Izzyu2019s Sudden Onset and Early Symptoms

I was diagnosed with pandas when I was 10. I was hearing voices. I was seeing things. And I remember being brought to the nurses that same day and my mom coming to pick me up.

And she was terrified because I literally was a different child. I mean, it was night and day within 12 hours. And then what came after that was a very long journey of exploration and trying to figure out what was wrong.

And my parents were really my biggest advocates in that. researching God knows how many hours on the internet, just scouring, trying to find something, something that was, you know, trying to understand what was going on with me.

And I was so young, you know, I didn't really understand what was happening with me. I wasn't able to attend school. I had a lot of different ticks, a lot of different really, really, really severe intrusive thoughts.

It was honestly just hard to function. I struggled to read and write. And after a few months of multiple misdiagnoses and trips to various hospitals and providers, it was actually like a child therapist that mentioned Pandas to my mom.

And my mom did some Googling and she was like, oh my gosh, this is totally what my daughter Welcome to Demystifying Pans and Pandas, the podcast where we uncover the mysteries, breakthroughs, and hope behind these life-altering conditions.

I'm Dr. Nancy O'Hara, a board-certified pediatrician, educator, and advocate with over three decades of experience helping children and families navigate the challenges of neurodevelopmental and neuropsychiatric conditions, especially pans and pandas.

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

If you've ever wondered what's possible for your child or how to find answers, this is the place to start. Let's dive in. Hi, everybody. It's Dr. Nancy O'Hara, and we're here for another episode of Demystifying Pans Pandas.

And you guys know I've had a lot of experts in the field on like Sue Sweeto, Scott Antoine, Sharon Housman Cohen, a lot of wonderful naturopaths like Lindsay Wells, Mariah Hinchy, Jill Christa, some therapists and psychiatrists like Shannon Delaney and Rosalie Greenberg and Eileen Devine.

I haven't really had somebody on that's lived this journey. You know, I've told you my story, but I haven't talked to anybody else. And I want to introduce you to Izzy.

As many of you know, I was at the Panda's Look Walk in Boston. And if you weren't there during Panda's Awareness Week, think about it next year, I'll try to be better at getting a bigger team up there.

But there were a lot of wonderful people talking, senators, congressmen, Peggy Chapman, Jennifer Frankovich, Mark Pasternak, I could go on and on. But I was most impressed with Izzy.

And she gave an amazing speech, raising awareness, raising understanding, and just being her. And I've known Izzy for several years and I am honored that she agreed to be on this podcast and tell her story.

So Izzy, thank you. Thank you, Dr. O'Hara. I appreciate those kind words. Thank you so much. Yeah. And you know, yours was a very difficult journey, a very difficult one.

And let's just start at the beginning. How did it begin for you? Yeah, it was quite the beginning. So I was diagnosed with pandas when I was 10. And I recall, this was back in 2010. So, you know, very unheard of.

And I recall driving with my family along the marsh. I grew up on the East Coast in Massachusetts. And I just remember this wave of anxiety coming over me.

And I woke up the next day, a completely different child. I was hearing voices, I was seeing things, and I remember being brought to the nurses that same day.

And my mom coming to pick me up and she was terrified because I literally was a different child. I mean, it was night and day within 12 hours. So it was pretty terrifying.

And then what came after that was a very long journey of exploration and trying to figure out what was wrong. And my parents were really my biggest advocates in that.

Podcast Introduction and Guest Welcome

researching, my mom would spend God knows how many hours on the internet just scouring, trying to find something, something that was, you know, trying to understand what was going on with me.

And I was so young, you know, I didn't really understand what was happening with me. All I knew is that I felt different. I wasn't able to attend school.

I had a really hard time communicating with other people. I had a lot of different ticks, a lot of different really, really, really severe intrusive thoughts.

So it was honestly just hard to function. I struggled to read and write. And after a few months of multiple misdiagnoses and trips to various hospitals and providers, it was actually like a child therapist that mentioned pandas to my mom and my mom did some googling and she was like oh my gosh this is totally what my daughter has and then what came after that was a very intense journey of trying to figure this diagnosis out and you know at the time I was one of very few who were officially diagnosed with pandas I think like one of like five or six that I knew kids.

So it was just really hard. It was hard for it to be taken seriously in the medical community. So I really appreciate providers like you, you know, spreading awareness.

It's very important. And it was just, it was just difficult. I felt so lonely. I really just felt like my body did not belong to me and I was inhabiting something that wasn't meant for me and that was incredibly difficult.

It gives me chills to see you today and know the beginnings of that journey. Yeah. We didn't meet till several years after your journey began, but, you know, so many of the kids that I talked to almost identify that part of them as a different person.

You know, they may name it cheeky or because you feel, like you said, almost out of body. Wasn't you? And that as a 10-year-old, that is just so scary and so undefinable.

Yeah. Thank God for your mom, both your parents, don't want to leave your dad out of it. And so what of all of the stuff do you think was the most difficult aspect for you, first of all?

That's a great question. I feel like there are a few things. I think for me, the most difficult was the loneliness. I felt so alone and scared. And, you know, when this began, I was 10. So I have to remind myself that sometimes when I reflect back or I'm having hard days, it's like I've come a really long way.

And I was just a kid and, you know, my journey, I would say, more so concluded around 20. So it was a 10-year journey and, you know, everyone's very different, every case and every child's different.

I want to emphasize that, but that was my journey. And yeah, I would say the loneliness, the loneliness of not understanding what was going on. And even though I had a diagnosis, right, of panda's pants, that didn't stop the complications that came.

And I remember I think it was, it was you, but there were a few other providers. Like I was not, like I had so many layers to my diagnosis. As you know, it was not a, it was very, it was a very complex case.

I was a very complex case. And I think that loneliness in that felt really difficult of kind of feeling like this enigma for doctors. You know, and that was, that felt very isolating.

You know, I would, I would just hear other kids, I mean, thank goodness, you know, being able to take antibiotics and really feel that difference. And in many ways I was that, but in most ways I was not, you know, it was a very long journey.

And it's not to negate anyone else's experience, but that was my experience. I think feeling isolated, not only in my own journey, but in within the pandas community and just feeling like, you know, traveling everywhere.

Again, my parents, especially my mom. My mom was my biggest advocate in that. She was the thumb of my Louise, as we say. Yeah, I would say the isolation, I would say, I would say grief.

That is one that I don't feel is talked about enough in the, at least for me, that I really had to come to terms with, you know, processing all of this trauma, because that's what it was, you know, years later is the grief I had for my childhood.

I really grieved what I felt I had lost. And that was, you know, not being able to do it in school, missing sleepovers.

Living Through Loneliness, Grief, and Misdiagnosis

And those were just the ones that felt big at the moment. But, you know, there were bigger ones. I mean, my junior year of high school, I missed three months of school.

That was incredibly difficult. There was a period of time in college college where I missed school. So there were a lot of different points that I just was grieving different aspects of like my childhood through my adolescence and young adulthood.

And that was difficult. I think comparison was something I really got stuck in, especially growing up and seeing all these people, you know, my age going to do sports or Being able to travel.

Traveling was really difficult for me. And just feeling like physically okay. You know, I had a lot of severe neurological symptoms, but the physical aspect, I mean, there was a time my junior year where I missed three months of school, like I mentioned, and I I couldn't read or write and so I just would sit in my room because I literally couldn't do anything because my headaches were so severe and I was getting a lot of IVs and so I would say that.

And then I would say lastly is something that was difficult that I found was over identifying with my panda's self. I think that was something that I have looked back on now that I'm more, you know, out of it.

I really struggled with that as I was healing from it, was being so used to chaos and my body wreaking havoc on me and my mind that without it, I like really didn't know who I was.

Or at least I felt like that. I was like, oh my gosh, like who am I without this really complex diagnosis? Who am I without, you know, being in fight or flight?

virtually my whole life. Like, who am I without all these different aspects? And I think what I've learned, especially the past few years, is like, I am so much more than that diagnosis and what I have endured in my life.

And that has been the greatest gift, you know, coming out of there. Yeah. That's pretty profound. That's amazing. And I think, you know, I know this doesn't even hit the tip of the iceberg, but I think it is important for families and parents to sort of say the, I get it.

I mean, you know, like trying to diminish it or tell a child, you don't feel that or, you know, You know, just suck it up, kid. It'll feel better when it stops hurting.

Like, all of those things that we as parents, in making ourselves try to feel better, don't do you as a little child any good. And I remind parents all the time, even when you don't get it.

saying, I get it and go finding somebody else that you can have a cup of tea or a glass of wine with and, but letting your kid know you're in your court and as a doctor, as a provider, you know, I think that's really important.

I know it doesn't touch the loneliness and the isolation, but And as a friend, I mean, it's important to do that for your friends. And the Pandas Youth Alliance does that for a lot of kids.

So I think that's really important. And then the piece you said about, like, that really hit me is I'm not just Pandas. You know, who am I without this diagnosis?

And it is a part of you and a pretty big part for how much you suffered. Yeah. but still it is just a part, it is not you. Yeah. And it's interesting thinking about kids whose families never really talked about the diagnosis.

Like, you can do this, you know, how do you feel about that? Like, do you feel that knowing from the beginning what this was called was to your advantage?

Or, you know, and I know again, everybody's different, but I just wonder from your perspective. Yeah, that's a great question. I would say it was absolutely helpful, you know, to know from relatively the beginning after a few months, but it was also difficult at the time because there weren't that many of us, you know.

And now it's, thank goodness, it's so much different thanks to providers like you and organizations like the Look Foundation and other, you know, Pants Pandas Alliance.

It was, yeah, that's a great question. I think for me, What I would say is that even finding out the diagnosis and knowing what it is, it's still hard.

It's helpful. I can imagine it brings a lot of relief for parents. I know my mom and my dad. such a relief for them to know that they weren't not only that I wasn't crazy, but they weren't crazy because they saw this change, you know, and my brothers as well.

But I think like, yeah, I mean, I would say for me, it was helpful, but it didn't stop the roadblocks that I experienced is what I would say. You know, I think and again, I think a lot of times have changed, which is amazing in the pan spandas community.

But I also think it's having a diagnosis doesn't negate the pain that you go through every day. It's validating and helpful in the medical community. It's really, really important.

And at the same time, I'm just thinking back to memories of me alone in my bed trying to fall asleep at night. And no matter the diagnosis that I had, it didn't matter at that point because I just felt so alone.

And I still, even understanding what PANS-PANDS is, even knowing what the diagnosis entails, it's so hard to live it's so hard to live as as the you know as or the young adult or the adolescent it's so hard to live as like the family and loved ones like it it's a name but the actual experience is so much more it's so much more complex and dark than i think a lot of people no or can even put into words.

And there's hope too, you know, like I think a lot of the beautiful things have come out of my diagnosis, one being a

profound understanding of myself.

That is one that I say has been a very wonderful gift. Hopefully that answered that question. Yeah, no, it did. And I think those profound aspects are also really important because I think what came through in your speech and what comes through just through your pores is that you really do know yourself now.

That you really have had to be introspective and do the hard work. You know, I also think people should know that you had multiple triggers. I mean, there are some kids that get strep-induced pandas, get treated appropriately right away, and that's it.

And poof, it's gone. Which is great. Which is wonderful. Wonderful. Wonderful. I love hearing those stories. That's awesome. Exactly. But then there are other people that deal with tick-borne diseases and multiple triggers and multiple severity of their immune dysregulation.

And that was you. Were there any other beautiful aspects of your journey? Oh, that's a great question. I appreciate that question. I think one for me is knowing I have the inner resilience to get through pretty much anything at this point, I would say.

And I think what this diagnosis amongst other things did for me was it humbled me in the best way. It humbled me to life and viewing life as such a gift and having gratitude for every single day and You know, I also want to say it took me a really long time to get here and speak like this.

Like I'm just thinking back to like my teenage self and I was just so angry at the world. I was so angry and gratefully so. I also think that's important to validate.

Like it's okay to be angry. like, it's okay to be angry at the world, angry at your body, even though it's not your fault, angry at your mind. That was really important and to really like validate that experience.

But I think, you know, yeah, I think coming out of it now and speaking about it now, I would say my my resilience and my ability to withstand really difficult things because of what I've survived in my life.

And for that, I feel incredibly grateful. I feel like many people who suffer, you know, different traumas in life, I feel that I have a really helpful perspective in how I want to live my life, you know, for A really long time, I was so accustomed to chaos.

Diagnosis, Validation, and Complex Triggers

I mean, most of my life, I would say. And I think I've finally gotten to the point, the past two or three years, where I've really come to want a peaceful life.

And I never, I never thought I'd get there. I never thought I'd get there, nor did I ever think I'd want it, which is another thing. Yeah, I never thought you'd want it.

I remember many conversations of the ping-ponging of chaos and just, you know, the grounding that I hoped would come and just to see it now is just so beautiful.

Thank you. Yeah, you've definitely witnessed you and Dr. Lindsay Wallace have witnessed a lot of ping ponging for me. And I think it's because I think it speaks to that.

What I went through throughout my life is just I always it not even always felt like there was a constant stream of chaos, you know. throughout my life from a very young age.

So I think now that I'm finally here and my resilience has brought me here and I've worked really hard to get where I am, you know, not only like help with, you know, healing from pans and pandas and what that has looked like on like a medical and neurological level, but the work I've done in therapy has been like, I think the biggest shift for

me, combined with everything else, but I've worked really, really hard to get where I am.

And I think my resilience has brought me there. And now I'm actually starting to be comfortable with a peaceful life, which is super new to me, but it's a wonderful thing.

That's amazing. And you know, and the people that are listening and watching know how much I am a believer in therapy. I will kick people out if they're not doing therapy.

And if you're listening and you have a little kid who can't do therapy yet or a kid that is so severely affected, you as a parent doing the therapy, it's so important, you know?

And it also brings up for me, Izzy, something that a lot of people deal with is all the trauma, not just from this disease, but other trauma that either comes out of it or that was part of it.

Can you speak to a little bit of the link between those and how that was for you? Yeah, I appreciate that question because I feel like it's not something that's not talked about, but I think for me that is one of my biggest passions of, you know, talking about this.

I had early childhood trauma and I think that was a big aspect of how severe my illness got and my pan-spantas diagnosis. And I would say That was difficult.

It was difficult to have multiple traumas not only occur at the time of Pandas, but before and after. And I think a lot of it was because of what happened in Pan's Pandas.

I mean, I don't know how detailed I should go, but I had a lot of very traumatic moments happen in that 10-year period when I was sick. And, you know, a lot of some of them are medical, you know, just really scary medical moments.

Some of them are neurological. I had some really, really, really difficult times. And I think having it's so hard to explain not only the trauma that goes on with, you know, this illness and how it attacks our body, but also just Like living and existing in a mind where it's attacking itself and trying to operate in a way that's still functional is traumatic in itself.

You know, like the thoughts that I had to deal with on a day-to-day basis for 10 years were very hard, very hard. And that was traumatic in itself. And then on top of that, the medical aspects.

and just how it's all intertwined. You know, when our bodies are in fight or flight for so long, like mine was, it is really difficult to ground and function in a way that feels regulated and healthy.

And I think It is so important. Again, I'm going to emphasize therapy just like you did, like therapy and having access to it is also something that's really difficult right now.

Accessibility, you know, having access to the therapist, whether that's the parents or caregivers going or, you know, the child is pretty critical. And I would say Honestly, I am where I am for a multitude of things coming together, but therapy.

I worked really hard in the past few years to process a lot of what happened throughout my life, before pandas, during pandas, after pandas. And I think the thing with trauma is it's, in my opinion, it's all intertwined.

That is what I've learned with my own journey that, you know, all of those combined really is what made my illness, in my opinion, so severe in addition to, you know, the multitude of triggers and diagnoses that I had with tick-borne illnesses and strep.

Yeah, it was, it was hard. And you know, I think for me, I've learned a lot from having multiple traumas throughout my life. And again, coming back to that resilience piece of understanding that I have lived a lot and I'm still here,

which is pretty cool.

That's pretty cool. I get excited. Exactly. And it reminds me of a few other things. First of all, that does take a village. That, you know, it's not, no matter what the diagnosis, especially what gets me is when we find tick-borne disease or something and somebody's like, just put antibiotics on it.

No, you know, this disease is at least three pronged, treating the immune system, not just IVIG and plasma freezes, but all the other ways we need to do it, including diet.

Yes. And the antimicrobials, you know, of whatever sort, but the therapy, the treating the symptoms, and sometimes that's medication and sometimes it's nutraceuticals, but the therapy itself, whether it be CBT or DBT, EMDR or hypnosis or, you know, finding a good practitioner is so important.

And then the other thing that it reminds me of besides the village mentality is also the detective work. You know, like for somebody that's not getting better, it's not just, oh, well, you didn't respond to that antibiotic or, oh, you're not doing the diet well enough, right?

No. I, as a practitioner, am missing something. I need or I as a parent or I as a therapist, you know, and, and we need to go back and like you said, peel the onion, but I'm much more of a gift with wrapping paper.

That's my analogy. Okay. So I'm unwrapping the layers of wrapping paper and there was this two true gift inside and, and, and that is you. And, and, you know, for many years we were not getting to it because there were still more layers.

Yes. And, and. but just also never give up. Like there will be some kids that still have a couple layers of wrapping paper around them and they may need to continue certain things, you know, but keep working at it because yeah, you're a living example of the worst of the worst.

Sorry, babe. No, it's true. It's true. It's true. It's true, you know, can be there and now, you know, be an advocate for other people, be somebody that can stand up in front of hundreds of people and talk about the difficult and the profound aspects of this disease and what it has given you as well as what it's taken away from you.

Yeah. And that's all, I mean, it's not okay, but it is okay. Yes. Exactly. I totally agree with you. I think it's not okay because it shouldn't happen to anyone, but it is okay because I think there's a level of acceptance that I've come to in my life that I hope every caregiver, parent, child, adolescent, young adult can experience.

Trauma, Therapy, and the Road to Healing

acceptance of what my life has been and not in a way that's invalidating because that's not something I would want anyone to feel because I think something that I wish I did more when I was younger and throughout my life up until this point and that I hope that you know, people who are suffering from pans, pandas, tick-borne illnesses, all of those things, caregivers, is validation is so important.

Validating your experience, validating your child's experience, whoever is, you know, dealing with this incredibly complex illness, like, validating is so important because it regulates your nervous system, which is crucial with this, you know, diagnosis and the trauma that comes with it.

You know, regulating your nervous system is so hard, but so important. And sometimes that's literally just a moment of being like, wow, this is hard. And it's okay to say that it's hard because I feel like I've given that gift to myself in the past few years is really just being like, wow, that was really hard.

And it's okay that it was hard and I'm here, you know, and that's pretty awesome too. You know, so it's kind of a lot of truths existing at once. Yeah, and I also think validating all the feelings, validating the anger, validating the grief, validating the humor and the ridiculousness at times, but not getting mired in it, like validating it, but saying, okay, we got that, we're gonna put it here and we're gonna get through today, or we're gonna get through the next five

minutes, or we're gonna get through the next hour, whatever it is.

So it's a validating, but not getting stuck in it, because I think sometimes we do too much of that, poor me, poor my child, you know, everything is taken away, and that's okay to feel that way, but you still gotta pick yourself up by your bootstraps, and that's something you did almost every day.

I really tried and there were some days where I felt like I couldn't or I felt like I wasn't capable of that. And that's where sometimes, you know, family members or my friends, I have to, you know, my friends also really carried me through this experience.

I have incredible friendships that I feel incredibly grateful for throughout the difficulties of my life. My friendships, especially my female friendships have really gotten me through.

every difficult moment in my life. But I would say, yeah, I totally agree with you. I just remember there were so many times I wanted to give up. So many times where I felt my body giving up.

I felt my body just so weak. It felt so weak. It was so tired. I was tired. My family was tired. Everyone was tired. And I just remember there were a few moments in my life where I really had to make a decision to like stay alive and keep going.

And those were some really, I remember one where I went to a treatment center and I didn't want to go and I had a very, yeah, I had a dark thought and I was like, okay, either I do this or I really don't.

And I woke up the next day and I walked downstairs and I told my mom, I was like, I'm going to go and do this. And that was one of the, one of those moments where I really felt like I pulled my bootstraps up.

And I was like, no, like I want to live. Like I want to try to find meaning in this life. Even when it's shown me. the worst of what life can get. So how did you get through those hardest days?

Yeah. I mean, it was probably different things on different days. You've mentioned your friends. You've mentioned your mom. But was there anything else for you that helped you get through the hardest days?

I'm going to try not to get emotional. I just remember thinking, even when I was young, I was like, this can't be all that my life is. This just can't be it.

I was such an imaginative child and still with very much of a vague imagination. I think I just imagined the things I wanted in life and I am probably going to get emotional.

I never thought that I would have those things. I, but I just had this hope. Even when I didn't, even when I didn't want to be here anymore, I was like, there was this inner hope that I sometimes wish would die.

Like I remember at times in my life, I was like, God, like, can't my hope to live just not be there? Because then I could just give up and not be here anymore.

And I really just chose, I was like, there's got to be more than this for me. There's got to be more out there for me. And I just fought for that. I fought for the version I am now and I feel so grateful that I'm still here and that I can look back and be like, oh, thank gosh I just kept deciding to do another day.

Even when I didn't know what that day entailed, and sometimes the next day would be really hard. Sometimes it was a harder day. Worse, exactly. Sometimes it was worse.

I had some stuff thrown at me, or stuff that I processed, and I was like, oh my goodness. I don't even know. But I think it was despite it all, I'm still here.

And for that, I feel really grateful. So I think just holding on to that inner hope, even when I didn't even want to listen

to it, even when I was annoyed by it, and I was like, God, why is this still here?

After all this, don't you think you just want to give up now? And I just kept being like, there's gotta be something else like there's just got to and now that I'm living that something else I'm like wow like there really was so yeah I just I it's so hard and I just I'm putting myself in the position that I was in years ago and what many people who are in this position of listening right now like I would just say, gosh, hold out that hope for yourself.

Even when you don't even know what it looks like or you can't picture it, I promise you it's out there. And it wants you too. I think that's the other thing is for a while I was like, my life doesn't want me to be here.

keeps showing me all this pain, all these things that I've experienced throughout my life that many people do, you know, and all my traumas that I've experienced, it feels lonely, but I'm not alone in any of them, you know?

I feel like my life just rejects me, like my body rejects me, my mind rejects me, like I don't feel like my life wants me to be here. And I promise you it does.

I felt like the destiny that I am in now and where I've arrived to is because it wanted me to and I wanted it. And I think that want is the hope that I kept inside.

Even when I didn't feel it, it was still in there and it never died. And I kept feeling it more and more over the years. Yeah. And I can literally feel that little girl.

imagining, you know, what could be, and that creativity and imagination that you always had, and being able to, in the darkest moments, there was that glimmer of light.

And I gotta tell you, Izzy, right now, there's light shining in from the background. I know you're in a different time zone than I am, and it's a little bit earlier in the day.

And I could just, it's shining around your face and illuminating you. in a way that was always there. That those of us who could see past the disease, past the trauma, past the, could envision this person in you.

And I think that's really important for families, too. You know, moms and dads, when you get really down, finding that glimmer of hope. Yes. Or that one thing in the day that you're grateful for.

Yes. You know, even if it's, she didn't kill herself today. 100%. I mean, there were days like that, and I'm glad you brought that in because, I mean, there were days where I would be close to killing myself, you know, and I, you know, had a suicide attempt my junior year of college.

And I think I'm pretty open about stuff like that because I think it is important because it is a very real reality with Pan's Pandas is having suicidal thoughts and ideations and or self-harm.

And it's not meant to be scary, you know, but it's important to talk about because that is something I dealt with throughout my entire journey. That was one of the most prevalent things that I really dealt with.

And yeah, I mean, I remember there were some days where I would literally be like, well, at least I lived another day. And like, I would take it as that.

And I'm sure, I can't speak for my parents, but I'm sure they felt the same way or my brothers felt the same way or my friends of like, well, at least she's still alive.

And I am, and I am very much alive and I'm happy and I'm healthy now. And I, I look back at those times where I did engage in self-harm or I did, you know, try to kill myself.

I think looking back, I'm like, gosh, like. if I could just give that girl a hug, like, you know, like, and I do. I think that's another thing is like, give yourself some hugs.

Give every, the caregivers, the kids, please give yourself a hug. I mean, goodness, I wish I gave myself more hugs when I was dealing with all this. Yes, and also no shame.

Yes. You know, especially when you talk about the self-harm, there are so many kids that go through that, whether it's suicide attempts or cutting or just not being kind to their bodies, whatever it may be, you know, It's not something we want for any of you, but don't be ashamed of it.

Talk about it. Find somebody that it's okay to talk to because it is a cry for help. It is. It is. I can confirm. Yeah. Yes.

Hope, Resilience, and Thriving Beyond PANS/PANDAS

I just remember even before my suicide attempt my junior year, I just wanted to feel held and I was so overwhelmed with so many different aspects of my life as you were aware of and like I just remember being like gosh I just feel so alone and like I promise you you know to anyone who's listening like there are like you know there is so much to life and I like remember even hearing people talk about it when I was experiencing suicidal thoughts or you know self-harm or you know my eating disorders that I experienced in which is another very real thing in Pan's Panda is that I feel like does not get us talked about that I had a very severe eating disorder I I just, yeah, I promise there is so much more out there.

And I remember listening to like, even videos like this, where people would talk about this. And I'm like, especially when I was a teenager, I'm like, I don't believe that.

And I'm like, I promise it's true. I am now becoming the person I used to listen to and be like, I don't know if I believe that. It's true. And even my junior year college self, I wish I could tell her that.

And that wasn't, you know, so many years ago, maybe, you know, five years ago, and I'm in a totally different place now. Yeah, yeah. And the other thing I just wanted to say about like the self-harm and stuff is sometimes some kids do it because it's the only way they feel.

Yes. Sometimes the depression, the sadness, the overwhelmingly of this disease, you cut to feel because the pain, at least then you're feeling. And again, not that it's okay, but it's okay.

Yes, exactly. It's that again. And I felt that too. I still struggle with disassociation. That is something I've dealt with since I was a very young child and I still try to manage it, but I remember I would…

self harm sometimes because I just felt so out of my body, even though my body's in pain, because that's a way of coping. It's a way our body does to cope.

So again, like you said, bringing it back to shame, like not shaming yourself or dissociating because it's not your fault. Like your body is in survival mode and is literally trying to cope with so many different things that are happening.

Yep. So agree. And, and, uh, I can't imagine anybody being in a better place than you are right now. And I know there will still be struggles in your life.

There will be other things that come up. But the resilience that you've developed, the ability to find that hope, that joy when the next thing comes along, and that's what a lot of young adults say to me, is that it sucked.

It was bad. But I am a better person. I am a stronger person. I can do more for my friends, for myself, for my career, for my life, and find peace and gratitude in all of it because of what I went through.

And you are doing it. Absolutely. I love that you brought that in. Thank you. I appreciate that. I'm always so used to calling you Dr. O'Hara, so it's weird to say Nancy, but I'll say Nancy.

I appreciate that. That's okay. If you're still a patient, I still like the Dr. O'Hara part, but you and I, you've been just,

again, it's Nancy. Yeah.

Thanks to you and Dr. Wells, I feel that, or not I feel, I know that you two are really, two that really brought me to where I am today, and I hope you both know that, and I hope you know that because it's true.

I said that to my mom, I'm like, yeah, like Nancy and Dr. Wells are the people why I'm here, you know, in a variety of ways. But I have to remind you that it is you.

It is you being willing, you know, even on your darkest days to take a step, you know, to roll over and take a bite, you know, and And that cannot be forgotten and shouldn't be forgotten by us as parents, as practitioners, but also as, as people and just acknowledging how much you put into this and now you're reaping the benefits of it.

Yes. And it's not easy, you know, it is so hard to like encapsulate, like, what Pan's Pandas is, the complexities of it, the complexities of trauma and what it can do to the mind and body, but it is so complicated and it is really hard and there is hope.

You know, it's kind of like a yes and, I feel like, for a lot of it. feel really grateful to be where I am. And I worked really, really hard. I worked, worked really hard in therapy.

I worked really hard. I mean, I also couldn't have done this without accessibility to providers like you. And I think that's something else I really want to emphasize is is accessibility to good therapists, good therapy, good, amazing providers like you is so important.

And it's hard, you know, it's hard to find that, to find good providers. And I mean, I remember when I was first diagnosed, there was nobody, virtually nobody treating phantasmans.

So to have this network expand has been such a beautiful thing to witness, you know, and I feel so happy, even though the diagnosis is so difficult, knowing that this, I hate, I mean, I don't know what generation is the right word, but generation of, you know, individuals dealing with pandas pans, like they have so much more at their fingertips to access, whether that's providers, you know, great therapists or, you know, like villages, you know, people like parents who understand, other kids who understand.

I didn't really have that a lot. So I think that's something that I've loved to witness in this evolution of, you know, awareness of Panda's Pans is like how much larger the community has grown because it really was not like this.

So it's quite a beautiful thing to see. Right. Yeah. And I think, you know, for those of you who are listening or watching that need help, The Look Foundation is a great group that provides scholarships and grants to people to get access, provide support groups, chats, you know, the ability to be heard.

And for those of you who are practitioners and wanting to learn, or you also want to donate to another great organization, the Medical Academy of Pediatrics and Special Needs, is really where we're training providers to understand this disease and how to treat it.

And I think both of those are very near and dear to my heart, and at least one of them is very near and dear to yours. All of them, but yes, definitely the Look Foundation has a special place in my heart thanks to you know, so many amazing people, but my mom and my parents, my dad, I wouldn't be here without my dad's resilience and my mom's strength.

I really wouldn't. And my brothers, it's really hard on the family. My brothers, you know, I have a wonderful relationship with all members of my family.

And that's pretty unbelievable with the amount we went through together as a unit, as you know, it was a lot. So I'm grateful for that. And I'm grateful for the people in my life, you know, my amazing partner, my amazing friends, and just all the people who have shown me that there's so much more out there, that peace is possible for sure.

Yeah. And any last words of experience, strength, or hope you want to leave anybody going through this right now with? Oh my goodness. Well, there's so many things, but I think the one thing I would say is I saw a quote today.

It was James Baldwin. And he said something like survivor, like survivorship or being a survivor is like a bridge. It was something like that. And I don't know the exact quote, but he's an amazing writer.

And I feel like all that I've survived in my life, all that I've survived with Pan's Pan is in various other traumas, you know, has been such a bridge for me to a deeper understanding of myself, a deeper understanding of the world and immense gratitude for every day.

That is something I found is as gratitude and peace and That's what I would say is this is a bridge. This is not going to be your whole life. Whether you are someone, you know, struggling with Pants Pandas or you're a caregiver or a family member or a friend, no, this is a bridge to a future of hope and peace.

And I can promise that as someone who's went through a considerable amount to say that that is possible. And I really don't think about it a lot, which is kind of miraculous.

That's amazing. That bridge is behind you and you are thriving. And Izzy, I so appreciate you as a person, as a spokesperson today and as someone who is really bringing a lot of gifts into this world.

And I am so glad you survived Pans and Pandas and all the trauma and that you're thriving now. Thanks for being here. Thank you, Nancy. I appreciate it.

And I'll see you all next time on Demystifying Pans Pandas. That's it for today's episode of Demystifying Pan's Pandas. I hope you're walking away with insights, tools, and hope to help you and your child on this journey.

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