The Part Of PANS/PANDAS Nobody Has Been Measuring Transcript

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Podcast Introduction and Guest Welcome

The sooner we can diagnose these kids and start treatment, the better the outcomes. And so if we could get this screening in, similar to earlier screening for autism, earlier screenings for so many different diseases, If we could get that into the minds of urgent care providers, primary care, providers.

Many different people, it really could help kids get better faster, more completely. Yeah. And prevent this long-term, you know, situation that does happen when it doesn't get picked up.

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, an 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 welcome back to Demystifying Pan's Pandas.

I am really excited to welcome Michelle Pinto to our podcast today. Michelle is a PhD, MSN, and RN and is member of the Look Foundation Board of Directors.

She serves on the Massachusetts Department of Public Health, Pan Panda's Advisory Council, is a member of the Massachusetts Coalition for Pans Pandas Legislation.

She's a registered nurse, she's clinical assistant professor at the University of Massachusetts, Dartmouth.

Michelle's Family Journey with PANS/PANDAS

a descriptive correlational study, making her one of the very few researchers studying the impact of these disorders on families. And beyond all that, and in my opinion, most importantly, Michelle is also the mother of two children who have lived with PANS Pandas.

So she brings both the clinical knowledge and the deeply personal experience to all of this work. Michelle, I can't thank you enough for being here today.

Thank you so much for inviting me. I'm thrilled to be here. No. So tell me why this matters so much to you. Absolutely. As you said, a mother of two children with Pan's Pandas, it's been almost 10 years for our family.

In January of next year, will have been 10-years. I know firsthand how frightening and isolating it can be. terrifying, how much uncertainty there is when you get this diagnosis that a lot of people don't seem to know about, and there aren't many providers.

And I know how it affects every facet of life, from daily life and your family routines and relationships to school. Then added on, sometimes you have to fight for insurance coverage or struggle to find providers, so the personal part of this work really drives why I became involved with advocacy and volunteering.

And so I just hope to be able to make a difference for others after what my family has been through. I feel like that's

one way to turn something positive out of our own struggles.

So that where we're at. We're almost on the other side, not fully, but I want to share that there is hope for families who get diagnosed and are uncertain and scared.

And as speaking from one mom to another, how's your PTSD going on all this? Well, there's definitely that too. And that's one of the things that is most important that I think I can share that with other parents and reassure them that They aren't the only one feeling the way that they are when they're struggling and they feel isolated.

A lot of times other friends and family members don't know how to help or what to say or they inadvertently say things that make things feel worse. make parents feel like they're to blame for this.

And so I'm able to talk to parents and say, you're definitely not the only one and it's really not your fault. There's a medical reason that this happened.

It's nothing you did. Its not you parenting. All of that. That's what's important about parents who've gone through it now helping the next family that come through because Unfortunately, providers, we understand that, right?

I work in the medical profession, and it's really impossible for providers in our healthcare system to have the time to give that part of the support.

If you can even find a provider, for them to be able to spend that time, you have to rely on someone outside of, physician networks and insurance. And so that's where we have this amazing opportunity to help because it's something that's very unique and It's not like all other illnesses because there's so many different parts of it Yeah, well, let's get back to the mom piece and all those other pieces in a minute But I do want to talk about look.

Yes, which is near and dear to my heart as well as yours So tell our listeners and viewers about luck and and everything that that involves Absolutely.

So the Look Foundation is a 501c3 nonprofit. It was initially started by parents of children with PANs, PANDAS. it was actually the merging of two nonprofits together to kind of maximize the features of each of those.

And it has grown over the past several years into a national nonprofit that I'm very proud to be a part of. What we're doing is we have multifaceted approach.

The Look Foundation and Family Support

The first thing we do is family support and community. We help families who are facing the diagnosis are overwhelmed. Um, we help them access care. Uh, We have a lot of lists and connections.

You know, if you live here, this is, you know hopefully you can contact this person. And so that's one big part of it is Family Support, Access to Care.

and one major part the Look Foundation that is very unique is that they offer these healing grants. And so we fundraise and families can apply for a grant and the grants are awarded to help with either accessing treatment that's not covered by insurance or it can be used to pay for parking or to really meant to kind of relieve that financial burden a little bit.

And it helps families kind turn that corner when they're feeling helpless or hopeless. So we have grant rounds that open once or twice a year. Last year, we gave almost $100,000 in grants.

In total, the Look Foundation has given over $500,00 in healing grants, our next grant round opens in September. It's all the information is on the lookfoundation.org website.

And families upload a application, they write a letter and the grant applications close in December. Then we have a

panel of reviewers that goes through and decides on a grants.

Interestingly, my family was a recipient of treatment grants, health healing grants and it truly did change the course for my make the appointment with a naturopathic doctor, pursue testing that we had put off for a long time.

And it really catapulted us forward as far as reaching a point of healing for one of my children. I think, you know, from my perspective, there are many groups I'm part of, Aspire. Care, Look, and there're many, many of them out there.

And I, think not only the support and the access that you mentioned, but those grants are so huge for many the families I've worked with. it really does take that burden off and get things started in the right way.

Because like you said, it's so hard to do this in an insurance model and it is so impossible to it on your own. It's just enough to kind of help with that.

And then other things that the Look Foundation does. So we provide education. We've done a lot of education with school districts, medical professionals, and other people that work with children.

There's been education to one of the court systems. You know, we're out there educating. What is Pan's Pandas? What do these children look like? And what do they need from the people around them?

One of the biggest thing that we educate is schools. And it's really helpful because teachers are integral. It's not just the school nurse, it is administrators.

Even if they just know a little bit about it and where to find more information, when they come across the child that maybe looks different from one day to the next or has an acute change, they can say, a light bulb went off.

There's something about that I can look back at. So we're really working on the educational part, advocacy, of course, working with legislators and state agencies, medical institutions.

We work with all of the nonprofits that you mentioned. There's a wonderful network of nonprofits, that each kind of have their own little niche area. And then really, what the core is, is community, creating a sense of belonging where families realize they're not alone.

So we support them through kind those hardest parts, help them see that they can move forward and then, you know, awareness. We have lots of parents and families who've gotten involved like I did after receiving, the grant, because, once you get on the other side, You do feel like you want to give back and help others that come behind you.

So that's another. way you can become involved with Look. But the take home message is really we're working hard on not just awareness, but supporting families and helping to drive change in those systems that exist, not only here just in Massachusetts, across the country.

And that's what we do with the advocacy and working on legislation and kind of helping kind to move that needle to where more people know about it than don't, hopefully.

And especially for the grants as, as that we, this podcast will be airing when you will by accepting grants. All of that information for TheLookFoundation.org will in the show notes.

all of the information, once they go to that website to apply for, the Grants will there. So watch for that on the podcast. So, and we both have something coming up very shortly.

So talk about that a little bit. Okay. Kind of our flagship event every year, this is going to be our third annual walk is called the Look Walk. And that is taking place this October, Saturday, October 3rd at 10 a.m.

at the Boston Common. The event is call Making Strides for Pans and Pandas. It is truly just one of my favorite days of the year and really symbolizes what community looks like to look.

And so, you know, it's been amazing. It's grown each year. Last year for our second walk, we had more than 800 people walking.

Look Walk, Awareness Campaigns, and Community Events

We expanded to where there were some virtual walkers last year And just being on the Boston Common, knowing that all of these people came for some connection to Pan's Pandas.

You meet amazing other children that are affected families. I've made amazing connections with other parents. We have the support of wonderful physicians that have attended and brought their families, and there's a lot of fun going on.

So not only do we have The Walk. We also have music, games, activities, Pan's Panda's resources. There's a DJ. And we will have the mascots of the New England Patriots, Celtics, and Red Sox.

and there's like a kids activity table. So it's really, really a fun event to be a part of. And this year, what we are attempting to do is to get participants from all 50 states.

So we're calling it Beyond Boston, and people can register to be a part of someone's walk team, or you can create your own team and you walk virtually from anywhere.

And so we want someone from every single state to participate in the Look Walk, and so feel free to share with others. Have anybody, you know, through social media join your walk team.

And, we'll share on social Media. Last year we had people climbing to the top of like a mountain and taking pictures together. We had some college students do it together was really amazing to see it all come together after the event and see the energy and excitement, carried beyond just Boston.

So that's our big push this year is beyond Boston. And then as part of the event, we are thrilled to have Dr. O'Hara as our keynote speaker this here, joined by one of our look ahead council members, Kate Landis, who will share a story of hope and inspiration.

The lookahead council is our young adult council where we're bringing together young adults who have recovered and are kind of going to be the next generation of advocacy and helping to create change.

So that will be part of our program as the walk kicks off at like about 1030 at the Boston Common. It's such a great event. I was able to be there in person last year.

And for anybody that's looking, of course, go to look and sign up. My team is Team Ohm, O-H-M. That's part of a little moniker I use for my name and my husband's name, and also ohm meaning the, you know, just chilling out and, doing some yoga or deep breathing.

a form of energy that gets us moving. And so if you want to join my team, you can do that from the Look information and website. You can also go to my website, drohara.com, and email us from there.

As you said, Michelle, come to Boston, do it remotely, donate to help. It doesn't matter if it's $10 or $1,000, whatever you to help these families is just so key.

And I'm so thrilled to have been asked to give the keynote. I just love this organization, love the message, I love what everybody is doing and want to see it be 8,000 people rather than 800 and get as many people there.

So if you're listening, and you don't have a team, make a Team. If you want to join my team join, my Team remotely

or in person. Just do something that helps these families because it's so important, so critical to so many people.

Yes, thank you. And we also have in Boston, we will have this banner campaign happening where we line the streets, Cambridge and Tremont streets. We'll have Pans Pandas banners hanging on the light posts in downtown Boston for the weeks leading up to and following the walk.

Last year we were excited to get a few banners and then it keeps increasing each year how many light post we can have. And so there's information about what Pans Pandas is, what Look is.

Just a way to kind of spread awareness, but it's such a cool thing to be in the city and look up and see, you know, something that we've all struggled to have be recognized.

And here it is on a banner in downtown Boston. It's just really, really cool. There will also be a couple different billboards across the state that are gonna be raising awareness leading up to the walk.

October 9th is Pans Pandas Awareness Day. And so there's usually a green billboard that gets put up by the electrical union. So keep your eyes peeled for that as well over 93 as you're going into the city.

There's just some really, really cool stuff happening. We have a lot of momentum and we're just so excited to have this event again and have it grow. Because really the more people that come to The Look and donate to the Look, and create teams, we can do so much more with our healing grants.

We also fund research. we've been able to fund some key research this year when, you know, funding things changed, We were able step in. So that's another thing that we're able participate in, not to mention continuing the education and the support, that Look is so passionate about.

Yeah, so amazing. So, Look Walk October 3rd, Pans Pandas Day October 9th, and in between those two, for those of you who are interested in getting more information from me, during that week, between the third and the ninth, I also provide half off my membership.

So watch for that too. Open to parents as well as all professionals, just trying to get more information out there.

Provider Education and Early Screening Advocacy

So that will be posted on social media. You know, I just, you know my passion as I know yours is, Michelle, is just to for families that need it. We are lucky that we're in the medical profession and have some amount of information when we get started on this journey.

And it's just so great to be able to help more families I don't know if I want to call it as lucky, but maybe as luck as we are. Yeah, truly. Families shouldn't have to become experts or advocates just to get care for their child.

And I also am passionate about the education for providers so that when a child goes to urgent care or to their pediatrician with some of these hallmark symptoms that people know to look for a medical cause, look And I think that sometimes gets glossed over.

A lot of times we have so much focus on different behavioral things that it's easy to just kind of like put blinders on. And it is a change to the way that we've practiced, but lots of things have changed, right?

The way we're taking care of hypertension and diabetes has changed too. It's time that also change the ways that, you know, we take care children and understand, I like to say, that the brain is part of the whole system.

We've always known that, but it hasn't always been treated that way. My hope is that if a parent goes into the doctor and says, my child has changed, they're not the same.

They have OCD or tics. They're having trouble in school. They didn't used to have trouble. These are all just red

flags that we can start really quick looking at infection on that first visit.

Because the research has shown that the outcomes are much better when children get treated and diagnosed right away. The terrible stories that we see and the most severe cases are because of delayed recognition, delayed diagnosis, treatment.

Those children had so much dysfunction for so long, right? But really, the ones who get treated very early on don't usually have such significant and long-term sequelae.

They might have a little flare hand there, but when people know what it is and they can treat it, It's just all of the outcomes are better, and it costs less financially, it's less suffering and burden and all those things.

Just as much as I want to educate the schools and others, I also want participate in educating providers who wasn't in their medical school. We just need to change our thinking a tiny bit.

and be open to the fact that these symptoms could be caused by a medical condition. The immune system is dysfunctional. And so we believe that for a lot of other illnesses, and there's been a lots of movement, but for some reason this one kind of still gets stuck in the weeds.

So we need to kind get it to move forward with other illness. And not only are you doing it with Look, but your other advocacy and legislative positions.

Talk about those a little bit more and how that impacts you and those you are trying to impact others. Absolutely. Back when my children were diagnosed in 2017, I, being a nurse, was like, how?

How is there non-insurance coverage? It just didn't make sense. And so in 2019, there was a hearing being held for a bill that was pending in the legislature, and they asked for people to testify.

I went to the state house and in 2018, I met some other amazing parents just at the State House that day and we became the mass coalition for Pans Pandas legislation and worked to help pass the insurance mandate that went into effect on January 1st of 2021. It was signed into law by Governor Baker.

And so we do have an insurance mandate in this state, so insurers in the state are mandated to cover testing and treatment for PANS-PANDAS. But when that legislation was passed, we had wonderful legislators that helped us with that, and they said, let's stick something else in there.

And they called it the Advisory Council. And so what that did is, along with the insurance mandate, it established a Department of Public Health Advisory Council.

And, so there are appointees to this council. We are finishing up our third year. I am honored to be on this Council, Along with other providers, advocates, parents, people that work in schools and, you know, several different providers.

and so through the work of the advisory council, we are working towards how to improve the care for children in Massachusetts. We are giving feedback to the Department of Insurance about the mandate.

Is it working? Are people getting coverage? We've met with the department of children and families. chapter of the American Academy of Pediatrics, Department of Education.

So we are working kind of agency by agency and kind educating them, understanding what their contact has been with children with Pants Pandas and making recommendations about how they can improve their services for those children.

And so we've written an annual report each year. Those can be found on the DPH website. If you look at if you search for pants pandas and we are looking forward to our September meeting this this September that we will be

actually talking to the commissioner of the Department of Public Health.

So the Commissioner I have his name here is Dr. Robbie Goldstein, and we will be talking about our work and our findings and concerns about, you know, the state of Pans Pandas in Massachusetts.

And so we'll be doing that at our next upcoming meeting and information about our meetings, all of our minutes, and you can actually listen to them. It's all available on the Mass Department of Public Health website under advisory council.

And you listen, they're a public forum and, you know, can see all the work that's being done in this state. We pride ourselves on kind of being a leader and so we are still working to improve.

Um, we're hoping to have a Pans Pandas page on The Mass DPH website. very soon. So we've been working on that so that families who are facing this can go right to MassDPH.

It's recognized and get connected to all of the other resources, nonprofits, providers, treatment guidelines, everything. That's amazing. And you know, it is such a role model for other states and other people that are interested in advocacy and legislation that may have already been through this and now want to give back.

There are other States that following the lead and more and more we see it getting into the legislation. And we're very grateful to all the legislators that are working with us to help pass these bills, bring about these councils, etc.

So it's not just in Massachusetts.

Massachusetts Legislation and Advisory Council Work

more and more all over the country because we know our listeners and viewers may not be in Massachusetts, but take the lead, look at what they've got, contact, and figure out what you may be able to do in your state if you're not as far along as Massachusetts even though we Massachusetts still has a long way to go.

Yes. But the amazing thing, of course, in today's world is with social media. And so all of the different states, all the of different nonprofits, we're all sharing everything.

You know, Connecticut was the most recent to pass their mandate and we were cheering for them on social. Other states have passed legislation and so, you know following look on Social Media.

We actually also have Massachusetts. legislation page that you can follow. Believe it or not, we actually have two pieces of historic legislation that are pending right now in the legislature.

One is a prevalence study to actually get a better understanding of how many children within the state have been affected. So this will be, we're hoping for a retrospective study.

This is pending legislation. And then our other is called, is a screening bill. What we are doing is hoping that we can improve the recognition of PANs, PANDAs, where when children and families go to providers, clinical entry points, annual physicals or sick visits or urgent care, that they will be triggered and required to screen for infection.

And so these two pieces of legislation are current right now, and you can find out the specific bill numbers and follow the bills. You can write in support of the bill.

So all of this information is on social media. It gets shared by look. If you're afraid to make a phone call or write an email, we have a form email. So you can just, it's super simple.

And so every little bit counts if, you know, we know that there's parents and families out there with all different professions and skills and, different things that they can do.

So if something you're really good at is sending an email from home, that's, super helpful. If you are a person that, wants to do something else and get involved, will welcome you.

There's always, a little something. Then at the very least, just join the look walk. Join a team. When you go on the website for Look Foundation.org, you can click on The Walk and then you see a list of teams and if you want you create your own team so it's super simple.

A team can be one person. or you can share with others and build a team. And we would love to see people with shirts on all around the country or sharing on social media how they're walking virtually with us on October 3rd.

and just as far as that advocacy and the legislation goes the screening is so important because of something you mentioned earlier you know the sooner we can diagnose these kids and start treatment the better the outcomes and so if we could get this screening in similar to earlier screening for autism earlier, screening So many different diseases.

If we could get that into the minds of urgent care providers, primary care, providers. Many different people. It really could help kids get better, faster, more completely.

Yeah. And prevent this long-term, you know, situation that does happen when it doesn't get picked up. And we're hoping that that's a way also of spreading this knowledge about Pants Pandas because it is such, there are so many providers and to actually do all of the individual education is a big undertaking.

But if we can get this screening included, then there will be information that gets sent out to everyone and it will really legitimize because we've been legitimized In so many ways it's recognized by NIH as a, you know, illness, PANS-PANDAS is recognized and so we just have to kind of get us over that hump of making sure everybody knows that it is there and knows what to do because the treatment guidelines, the diagnostic guidelines have been published.

They're there. really any pediatrician can diagnose it. And so that's the other thing is empowering pediatricians and other primary care providers to recognize it and start treatment versus waiting to refer to a specialist.

We have a shortage of specialists around the country. Massachusetts especially right now is in a dire situation. So we need to empower those providers, to take action right when the child is there.

because you don't need to be a specialist in order to start, you know, simple antibiotics and ibuprofen. And the treatment is so simple when it's at the onset, not when its years in.

It can be little more complicated, but there's just such an opportunity and providers that I've spoken with have said, as soon as you see it and you've see the benefits of the treatmen, t you can't deny it.

But if you never seen it, if have never been the one to do that treatment, You don't know, you don' see it. And so I just wish that there was a way, cause they've told me, in person, they said, as soon as you see a child get better, You can never deny it again, that it exists.

So that's part of where I hope, now that I've finished my degree, I'm hoping that, can help with the education of providers, across the board, nurse practitioners as well, physician assistants, just to kind of help them feel empowered.

This may be something that they weren't necessarily taught, but you don't have to be an infectious disease specialist to recognize it and start treatment.

Right. We want more people to see it. Absolutely. So talk a little bit that leads me into, you know, what led you to get this degree and your research and being a mom of two kids that have been diagnosed with this disease.

So, talk little about that. Yeah, absolutely. Interestingly, my two children had really different courses. We realized

once my son was diagnosed, which we are so blessed that our pediatrician realized what was happening.

He had the very much overnight onset and he was able to be treated right away. And she was not afraid to give antibiotics and ibuprofen while we waited to see a specialist.

But what we realized, once I started reading about it, I was taking notes in a book and I highlighting in blue for my son and purple for daughter and had very different presentations and that's one of the hardest parts about this illness is that every every kid looks different you know and so it's it hard it not easy thing to do this clinical diagnosis, but she had probably been missed for about four years.

Research on Family Burden and Validation

And so, and it had different presenting symptoms. She had much more of the separation anxiety and irrational fears that were, they were life disrupting fears of things like bark mulch and snow, you know, just everything.

Whereas my son had more you know, the behavioral or the, you, know oppositional, which we now I've learned is really part of saying school became hard because I can't think like I could yesterday.

And so that's what I am so passionate about telling educators that yes, these kids can look one day, one way on one and look different the next day. Yeah.

Sometimes we just have to change our expectations of them because in another few days they might be back to that, exactly. The episodic nature. Episodic major and understanding that, you know, I've learned it's not behavior.

Behavior is a communication of what's going on. And all behavior is communication. So even as a parent, I truly think that's what we need to spread, not just for Pan's Pandas, but for any child, that in schools we do need a little bit more flexible and understand that people can feel one way one day and different the next day.

So that is what I like to share because I can say, and teachers say that about my son, we know there's not so much now, when he was younger there were two different kids in the class, right?

And so the teachers were actually integral in him being diagnosed to begin with because a teacher kept detailed notes of how different he was day to day and the doctor knew once she saw that.

So that whole experience of like realizing that and also experiencing a child who was diagnosed straight away and wasn't, you know? And I think back to what that experience was, and clearly no one recognized it in my daughter.

And then going through all of this, I just felt like there was such an opportunity to make a difference because of my career and that kind of thing. I'm also passionate about nursing education, so I knew I always wanted to go back school, that kinda thing, going back for my PhD really just became part of my future profession as far as teaching and nursing but now I have this really cool ability to do research and make a difference.

I don't know that I would have gotten my PhD if I didn't have such an area of passion that i wanted to research so it kind of catapulted me even though it was definitely complicating things for the past five years but you know now because I am also a nurse researcher on top of an educator I just this population is dying to be heard and validated.

And so when I did my research, I surveyed parents or primary caregivers of children with PANS and had them score levels of burden. This was more than just caregiver burden, we looked at family burden it included the stress of a parent not being able to work, changes in income.

The impact on sibling relationships, the impact of stigma, uncertainty. So more than just like the caregiver part. And so I was able to measure that. When I put out my study, my survey was answered very, very quickly.

I reached the number of. participants that I needed very, very quickly. And everyone said, you know, there's

probably bots, blah blah, and you've got to check for that.

The most amazing part was that, I had some open-ended questions where families could write, what do you wish others knew? What do wish a provider knew.

I have unbelievable qualitative comments from every single one. Every single response was not a bot. and people wrote the most amazing things and so my plan is my original dissertation work is hoping to be published and I'm excited for that and then I am actually going to write another paper about all of the things that the families told us because It was just jumping out of isolation and fear and, you know, just not being heard.

And so, I'm looking forward to publishing that and validating that family experience so that, hopefully, it's another reason why we need people to become aware.

recognize it, treat it and support these families because it's so real. It's amazing research, but it is also amazing how much of a response you got so quickly and it just shows again how starved people in this community, families in the community are to being heard and how much that being hard can help other families, you know, and I'm so thrilled you went through this.

I am not saying that with any amount of not understanding how Heckish and more it has been, but that you had the ability to use that as I have in a lot of ways to get that information out there and how you're not just an advocate, you are not an educator, your a researcher now because as a mom you saw it, lived it and now you can put all of your knowledge and all your expertise to work to help more families.

it's amazing. Thank you so much, thank you. I truly am blessed, I mean I have been really well supported throughout my journey and I would be remiss if I didn't say that Peggy Chapman is the one who saved our family and me throughout met much of that.

So I thank her very much but also all of the wonderful parents that I've met and you know through look but beyond that because there's others and And I also have an extremely supportive family and a husband that keeps our house going because I was not cooking a lot of meals while going through with all of that.

So it truly does take a village and I'm grateful for my village. I have several really supportive villages that made it possible. And I have to say, I'm thankful for even things like this podcast because there are other things that I listened to when I was Googling, right?

And, and trying to figure it out. And so every little one of these, you know, helps and everyone's, website that they do have, different foundations are so helpful in their own way and validating the experience when you think.

What are you talking about? No one knows what this is. You know, all of that. So. Yeah. And you were lucky to have a village. I know many of our families do not, but Look and other groups like it can be your village, you can find it may not be you're Aunt Ethel or your parents or even your spouse, But there are people who are there to listen and we all need that And one thing I didn't mention about Look Foundation is that we have village hours calls.

And so one big part of the support has been the village calls and so anyone can join. If you're interested, you can just listen. You don't have to talk.

Some people come once or twice and some people every single week. We have expanded it so that a social worker who works with Pans Pandas joining those calls in helping.

Hope, Support Networks, and Closing Remarks

with all of that. So we do have, they're coincidentally called village hours and they have grown and anyone is welcome. And like I said, you don't have to talk.

You can just listen. you can, try it out and see how it is. See that that's other parents, like you, some of the most

valuable information has been shared through those village.

Like just something that someone says, Try this or one little trick. Or, you know, did you try, this? And so, we're able to share some of that because really the parents are the professional, the experts on this because each kid is so different.

What works for one kid might not work for another. Sometimes when you're in it yourself and you are a parent, You don't know what works your own kid. But, my best friend is a kindergarten teacher and her approach I've learned so much from her and sometimes that's what you need is like, why don't you present it this way?

And you know, not that you can parent this out of a child, but it can be such a difficult road that, you start to doubt your own parenting, what I mean.

Or you just have a sounding board, somebody that doesn't say, I'm sorry, it'll be okay. Sometimes you don't know if it will. So sometimes you need someone to say, no, that's really hard.

Like, what can I take off your plate? You know, what can I pick up your plate? Can I drive your other child's where can i you know? Whatever drop off and often as a practitioner i'm saying to families, you, know I see myself as your gps I may know all the routes to go down I, may be a little pushy sometimes and and tell you why this route is better but you as the parent is still driving the car and And you need to trust your roadmap, yourself, and you know your child better than any of us ever will.

And I think that as providers also, because there are some on this podcast, we need remember that we have to listen. We don't need to just direct, we don' need just to prescribe.

We need also to listen. And that listening in the village hours, on the walk. I remember last year I was walking with a couple of people that just needed to talk.

Need to get it out. Like we all need that. As a very verbose person myself, I know. We all need it, and our kids need. And that's the other thing, you know, Look provides this, this also this organization of young people, as you said, there will be somebody speaking because our Kids need that support system to know that they're not alone and the siblings of our kid's who need to Know that They're Not Alone and that their sibling is not a horrible person.

That this isn't them. that this is the inflammation in their brain. This is a dysregulated immune system that's making them act this way. And there's so much that Look and other organizations and that the advocacy and the legislation and your research are so important for.

Thank you. I hope that we can do another podcast when your research is published and dive deeper into all of that. But are there any last words of hope, experience, strength that you haven't said that that want to leave our families with?

The biggest thing I would say is if you're having that, if feel that need for connection or you haven't, you know, attended a village hour or haven t, called that person that you reached out to on Facebook, just do it.

It's really hard to make that first phone call. I get connected with lots of different parents and sometimes the person doesn't call or because it's so hard to make that first step or to add that to your calendar or To find time for it because you know, it''s going to be an emotional Draining thing to talk about and so, you, know if you're out there and you feel like this tug follow that.

Follow that tug, or if you feel like the answer you're getting at your provider isn't quite right and you have a tug. That mom instinct, that dad instinct is really, really important.

And we can always get second opinions for a knee replacement or anything else. So you can get a second opinion when it comes to your kids. There are people out there And so, you know, in even the first step, just go to lookfoundation.org, sign up for our emails, peruse our social media, and you'll start to see, maybe something will

click for you, or maybe in a month you will sign-up for a village hour or something like that.

So, if you're getting that tug, trust your instincts, because you are a great parent and this illness, it makes you feel like you aren't. And it's just not true.

It shakes you to your core. But if you're here listening to this podcast, it's because you really care for your kids. And that's really, really important.

There's resources out there and we are so happy to connect you with them. Yeah. Join us on the Look Walk. October 3rd, Boston Comet. Yes, October third.

Hope to see you all there in person or virtual. Bring the kids and yeah, It'll be a really fun event. Oh, Michelle, thank you so much for doing this and thank for your research and being a great mom.

Thank you, Dr. O'Hare. You've been a champion for these kids and this population. There's hope. They can get better. It doesn't matter who it happens with, you just need to put one foot in front of the other and keep going.

So thank you for everything. Thank you. And join us next time on Demystifying Pan's 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. If you found todays conversation valuable, be sure to subscribe so you never miss an episode.

Share this podcast with anyone who might need it. It could be the lifeline they're searching for. And if you have a moment, leaving a review helps us reach even more families who deserve answers.

Also, for more information, training, and community, check out our website, drohara.com and join our annual membership. And remember, every step forward, no matter how small, brings us closer to healing and understanding.

Until next time, be present, Be hopeful, And we look forward to seeing you next on Demystifying Pan's Pandas.