Listening to Parents and Caregivers

Listening to the parents, right? They know best, right? I. One doctor said to me, like always listen to the parent. Right. They watch their child change. They know.

I mean, all the people in our community that I know in the pants benders community do more research than probably any other illness. Right? So like we do know and we know what our child was like prior, we do see what the flares mean.

Sometimes we know. I mean, my daughter, for example, was put on SSRI. It made her exponentially worse. Right. And so I knew that because I knew where we were here and not here.

And so you just have to listen to the caregivers, because all of us want our kids to go to school, all of us, our kids, you know, we want all our kids to sleep.

We want all our kids to be able to socialize. None of us want this. So. Right. So listen to us because and we're not going to stop until we get there.

And we want a partner, right? We don't want a battle. We want a part. This is doctor talks. Real talk from real doctors. Only issues that matter to you. Most.

Welcome back to Demystifying Pans Pandas. I'm Doctor Nancy O'Hara and I am really excited to welcome two amazing women, Jennifer Vitelli and Kathy Wilcox, who are the founders of the Look Foundation.

I just want to give you a little bit of background on who they are, because they're really two remarkable women. About 15 years ago, you know, the word pandas was virtually unknown, as many of you that are listening or watching now, parents facing this devastating, complex illness found themselves isolated, confused, dismissed.

And Kathy and Jennifer were two of those moms living in neighboring towns, fighting parallel battles but unaware that their fate was quietly stitching their stories together.

Kathy was the owner and designer of a very successful national jewelry company, where her family's world was upended by a sudden, nimble shift in her child's behavior and health.

It was a crash that nobody saw coming, and you guys all know this story.

Introducing the Look Foundation Founders

Determined to understand what was happening, Kathy began a relentless search for answers, and she uncovered pandas, which we all know is pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections.

And as Sue sweat on said on a previous client, I talk podcast, she wishes she had called it, you know, autoimmune encephalitis of the basal ganglia caused by streptococcal infections.

And I wish she had called it the psuedo disease. But we have pandas and it's a condition few doctors recognized. And still we're fighting that battle.

And even fewer doctors treated it. And we're really still working on answers. Kathy transformed her grief and her fear into advocacy, becoming a founding board member of the pandas network in 2000 and and a trusted voice in one of the first state advisory councils in Connecticut.

And she co-founded New England Plans in 2013. And then in 2017, together with Jennifer, launched JBC Pans Pandas Foundation to provide direct healing and financial support to children and families.

And then Jennifer. So at the same time, one town over Jennifer, longtime recreation director, the town of Scituate, was watching three of her four sons slip away.

And an illness that nobody could name. Emotional and physical toll was profound. And like Kathy, Jennifer crisscrossed the country searching for treatment, piecing together care through trial, error, resilience.

And in 2013, her advocacy ignited, and she co-founded New England Pans alongside five other parents, including Kathy and united by a fierce will to educate, support, spark change.

And then in 2019, she co-founded the Massachusetts Coalition for Pans Pandas legislation. And as many of you may know, that she played a pivotal role in passing that statewide insurance mandate for Pandas and Pans treatment that we still need in Connecticut, and establishing a permanent Massachusetts Department of Health Pans Pandas Advisory Council.

She now co facilitates landmark victories that she reshaped access to care to families across Massachusetts and then through their own stories and in spite of their own stories.

Beginning separately, Kathy and Jennifer met in 2011 were drawn together by their shared diagnoses, shared determination and quest for helping other families.

And at a time when pans Pandas community was still in the shadows, they became each other's lifelines and sounding boards, as I know, often participated in some of those conversations, and over the years their friendship deepened, becoming the bedrock of some of the movement's most powerful initiatives.

And in 2024, their joint version vision, came full circle, and they launched the Look Foundation. As you can tell in the background from Jennifer's profile, it's a national nonprofit born from the merger of New England Pans and JBC, and Kathy and Jennifer lead look with the same grit, heart unwavering belief that brought them together that No Child with Pans Pandas should be left behind, and no family should face this journey alone.

So they're laying the groundwork for a legacy that will endure. So in the future, families won't have to struggle as much for diagnosis, access to care, and to be believed.

So I can't tell you how much I appreciate you guys being on, and thank you for all you're doing to try to get lasting change for this disease. Thank you, thank you.

Did I forget anything? So I really mean that. And I think, you know, look as well as the other advocacy groups that you co-founded are amazing. So Jennifer, let me start by asking you, you know, many families dealing with pans, pandas obviously face overwhelming hurdles, you know, financial pressures, difficulty finding knowledgeable providers, that sense of isolation.

What's Luke doing to tackle that. Thank you. So look we're trying to tackle it all Nancy I know you're being honest, but what we there are three pillars that we're working at it support education awareness.

And so what I mean by that if I initially our financial support the look foundation does provide healing grants to families across the country. To date we've done a little over $400,000 in healing grants.

So we do. Right now, we do one grant round a year. And our hope is is as the foundation expands, that our support can expand beyond one grant round. So we do the grants, the financial support.

Then we provide resources. And so what started out as Kathy and I fielding phone calls and talking to parents one on one has grown.

How Look Supports Families

Unfortunately, fortunately to almost a call a day, an outreach from someone. So that was not sustainable. So what we do now is we have what we call our new caregiver call.

So the new call is for anybody that's new to the foundation or new to pandas pans. And it gives them an opportunity to come together. And we do it once a month.

And to meet with other caregivers. And then for us to be able to provide those resources because, as we know, information is time and something that Kathy and I wished.

And all of these make, you know, kind of ground level advocates had at the beginning of their journey. And then from there, we invite them into what we call our village call.

So that we meet twice a month with families from all across the country. It is incredibly empowering and inspiring and, you know, not to be too cliche, but like one parent's experience becomes another family's roadmap and we get to see that on every call.

And it is just incredibly powerful and beautiful. And they find hope and strength in each other. And something that Kathy and I found with each other, thank God, 15 years ago.

And nobody should walk this path alone. And then beyond that, we also do education in education of pandas, pans in the schools, medical community and then the community at large.

And then our last piece is the awareness. So basically in the fabric of everything that we're doing very strategically, we are trying to bring pandas pants awareness into the world.

And I think unlike a lot of other illnesses, we are trying to educate at the same time. Right. Because as you know, so many people don't know about pandas span.

So that's what we're trying to do. Kathy, did I miss anything? No, I think it's just for parents and caregivers to know they're not alone because as we all know, it is very lonely.

And these village calls and this awareness and our ban. So if we I wish we had had that, you know, 15 years ago, but so grateful now that we're building this community because it really is changing lives and support that these that we're able to provide, but just as importantly, that they're able to provide to each other and just kind of giving them the the power of community so they can take that next step forward.

Because sometimes, as we know, we all get frozen. But if you know you're not alone, it kind of helps with them forward. And you know, it's it's helping children heal.

It really is. Yeah. And families. And families. Yeah. You know, and and you know, I know firsthand how much the Earth Foundation's financial support has made a difference for so many of these families.

And I know it's not everybody, but, you know, Kathy, do you have an example of how it made a real difference for families struggling with pans? Pandas?

Yeah. I mean, it literally helps every family, right? Like it gives them money to towards care that they couldn't diagnosis and care that they couldn't afford.

But it also again gives them that next step forward. They have the ability to take a step forward, which is such a huge part of healing. Like John said, we've given over $400,000 worth of grants to date.

We do surveys after 100% of our grant recipients have said that the grant money has helped their child their path to healing, which is amazing. You know, one that stands out for me is we had a 12 year old girl whose family came.

They diagnosed with pans. They were pretty sure that tick borne illnesses were playing a role in her symptoms, and they used their grant money to get specialized tick borne illness testing done.

It came back that she had Bartonella. It gave their functional doctor medical practitioner the knowledge they needed to start treating. They started treating for Lyme and Bartonella and her symptoms started to resolve.

And she is on a path to a full recovery, which they never would have been able to do had they not gotten the grant money to get the proper diagnosis. So, you know, they use it for testing, they use it for practitioners, they use it for alternative types of treatments.

And honestly, I can say it helps every family. Yeah. Yeah, absolutely. And I think. Too, I mean, the amount that we wish we could give, you know, tons away.

The other thing it does is it validates what they're going through and that hope that there is that there's this whole community and foundation behind them that's saying keep going.

Yeah. Yeah. And, you know, my example is very similar to the one you gave Kathy. I mean, it was I don't think you were talking about my patient there because my patient ended up having the visa.

But it was a very similar story. We didn't want to do a shotgun approach. We were already treating mold and mycoplasma. But, you know, they were able to use the money to find out that that baby zero was also present.

And treating that made a big difference for the child. So whether it be therapies or, you know, nutraceuticals or herbals or testing or, you know, paying for care, yeah, it validates it.

But it also provides that support. So many of these families need. It, and it also helps other families because then they get on our village calls because they're a grant recipient.

They're on our yeah, they're in our village and they're saying, oh, my child had these symptoms. And it turned out to be Bartonella or BPA. Oh, we tried this treatment with this doctor and those connections.

So it just kind of has this spiral effect on all the families. Yeah. And and that has a lot to do with, with building the community too, right? Jennifer?

I mean, that's part of what the money does. Yeah. It does. It builds community isolation is I mean, I think like, I don't know if there's any other illness like pandas patterns, but it is incredibly isolating and financially crushing.

But the and there is so much shame and guilt and fear and bringing this community together and knowing that that gets it. And Kathy and I say this all the time that nobody gets it like a panda's pants family pants parent.

And I don't mean that like, people are so wonderful and they've got family and friends, but no one truly understands. Like another panda's pants caregiver.

And it's not just parents we've got grandparents on. And what ends up happening is that they become a lifeline. They truly become a lifeline for them.

And when they start doing that, it empowers them to keep going. We see that all the time, like they might get on a call and they're feeling down, or they feel overwhelmed.

And then there's another parent that's like kind of meeting them right where they're at and pulling them through. And so we've got that community. But as important as that community is the rest of the community, the medical community, the school community, the community at large.

And what we're really hoping to try to do here at look is breaking down those silos, right? And bringing all of these communities together. And by doing that, we're reducing stigma around pandas.

Pandas, and we're empowering the families to be able to talk about it more openly. And the children more openly by bringing them together. It's it's powerful.

We're hoping to create a little movement here or a big movement. Not absolutely big. And, you know, the other silo is nurses. You know, one of the things that we found out on that Connecticut council all those years ago, Kathy, the only group that really responded to a survey about Pans Pandas were the school nurse, Scott Mills.

So, you know, we used to go out and talk to all the school nurses, and I can't tell you how many times I hear from a family, you know, we didn't know what was going on.

But the school nurse said to us, did you ever hear about Pans Pandas? And I think getting your foundation in front of those school nurses also is really vital.

Yeah. Agreed. So why do we go ahead? I just did.

Building Community and School Awareness

A presentation on a local school and it was every presentation that we've done is the school nurse after this particular one I'm thinking about came up on a piece of paper with a list of ten kids, and she said, oh my gosh, this is them.

Like right, like so right then that school nurse right off the top of her head was like, you have just explained ten kids to me that have been to my office over and over again, aren't coming to school, you know, aren't accessing the curriculum, like just right there and that it's so powerful to think, you know.

Yeah. And we've done every to that point, every presentation that we've done at a school. On average, 20% of the audience is coming up to us after the presentation.

There is a line and I did they're talking about somebody in their classroom, but more than that, they're talking about someone in their life. Yeah, somebody that they're thinking about, whether it's their child, their grandchild, their niece, their nephew.

And also there hasn't been a conversation or meeting in the last 5 or 6 years that we've done that hasn't ended. Was somebody in that meeting saying, wait a minute, I think I know somebody with this.

Yeah, absolutely. That's huge. So. So why did you rebrand? Why the new name. So we were we had so we had JBC, which was primarily giving grants. And then we had any pans that Jen and I had helped found in 2013.

And we were no longer on that board, and we decided to come together and create one stronger foundation. And interestingly, I had done a social media post about Pans Pan this, and I had in part of it I said had said, look for root causes with a big look.

And the reaction was crazy, right? Like it was just kind of went, you know, for us it was it was it exploded and we were like, wow. And so then I started doing more with look and it just started resonating and people were liking it and sharing it.

And so we were trying to rebrand and think of a new name. We just kept going back to it. Well, what about look, what about look? And it just makes sense, right.

Like it is a word that we find ourselves saying over and over again. Oh yeah. Right. Like look for root causes, you know, look for doctors, look for answers.

And I think for it's just turned out to be very simple. Yet very powerful and something that parents can really use to, again, keep driving them forward and share with the people in their life.

Like see, look, we need to look. So yeah, that was kind of the backing behind it. And it's really turned out to, I think, been turned out to be a really good name for the foundation.

Yeah, I love it. That's been great. And we wanted to be bold like we're done. Nancy, look. Why it's like you get asked like we just need everyone needs to look.

Yeah, exactly, exactly. And and you know, we've talked around all the misconceptions. You know, there there's so much misinformation. And I always share in my talks, you know, follow those who seek for truth but flee from those who have found it.

And, you know, unfortunately, the American Academy of Pediatrics is one of those that in December of 2024 came out and said, yeah, it exists. But, you know, that was about as far as they took it and basically said there's nothing that they that can be done, which we all know is a huge amount of misinformation.

And as we also all know, they they didn't even look at or at least mentioned in their report, the over 200 articles that have been done since 2017 and all the new information that we have, what is look doing to to improve, you know, the early detection, you know, the AARP came out and said, don't even do a throw culture, which is is crazy and really is is hurting so many of our families.

It really what's look doing to try to create some of these correct some of these misconceptions. And that was painful. The AARP report. So we'll just name that for all of us in this community.

So look, in everything that we do we're telling we are building awareness around it. So our specific some of the specific programs that we have, we have this athlete advocate program where we have athletes that are competing in premiere events like the Boston Marathon, the Cohasset Triathlon.

And when they're doing that, they are promoting through their press releases and all that. They're promoting what Panda's pants are, the shirts that they're wearing says mental health symptoms look for root causes.

And it's got the website. So we're that's one area. And as we do that to their communities are learning as well. Last year. Additionally we are getting very bold.

We started a banner campaign in Boston, which I'm not sure if you got to see those, but they were pretty incredible. They lined Tremont Street along the Boston Common for the month of October with information on Panda's Pants, a Look Foundation incredibly impactful campaign, bringing it literally to the streets.

Right. So people that are commuting and walking or visiting Boston, we're seeing that in our we would love to expand that nationally. As we continue to grow other initiatives.

We did an amazing evening of storytelling last year where we brought together three caregivers and two young adults who have healed from pandas, pandas, and they shared very honestly, raw their experience.

And they did that to an audience that was filled with family, friends, aunts, uncles, grandparents. It was. And again, breaking down the stigma, making it okay to talk about this.

Additionally, we just started we just this came out our lookbook. So this I know it's so you can find this on our website. And it's challenging people to rethink about mental health symptoms.

So for those of you at home are listening, it says mental health symptoms look for root causes. And it has these beautiful stories of our grant recipients.

And you know, the symptoms of pandas pants and an amazing take away to like, leave at your pediatrician's office at a state legislators office, because we're doing that as well, or at the federal level in a classroom.

So these are on the website, and we have them here on the office. And then our big not and signature event was

the look walk. Last year we were like, this is it.

We need to get big. We need to get bold and we need to bring this to everyone. So we hosted our first annual Wolf Walk making strides for pandas. Pandas on the Boston Common last year and virtually so.

We had 350 people come to the Boston Common. We had another 100 virtually walk in across the country. It was so beautiful. Powerful. Kathy and I are still hearing stories from families that were there, and how it changed the trajectory of their healing because they thought they were isolated, and they showed up at this walk and realize I'm not alone.

Yeah. And, and, and kids who felt very othered were like, oh, they have pandas too. Yeah. Well, you know, it was beautiful. And then in everything that we do, we're always looking to collaborate with community partners.

So then the reason we're doing that is, again, to bring this awareness to into the community. So last year at the walk, we had the Boston police there, the the Red Sox and New England Patriots.

Rebranding to Look and Expanding Outreach

So any time we had our state legislators. So we're trying to do kind of do it all the RNC you are you are Kathy. What did I miss? I mean, I think the other thing which Nancy you were involved in, you know, it's kind of like a it's a grassroots thing, which I think is important for listeners right across the country is like, actually, you came and spoke to some of our local pediatricians, right?

You presented we had a lot of school nurses there. We had a lot of parents there. You know, we created a local event for anybody that could come. Listen, doctor O'Hara, speak.

But even like I think about our pediatrician, Jen and I are in the same office. And just what they have learned from watching our children heal and talking to you, it's like, that's what we're changing, right?

We're changing pediatricians that maybe aren't. Maybe their practice or or the hospital that they report up to are not like educating on pans. Pandas are supportive of it, but their practice now is.

And that in itself, just watching that change over the years is incredible. They are helping so many of these kids based on how you helped them, how were educated, and how they watched our kids heal.

And I think as pediatricians and doctors get on board watching our children heal, that's just going to grassroots change work, you know? And hopefully then that leads up to the American Academy Pediatrics.

Right. I heard Doctor Speedo say on your podcast, you know, if every pediatrician could have just one pandas fan shot right in their practice, it would change everything. You just see. I yeah, seeing is believing.

And and I would also say to like just empowering parents that they have power in this to educate, to advocate, to make a change. It's one voice, one person in each community at a time.

As we've watched this right over the last 15 years bubble up. And it started with a few parents getting together, and hopefully with the resources that we have here, we can empower parents, caregivers, their family and friends to, you know, to go to their schools, to go to their pediatricians or school nurses and, and help them to learn and to share podcasts like this with them.

Yeah. I mean, and and you know, as Sue and I said on that podcast and, and as, as I've said in so many of my lectures earlier, diagnosis equals better outcomes.

So if we can just get pediatricians to understand if a child has an abrupt change in their behavior and having an abrupt onset of OCD or restrictive eating or anxiety or tics, if they could just do that through culture because two thirds of them early on are strep related.

Yeah, do that throat culture, the strep culture of whatever area, you know, they may have it in a bad psoriatic eczema. They may have it in their rectum.

They may, you know, just do that strep culture and put them on the antibiotic when it's positive. And you as the practitioner can see that change. Yeah.

So that's so vital. What we are seeing here and that which I think is pretty amazing too is that will have parents reach out and it's some good. It's they it's not necessarily been months or years.

It's weeks my child changed. So I feel like there is this grassroots bubbling up right of awareness. And when parents, as we break down the stigma, like in being able to talk like my child has changed, it's not my parenting, it's that there could be something else going on.

They're questioning it. And that's why I think that this building, this community and the work that's being done is so it's so important. It's like everything that's happening at once. Right?

And the parents are kind of demanding it or hopefully, you know, as they learn. And the other. Thing that was very impactful for me and always has been, is hearing it from the young adults, the teens or the children that have recovered.

And I've taken several to talks with me where they've talked rather than me, and hearing it from their voice, hearing their recovery story is just so impactful.

And I know the Pandas, Youth Alliance and and others like them are trying to do that and provide a community for the people that have gone through it.

Yep, 200%. Those voices are those are they they are going to change the future. We're laying the groundwork, but they're going to change it. And I agree with you 100%.

There wasn't a dry eye at that look like last year, when Ian Gulch got up and spoke and shared his story with 350 people of, you know, his journey and and we've yes.

It's just it's powerful. Yeah, yeah, yeah. And we're talking now about what we want to see. But what is looks Foundation's strategic priorities looking more long term.

Oh well we've been at this a long time. So 15 years or so and, you know, kind of like we're all of us here, right? The first generation of advocates. And to make lasting change, we knew that we needed to put together a aggressive, bold strategic plan.

So that's what we're doing. You know, when we look back at where we started from in 2013 with that, you know, who like, who were we? Right. Like here you have five mothers in a medical, you know, Peggy, the brilliant Peggy Chapman with us at that time, you know, coming together to say, like, we need to do something different.

We need to bring these providers together and put on this conference and and medical and caregivers. I think it was the first of its kind doing something like that.

And at that time, we were parents of very sick children just responding to a crisis. And what we've been doing ever since. And it's been great, wonderful, like any JBC and now is look, but we've kind of been triaging and and we continue to do that, but we also need to lay the groundwork so that there is a legacy for the next generation.

So our kids kids are not fighting for care, recognition or to be understood. So our hope is, God willing, what looks to it today will serve generations to come.

And so in our strategy, our goals are three areas are still support, education, awareness. Some of what that might look like would be like.

Correcting Misconceptions and Promoting Root Cause Medicine

Ideally, imagine a national infrastructure with full time, you know, caregiver advocates, financial assistance programs, peer networks. Like enough of this crowdsourcing like families shouldn't have to crowdsource their like.

And that's what they're doing. You know, we're trying to change that. And honestly so, so, so much more with a goal in mind that never again should a child, a young adult with pandas plans be overlooked, misunderstood or left behind.

I mean, that's our that's our dream. Not yet. That's all we're going to have. So like ultimately when a child, young adult have a sudden or even gradual onset of, you know, mental or behavioral symptoms, that step number one is a medical roll out, like they go to their doctor.

Step number one is a medical roll out. And like Jen said, people, schools, doctors meet them where they're at and their care and treatment doctor recommended treatment is covered by insurance.

And because every every child deserves to heal, which is why we started the grant program, it's like some people can heal because they can afford to go to the specialized treatment they can afford IVIg, which, you know, that's really expensive, but right, like that's not it's not okay.

That one kid can get better and one can care. Like that's just not okay. Like these are medical conditions. And that that to me like that is the ultimate goal.

And I think none of us are going to stop until that happens. And like Jen says, set it up. So the next generation can keep the work. Yeah, yeah. And it's so inequitable, right?

This illness, it's just so incredibly inequitable. And if to read my gosh, to read these grant applications that come in from across the country, they are so painful.

And to Kathy's point, like nobody should be suffering, should have to struggle to get care or to be recognized. So yeah, that's yeah. And have enough money for where we are now until that ultimate dream happens, right where everybody has access to equal care, having our grant program expand so that we don't have to say no to people that are applying because everybody that are applying is in need.

And one story is more heartbreaking than the next, and they all deserve the same. So I think, you know, we have part a big part of what we will continue to do is try to raise more and more money for our grant program so that we can at least keep these people on the path that they deserve.

Right? Absolutely. And I think one of the things you said Kathy was about, you know, the medical causes. And I just want to make sure because we do have practitioners listening, we we do have families, you know, watching.

I think it's important that we all understand together that that's looking for the triggers, looking for the root causes. Yeah. There are triggers to mental illness that it's not just about putting, not that they may not need an SSRI or a medication to treat the symptoms, but we have to look at where their underlying infections, like strep, like mycoplasma like viruses, including Covid, like tick borne diseases like Bartonella bbca, Borrelia like mold, mold like figuring out what triggers are underneath.

And that's what we as practitioners need to be better detectives and as doctors. You know, the the root word for that is teacher. You know, then we have to educate ourselves and others.

But I want our medical community to really better understand root cause medicine, not just name attainment. Blame it medicine as our Western medical model has more often become.

Yeah. 100%. And I also think listening to the caregivers, listening to the parents. Right. They know best. Right? I one doctor said to me like always listen to the parent.

Right. They watch their child change. They know I mean, all the people in our community that I know in the community do more research than probably any other illness.

Right. So like we do know and we know what our child was like prior, we do see what the flares mean. Sometimes we know. I mean, my daughter, for example, was put on SSRI.

It made her exponentially worse. Right. And so I knew that because I knew where we were here and not here. And so you just have to listen to the caregivers, because all of us want our kids to go to school, all of us, our kids, you know, we want all our kids to sleep.

We want all our kids to be able to socialize. None of us want this. So. Right. So listen to us because and we're not going to stop until we get there.

And we want a partner, right? We don't want a bottle. We want a partner. Yeah. And two things along that line. You know, I often tell my parents I'm just your GPS.

You know, you're still driving the car, right? I may tell you a route to go down. You have to tell me whether that route works for you. It may not work financially.

It may not work because your kid won't do it. It may not work because you're not comfortable with it. Right? But you have to be transparent with your practitioner and listen to each other.

And then the second thing I wanted to say is take videos, whether it be surreptitiously. And I'm not recommending lying to your child, but sometimes you can't just put the video and say, oh, let me catch that again.

Take that picture of the horrendous text. Take that picture of the horrendous flare. Show it to your doctor. Sometimes that's the only way they can really understand what it is.

But also it may give us a clue. Wait, that that's not a tick. That's actually a seizure. We got to do this, this and this or that flare has a different ring to it.

This kid has decided, no, Mia, we need to, you know, whatever it may be, that you know, that communication, that transparency with each other needs to happen both ways.

And it really, really does. Yeah. So now how do they find you their new person they've never heard of look Foundation. They want to get involved first their parent.

They need your help. And second they've heard this. They want to donate. So how do they think you can do those. So they can do both on our website. Look Foundation dawg you can donate there.

You can find information there. There is a form to fill out there. If you are a parent listening or caregiver and you want to connect with us directly, email us at info at Look foundation.org.

You'll receive an automatic reply with a survey to get into the village calls and I. Yes, that's step number one. I would love to have you. And I also think that if you want to get involved we do do this October 4th.

Oh yeah walk. But it's also like Jen said earlier across the country we had people hiking mountains. We had. So, you know, whether you're a donor sponsor or you're a family that just wants to walk, if you're in the Boston area, please come join us.

But if you are not in the Boston area, please reach out to us. You can create remote teams. It's about spreading awareness more than anything. So it's just another way to get involved.

That family. Yeah, we're going to do that this year. Yeah I'm glad you come I put it aside. So awesome. Anyway, and anything else either of you would like to say to any of our parents caregivers that are in the thick of this, what

what advice, what words of wisdom would you like to leave them with?

I'd say, look, look up honestly on your hardest days because healing is possible. We've seen it and you are not alone. Look ahead with hope and if you haven't found your people, you need to find your people.

Find your community. They will that we know and know until you find that community. But you can find us right away that we see you, we support you. We're working for you.

Keep going. Take it one day, one moment at a time, and you will get through it. And yeah, that's my advice. Yeah.

Finding the Foundation and Getting Involved

And I think just watching I mean, because of what we do, we see these children heal. You know, it's not sometimes it's very quick, sometimes it's not.

But they do heal. And so I feel like for parents like I was in it, I didn't have a lot of hope on some days, some months. And just stick with it because healing is possible.

And there's, you know, the network of available practitioners and care and support. It's growing. And so just kind of latch on to that and also want to say thank you to Nancy, doctor O'Hara, because you have changed so many lives.

Like truly, from the bottom of my heart, I really do mean that, like, there are not that many people. There are no other Nancy O'Hara's out there. So thank you for sticking with our community and helping us heal our kids, because I don't know where we would be without you, honestly.

So thank. You. That's very sweet, but it takes a village. And, you know, I'm really just trying to find more of us out there so I can retire. Thank God you know, God and stop doing this someday.

Oh, I just keep spreading the word and hoping more and more people understand that this is a challenging, devastating, but treatable disease. And and our kids can get better.

I thank both of you so much for everything you're doing for your own families, for so many other families, and for the community at large, because this is needed and you are making a difference.

So thank you. Doctor Nancy O'Hara and I had a wonderful podcast with Jennifer Vitale and Cathie Wood because of the Look Foundation. And after we got done with the podcast, we realized there was more we want to talk about about collaboration.

So in our different clothing and from our different locations, we are reshaping a few things to add to the podcast. So Jennifer, I really just want to talk about how much our families and our organizations and our doctors and everybody just needs collaboration and and tell us about that from your perspective.

Yeah, no, 100% like collaboration is at the core of everything of this illness, as we've talked about. Like you have to collaborate between patients and providers, families and advocates, caregivers, educators, legislators, researchers.

So it's all it's everyone coming together. And Kathy and I say this often, it's all of us locking arms to ensure that no child or young adult is missed.

And it's really the only way, in our opinion, that we're going to move the needle on. This is all coming together, and we feel very blessed to see how far we have come as a community, like when we started with this illness.

You know, 15 plus years ago, there were a few, maybe a couple of nonprofits and organizations, and yesterday I was looking and now we're at over 30 or so pandas pans nonprofit organizations around the world.

So I think that that's pretty incredible how far we have come. And everyone's doing amazing work, and there's some that we work with very closely. Yeah, some of the organizations that we're working with aspire and and Pandas Network, the Alex Mantle Fund, Napa, the Louisa, the Luis Louisa, excuse me, Lulu Johnson Fund locally, the mass coalition for Panda's pants legislation more recently and very exciting the National Pandas youth Alliance.

So now these young adults are having their own voice in this illness. So yeah, it's been very it's incredible. And there's so many there's actually so many we shouldn't be, you know, totally gone. Yeah.

And I also think what's so nice about it is that we all complement each other. Yeah, we all work really well together and we complement each other. What our focus is our what we excel in it just as a really nice group of people, all with the same common goal.

Right.

Hope, Healing, and Advice for Families

And all with the same common goal, but all also with slightly different bent, slightly different ilcs things that they're talking about. You know, those who are listening to or watching the podcast know that I've interviewed Gabriela true and and Sue sweet and we're together on inspired Care.

This is a wonderful advocacy organization. We all know the manuals very well. And the manuals have another wonderful podcast, Unlocking Pans Pandas, and are doing so much to gain money and so many of the other organizations and and by the way, I love meeting all of the young adults.

Yeah, we're out there stomping the pavement, doing the, the the races, doing the legislative ad. You see everything because. They've lived it. They've loved it and you know it.

They're they're going to be the, the future. So yes. And we can't nobody can do this alone. This whole illness we can't do alone. And then the organizations can't do it alone.

So we're really lucky to be working together. Some recent examples is that we all came together for Columbia for the funding to cover the funding that was cut there on that.

On doctor, I want to make sure I say his name correctly. So I thought you saying. Yeah, well, it didn't go well. Yeah. Doctor Agnew's in his lab. You know, the nonprofits came together and made sure that we could cover or help cover the funding for the rest of the year.

And then more recently, while locked arms and standing up to the AP. In that report, you know, we all felt very strongly that that report was pretty irresponsible, deeply flawed, and honestly quite harmful.

And we felt a responsibility to come together. And so that will be coming out soon as well. And for our listeners who don't know. About the. Report, in December of 2024, the AP finally came out and said that pandas exists.

Which is wonderful and thank you. But they then went on to say that there is nothing that you can do about it, including not even do a strep throat culture.

And the research that was presented missed the last 200. And some articles that have been published already about the existence of this disease, the appropriate assessment and treatment of this disease and its validity.

It it was so the AP really did get it wrong in this instance. And anyone who has lived this as treated this has read that report understands that. And yet our families are practitioners, our foundations are all having much harder of a time since that report came out, because not only is funding dry drying up as as you said, you know, in some of our labs, but IVIg and other necessary interventions are not being covered by insurance because of that report.

Yeah. And kids aren't getting diagnosed properly. Yeah. Yeah. So and yeah and we live we live the heartbreak but

we also live the healing. So we see these kids heal and these young adults heal.

And so it's it makes it so hard to hear that in a report. Because we've watched the success over and over and over again with our own kids and with the people in our village that we support.

So. Right. Yeah, right. So absolutely agree. Collaboration is so important. I wanted to also say collaboration between practitioners. Oh yeah. You know, so much of our world these days is divided.

You know, you believe this. Well, I believe that I can't talk to you, you know, whether it be religiously, politically, whatever it is. And it's it's in our medical world, too.

Collaboration Across Organizations and Practitioners

And I think my plea to practitioners of all ilcs out there is just listen, listen to the families, listen to the children, listen to other practitioners who may have lived this or are treating it and, and, and and maybe just take one step.

You may not agree with everything that's being done, but just come to it with a spirit of cooperation, collaboration and curiosity. You know, we're not going to do any harm.

But, but, but let's figure out what we can do together. Absolutely. Curiosity two we had another cool project with the University of Michigan. I'm not sure if you heard about this, but they actually they had a class that was writing a book on pandas pens, and quite a few of the nonprofits came together, some medical practitioners, clinicians, and helping them with that editing process.

So yeah, it's 100 questions on Pandas Pan. So another collaboration. And then another cool thing is globally, I'm not sure if you heard about that with Inflamed Brain Alliance in Canada, which is wonderful, is bringing together a lot of I think it's 14 or so of the organizations around the world to light up for pandas pans in October, so we're all working from now until October to light up landmarks around the country.

And around the world for pandas Pan. So I don't know, just it's it's really wonderful to see how far two we've come with collaboration. Right. And I also was going to say like, it's not just the nonprofits, it is our state legislators here.

You know, we've seen that in Massachusetts. They have been our heroes supporting and passing legislation. Claimable a company that's out there right now that is helping assisting families with pandas, pans, insurance rebuttals and whatnot.

And it's companies and it's donors and it's families and it's everyone. Like it's all it takes a village. This illness takes a village. And we need to all lock arms and together we will change.

I feel like we're going to change the course of mental health as we start healing these kids. I agree, I agree, and you know, it's all about microbes and mental illness.

Whether we're talking about strep, mycoplasma, viruses, tick borne diseases, Borrelia, Bartonella, Busia, mold, yeast, these infections and other things are triggering mental illness in our children and our adults.

And until we recognize. That. And assess it and treated appropriately, our kids are not going to get better. I was lecturing last night and a 39 year old with schizophrenia.

It was shared that after many years, decades of dealing with this illness, it was found that that person had tick borne disease and is now finally getting appropriate treatment.

And what do you know? Does it really have schizophrenia? Right, right. It's wild. It is. It's just healing is possible. We just need to be curious and look for root causes, right?

Yeah, yeah. And work together. Work together on 100%. That's how we're going to. Yes. Work together.

Collaboration is really the driving force behind all of this.

I think. I really appreciate everything you guys are doing. I appreciate the model under which you work. Is there any last words of encouragement or hope or wisdom that either of you would like to to leave us with on our second half of our podcast together?

Yeah. I mean, I think at the end of the day, like I said, like we've we have this village and, you know, we get some of these families with the sickest kids on our village calls and just not even Jennifer and I, just them supporting each other is amazing to watch.

And honestly, watching them heal and then watching those parents support the other parents that are having a really hard time. And honestly, even parents that are in are in the thick of it.

They're still supporting the other people and I think just having these, having this community of people that have healed, that have hope, but also people that are in it with.

Each other. Supporting each other, it's just super powerful. And like Jen said, like we will change the course of mental health, right? We will. Right? Because we see it every single day.

I do, yeah. Yeah we will. And the mental health of our children and of our parents, because there really is absolutely a lot of PTSD and stress and everything on our families and our parents.

And but there is hope. Hang in there. We'll get there. And if you're listening to this after Pans Pandas Day, which is October 9th, also remember every year we're going to light it up for pans pandas, and every year it's going to grow more and more and more and just keep at it.

Yeah, keep the faith. We're going to do this together. Yeah. Yeah, absolutely. Well thank you both again. And thank you. I'll see you soon. Thank you for tuning in to Doctor Talks.

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