would say is, as difficult as this has been to navigate, I think it has really taught us a lot about empathy.

trying to see things from multiple perspectives. Things don't always seem as they are on the surface. I now see, if I see another mother struggling, you don't have that judgment, which was maybe a younger version of yourself may have or rolled your eyes.

You see things a little bit differently. Because you don't know what's going on, you don't know what's going on there. If there's a kid like, if there's an older kid who's like, who's like misbehaving, that could just be a bad kid, but normally like a, like a, like someone who's like 11, 12, like a teenage something, and not like misbehaving like a baby.

Yeah, something's going on. It's not always correct, you know? It's like, when someone is like a small person, I mean, the small person has nature, but then that's like visible, but if you're misbehaving, it's hard to tell, you know?

You don't want to say, oh, I see you have pans, I mean, because that could be an insult, you know? But then you could also, you're not going to say, oh, you're misbehaving, you know?

Let it be, you know? It's not your business in that case. Yeah, just want to have compassion for everybody. You don't know what they're going through.

Can't walk in their shoes. So, and Aidan, you've given me so many insights and talked about so many things, but I want to ask you, if you had a day where Europeans didn't bother you at all, what would be your perfect day?

What would you be doing? What would you be feeling? What would be your perfect day? I don't know. I'd probably do, like, all my schoolwork, and then I'd probably, like, play games.

Yeah. We do have a lot of family game nights, that's for sure. That's really cool. Well, I'm really proud of you, Aidan, and I am so proud that you asked to do this and that you're sharing your story and sharing what it's felt like for you.

And I hope that from this, more people can gain understanding, but also gain some compassion. And the next kid that they see, they can maybe have a little bit more understanding of what they may be going through.

So there are any last words you or your mom want to say to any of the kids or. adults or teachers or anybody out there? I have one thing I'd like to say.

If your mom or dad gut feels something isn't right and you're going to get it checked out, I cannot emphasize enough before going on any prescription medication, get some blood tests, get a strep test.

I'm not saying that's what it's attributed to, but it's such a great idea to have that because it really would have saved us so much difficulty and having to wean off of this, ramp up and wean off.

It was just a circuitous route to get where we are. And the person who suffered the most was Aiden. And if I had known blood test, strep test. And if you do, if the right course is to go on medications that's prescribed by a psychiatrist, you can take a test to find out which medications are best for you genetically for a couple of hundred dollars.

And it is a very good investment because after we took that genetic test, we realized the two medications he was placed on were completely inappropriate.

And if we could have saved that heartache and those struggles by doing those few things beforehand, It would have made a world of difference. But also, you know, no shoulda, coulda, woulda.

You can't know what you didn't know then. No, but hopefully other people can know. But now, hopefully, if they're listening and watching. Can know. Exactly.

Yeah, can know to hopefully do that. But thank you so much for this opportunity. Thank you. Aiden, anything else you want to say to anybody that you haven't said yet?

No, I think I'm good. You think you're good? Just hopefully provide awareness, right? And people know what this is. Yeah. And you just had IVIG yesterday.

So I just want to say how proud I am that you did this today and had, you know, because that's a lot in your tank too. Even as you're trying to get better, taking those medicines take a lot out of you.

So I'm so proud of you. That was an eight hour day yesterday, not to mention commuting there and back. So I'm really, really proud, really, really proud of where he's who he is, where he's come, and how much he wants to help other people, whether that's spreading awareness about this or distributing bags of food and supplies to people in need.

Yeah, that's amazing that that's what you do with what you get from the bottle caps, too, to help the homeless. So you're an amazing young man, Aiden.

Thank you so much, Dr. O'Hara. Thank you. And I hope to talk to you again sometime in the future, Aidan, and hear more about your journeys and all the wonderful things you're going to do with your life.

Because I know that this is going to continue to get better and better, and you've got a great mom and dad that are helping you through it. So I'm really proud of you and really grateful for you being here today.

And we'll send you the update after all six are done, all six IVIGs, and maybe you'll get to read the study once it's complete. Yep, absolutely. Well, thank you so much.

And thank you, everybody, for listening, and we'll see you next time on the next episode of Demystifying Pans Pandas. Thanks, everybody. That's it for today's episode of Demystifying Pans 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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Until next time, be present, be hopeful, and we look forward to seeing you next time on Demystifying Pan's Pandas.