Introduction to Mental Health Stigma

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Well, first of all, we have a history with caregivers, right? And just how we talk about caregivers. We've talked about schizophrenogenic mothers, you know, the mothers with children with schizophrenia or the refrigerator mothers, right?

Mothers with autism, children with autism. And all of those things have been debunked, but they stay with us, right? This is our history and this is kind of how we view caregivers.

And just the part of the, The problem really is that when we, and we don't have a lot of answers. So when we don't have answers, we go looking for answers.

And unfortunately in mental health, where the answers often lie is with the caregiver or the impacted person, right? So we kind of have this weird thing where you can look at the research on treatment resistance.

Um, we've kind of allowed that some mental illnesses, people just don't get better from, and they just live lives of, you know, um, symptom management.

This is doctor talks, real talk from real doctors on the issues that matter to you most. Hi, everybody. It's Dr. Nancy O'Hara, and I am so thrilled to welcome Sheila Ghosh to the program today.

She's the principal and clinical director of Dearborn Academy, which is a therapeutic day school that services students with social, emotional, and learning needs.

She's a licensed independent clinical social worker, educator, with over 20 years experience working with and advocating for students with complicated mental health needs.

Sheila Ghoshu2019s Personal PANS/PANDAS Journey

And in addition to all this work, she also engages with caregivers, educators, mental health professionals through consultations, trainings, and public speaking.

She also has children who were ultimately diagnosed with PANS and PANDAS and co-founded the Massachusetts Coalition for PANS-PANDAS Legislation which successfully championed the passage of both an insurance mandate and established a permanent Department of Public Health, Panda's Advisory Council.

And she serves, of course, as the co-chair for that. And Boston College, she received the 2020 Common Health uh heroin award and the boston college school of social works distinguished alumni award in 2024 and then lots of boards that she's on some of which we'll get into and then she writes for psychology today um and her blog's called the whole child so so many wonderful things you're part of sheila and and i just so applaud you Just for being a caregiver with all the PTSD and stressors that we have for also doing all you do.

So thanks for being here. Thank you, Nancy. Thanks for having me and inviting me. I'm so glad you're here and just give everybody a little bit of a synopsis how you got here.

Sure. Okay, how I got here. So I have two children who both started presenting with mental health symptoms around age five and seven. And that kind of, in a lot of ways, made It didn't make sense.

It was hard. But we have a pretty significant history of mental illness in my family. And I'm a social worker. And so I kind of went about using all the tools that I know in my toolbox to really help what looked like anxiety, OCD, sensory issues, lots of different presenting factors.

But unfortunately, they really didn't get better. They actually started progressively getting worse. And at around, it was really when my youngest child was, had really become so acute that I thought that we might lose him, truthfully.

And I had heard another parent, I was working at a school and another parent just mentioned Pan's Pandas. And I was like, wait, what is that? And I went and got him screened and he met criteria.

And at the time we had a full state mental health team in the house helping us We had both kids were in therapeutic day schools like the one that I work in now.

And I think watching him finally heal on antibiotics and anti-inflammatories, it was nothing that I'd ever seen as a social worker. And my entire in-home team watched him start to get better.

And then it was suggested by an ed advocate that I test my other child. And I would have told you totally different presenting children. I would have told you their immune systems were great.

They never had a fever. They never got sick. And it was nothing I had heard of as a social worker. So truthfully, I wanted to discount it. And yet, I was desperate.

So I ran towards it. I got my other child tested or screened. And they also met criteria. They also got to get better. And I think now that I've done so much research and understanding and really digging into what is Pans Pandas and just having been in the field for so long, but also realizing as I've gone down through this journey, realizing that this was actually also me.

In college, I had my own acute onset of symptoms. I was at the time a Division I swimmer. And it pretty much lost everything, you know, within a couple of years.

Why PANS/PANDAS Needs Medical and Mental Health Care

And it was really painful, but I think once I learned what they had, it actually made me reflect on like, wait a second. Yeah, I think that was OCD that I had, and no one diagnosed it right, because OCD is often misdiagnosed, right?

Yeah. And we didn't understand the science and the understanding back then, but I think it's really made me wonder, gosh, if this were my kids and this was me, how many other family members could have been helped with this?

And then how many other people could be helped with this? Because I think it actually offers us kind of a roadmap into you know, understanding the body and brain, right?

Yeah, absolutely. Yeah, and I think you talk a lot about understanding these illnesses, PANS and PANDAS, as needing both medical and mental health interventions.

I mean, so much of the time, like yourself and so many of the kids we see, they may well be getting the mental health interventions, the support, the therapy, the neuropsychiatric or psychoactive medications, but not being seen as medical at all.

So I think that's really important. Can you speak to that a little bit more? Yeah, so it's so interesting for me because I think the more I learn, the more it evolves into such a both and scenario, right?

So, you know, Part of the reason I was so curious that I had never heard of it before is as a social worker, my training is we're always supposed to rule out medical.

The DSM-5, our Diagnostic Statistical Manual for Psychiatric or Psychological Disorders mandates, not mandates, but it tells us we're supposed to rule out medical.

And I felt like I sort of understood what that meant. And then I had And I started to learn, oh, wait a second, like, first of all, I want to run towards the medical once I heard about it, because truthfully, any caregiver who has you know, has struggled with mental health issues or has children with mental health issues knows the shame and stigma attached to it.

So hearing it's medical, you're like, great, I'm gonna run towards that. And then the more I researched and the more I learned and understood, the more students I saw with it, the more I was helping my own children, I realized like, oh, we actually also need the mental health.

So it's not ruling out and then you're running towards medical, although you need to do that and that's, And we know mental health is medical anyway right that's kind of what you're saying as well so there's this balance of like really embracing both and and that's really hard.

Yeah, I think most of us want to run away from the mental health because we've been so shamed and othered and stigmatized and yet. I truly believe with this illness, it will be kind of embracing that peace, not only to go find other people first, but who might have been missed like myself or my kids, but also to make sure that they can truly find healing because we if you know, once I started digging into the medical aspects, I then also went back to all my old trauma books and understanding like, what's happening in the body?

Like, what's the research on the brain when it maps down this level of stress for so long? you know? Yeah, that whole fight, flight, freeze that we all go through.

Yeah. And I started wondering, like there's certainly all of the limbic system, the amygdala, like all of the things in the brain that, you know, are such evolutionary responses to stress and fear and anxiety that really create pathways in the brain and kind of those pathways get solidified the more the thoughts happen.

But then there's also the nervous system. And so I started looking at like polyvagal theory and Dr.

Mental Health Stigma, Shame, and Treatment Resistance

Stephen Porges and like what's happening to our children and ourselves when we're having these issues and how can we use the medical but then also go back and all that we've learned in mental health and use all those tools too.

But I think it speaks to the complexities of panspandas because- Yeah. And I recently spoke to Dr. Scott Antoine on this podcast, and he's one of the other functional medicine physicians who's also written a book, great doctor.

And he's been doing a lot more in hypnosis and neuro-linguistic training and really looking at the therapeutic aspect. And I don't know, maybe I was lucky that I taught children with autism and was pretty lousy at it before I went to medical school.

and also was very involved in therapies and really thought about being a psychiatrist before I went into pediatrics. But I think that the medical community in general has become so fractured that we cut off at the head for sure.

And we don't include the body and what the body goes through in discussing mental health problems. And we don't discuss mental health problems when we have body stuff going on, except in that horrible term, psychosomatic.

You know, and it's true. And I think that that also really fascinated me. So I went exploring that too. And there are some really great kind of, there's great books on there's one called like mind fixers, but really talking about our history of like, how do we get here?

And like how, you know, Because I think sometimes when you understand, we got here, honestly, we didn't think

we had the science and the understanding.

So mental health kind of went over here and medicine went over here. And yet we know they're connected. We have the research to know that if you have chronic mental health issues, you are going to have a shortened lifespan.

That's the research, right? But then you're also going to have comorbid issues. I mean, we know from the ACEs studies, the adverse childhood experience studies, that longitudinally people are sicker.

And I don't see why people with mental health issues don't deserve to heal too. live long, productive, healthy lives. And I'm so grateful I found the information because I felt like I got to finally heal as well at like 40. That's incredible.

Yeah. And we'll get to the caregiver piece in a minute, but what else do you think is part of the mental health stigma that doesn't allow us to access true healing?

Yeah, I think we have a really complicated relationship with mental health, and I, I actually I did I just recently wrote a blog post on it I'm so fascinated by it because I think we have this kind of history with mental health that if we don't.

Well, first of all, we have a history with caregivers, right? And just how we talk about caregivers. We've talked about schizophrenogenic mothers, you know, the mothers with children with schizophrenia or the refrigerator mothers, right?

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And just the part of the, the problem really is that when we, and we don't have a lot of answers. So when we don't have answers, we go looking for answers.

And unfortunately in mental health, where the answers often lie is with the caregiver or the impacted person, right? So we kind of have this weird thing where you can look at the research on treatment resistance.

We've kind of allowed that some mental illnesses people just don't get better from and they just live lives of, you know, symptom management. And there's research on, it's like 20 to 60% of people are considered treatment resistant.

I mean, that's a huge range, but that's the research. And a lot of times, if you look into the research, what it will also talk about is that when professionals in particular start to feel like they're at the end of their abilities, that they often will say, what could you do caregiver?

Or what could you do? patient. And that's complicated because that assigns shame and blame to someone who's suffering, right? Totally. So I think it's mental health stigma is really layered.

There's professional stigma, there's personal stigma, there's societal stigma. Um, I mean, there's the stigma of like, I never wanted to share my story because what would that mean?

Right? Like for me as a professional or, um, and so, but okay, the research actually also says that if you stand up and share your story, that that's actually how you break down stigma.

So, right. Right. And I deal with it myself. My own son didn't want to be called out. And although he's one of the chapters in the book, I never identify that.

And it's hard. And I think it also, in some ways, needs to be individualized. because there are ways that some people may want to stand up and others may not.

And that's okay. Also not stigmatizing what each person feels, but understanding. I mean, it's the awareness and the understanding. for each person. And I was talking to Nicole Bell earlier on this podcast, and she's written Lurking in the Woods, a story of her own husband's mental health decline and Alzheimer's that was all due to tick-borne disease, and talking about his shame his guilt as she, as his caregiver, would talk to the doctors about what she was seeing.

And yet, you know, he didn't want to identify those things. He didn't want these colleagues to know about them. And I think that happens for our kids too.

The intrusive thoughts, for instance, is one that comes to mind. They don't want to tell us about them. They're ashamed or guilty or scared. No, totally.

And I think you can't shame someone into coming out and talking about their, they're allowed their privacy and they're allowed to kind of keep private what they don't want to share with others for sure.

I think for me, the mental health stigma piece is more around myself as a professional and other professionals of like constantly reminding people that you know, people are doing the best they can.

And they're doing the best they can with the tools that they have. And if something's not working, or they appear treatment resistant, or they're not getting better, not turning to them to say what, what could you do differently?

Although, PS, we could all do things differently. So that's fine, too. Like, it's not to say that there aren't things that you could do to help improve your mental health.

School Avoidance, Anxiety, and Exposure-Based Support

But if someone's really markedly not getting better, wondering curiously what you could do as a professional to help them and having enough kind of intellectual humility to wonder what else there is out there.

Which quite honestly, I don't think as a young person I had. But knowing what I know now, I'm like, we need to get people better. They deserve to get better.

Absolutely. But also not the should have, could have, would have. You can only know what you know at the time and not going back and beating yourself up for what you didn't do for your child or for yourself, you know, and just taking the next right step now.

Yep. Yeah, absolutely. Absolutely. And you've written some great blogs. It was so fun reading them on school avoidance and anxiety, talking about the way through is through.

Can you talk about that a little bit more as well as the work you're doing specifically at Dearborn? Sure. Yeah. So I think, you know, again, One of the things I've learned from my children, I mean, and also from my work is really digging into the science of anxiety and the neuroscience of anxiety.

And we've really used it here at the school I'm at at Dearborn Academy to really train up the entire staff team in the neuroscience of anxiety so that, because really it just, it gives everyone empathy.

If you know that what's happening in someone's brain, whether it's mine or yours or my students, Is really a very primitive reaction to, you know, a survival mechanism right when you feel stressed, your brain is going to behave, you know, in a very predictable way and you will feel fight flight or freeze.

Everyone has it, you can't get around it, even if you want to, you're not going to. So really understanding it through the lens of like, this is what's happening in our bodies and brains.

It takes away from that shame and stigma of like, I could do something different. Like, well, here's what's actually happening. What is in your power to do something to help maybe if in fact there is no danger and stressor and your

brain has kind of mapped down that response, how do we go back in and remember and help your brain remember that it's safe?

And that's through exposure work. We've been really grateful here at Dearborn. Our whole clinical team just got trained by some experts in OCD, but in exposure response prevention therapy.

And really that idea that exposing yourself to the stressor really helps your brain and your limbic system and your amygdala, which is where the… house of fight, flight and freezes, right?

Your alarm system. It helps remind your body and brain that you're safe, right? So when you expose yourself to a stressor, like if you have school avoidance and school is actually there, there is no danger at school, but your brain is telling you there's danger at school.

It's really stepping into that discomfort and helping your brain relearn that school is a safe place, that your brain is telling you something that is not true.

and kind of remapping that. So we've been doing a lot of that work here, just as a whole school team is really leaning into that science of anxiety. And then you asked about kind of some, we've taken that and really also extrapolated it for our caregivers who are really, myself as a caregiver, knowing what caregivers are going through.

really using that to understand caregiver stress and trauma and anxiety as well and how we all kind of understand anxiety best to help ourselves and our students.

those who are supporting. That's amazing. I wish more schools, you know, it would be nice if we could figure out a way to generalize the model that you're using.

You know, because I think so many children that go to more typical schools would benefit from, you know, this way through this fight, fight or freeze that they're dealing with.

Do you have any thoughts about how to help people see that more? other parts of my job that I get to do is do training. So I'm actually running a school avoidance webinar for educators in Massachusetts.

And I mean, I have to say, educators, in my opinion, are heroes right now, like are on the front lines and they are willing to learn. It's to your point, it's kind of how do we get the information out there?

And I think in education, it's so challenging because we are kind of asked to be um mental health experts as well as educational experts right even in public schools like we we care for the whole child like that's our job as educators and so it is really challenging and i but i find educators to be incredibly open and willing to learn so i'm grateful to be able to do some teaching around it too so that's great that's great you're doing that training bring it to connecticut next And how about the differential diagnosis, you know, in ruling in or ruling out these illnesses.

How does that play into what you're talking about. Yeah, so I think one of the things like when we're here at Dearborn when we started to see We had a lot of students who weren't getting better and we started to see they were more treatment resistant, which I don't love that term, but that's what we have to use.

And, you know, especially in a school like ours, where we are a therapeutic day school. So these are students who have.

Differential Diagnosis and Finding Missed Cases

not been as successful in their public schools and they're coming here and we're hoping to learn new skills and get them back to either their community skills schools or a least restrictive setting.

That's my job as a special educator is a least restrictive setting. And as we saw students who are more treatment resistant we started wondering like what could we do differently to help them?

And we started seeing maybe the diagnosis they're presenting with isn't always what… They're coming in with one diagnosis and we're seeing something different, if that makes sense.

And that matters. So if you're coming in with depressive disorder, but you we noticed like, oh gosh, I think that's OCD or that looks like panic disorder.

That's a different treatment modality we're going to be using to help you gain the skills you need to, to kind of move to that less restrictive setting.

Yeah. So we started wondering about the differential diagnosis of what we're seeing just diagnostically in the DSM-5. And then we also use the information we have with this new research around PANS-PANDAS and kind of these immune mediated issues to really wonder, did someone do that differential diagnosis in that DSM-5?

Like, did someone before they came to us do a medical rule out? And so we kind of combine this understanding truly the DSM-5 diagnosis with making sure we did that medical rule out.

And, you know, we've found some pretty amazing things. Like, we've been able, we've teamed with Peggy Chapman, who I know you just had, on your podcast and been able to really help students access, we don't diagnose at a school, but like access different kind of different tools in their toolbox, whether it's going down the road of exploring PANS-PANDAS, because they kind of miss that acute onset, and then they miss the clinical criteria for PANS, or a lot of times we have students that just miss that it's OCD.

And that leads us into like, could that be PANS, right? Because it's been called something else. And then we do the CY Box, because we're using empirically back screening tools.

and discovering that students have these kind of misdiagnoses that then they get to find additional healing, right? And they can start to feel better and hopefully move on to college or back to their community schools because they're feeling better.

Right. Absolutely. And it sounds so much like what we do, Peggy and I and other clinicians like that. It's being detectives. It's getting all the information because when you have that knowledge, it can just help you help the child so much more.

Yeah. And they deserve to feel better. And they deserve to be able to work, right? I mean, like children should enjoy school and school has become not enjoyable, maybe because of learning challenges or because of the significance of their mental health.

But I think for our entire team here, I mean, we've watched student after student get the correct diagnosis. And often we have found a number of students with Miss Pan's Pandas.

And when they start healing, I mean, it's miraculous, like just to have the entire school team. I mean, I will often have our high school English teacher coming in and saying, Sheila, they're writing again.

They're actually writing five-paragraph essays. They weren't writing before. You forget how much suffers when you're not feeling well, right? Yeah, absolutely.

And I feel that this has worsened since the pandemic. But like you, I am always looking for silver linings. And I know you wrote a blog last year about the unexpected silver lining of the pandemic being the knowledge that a virus can and often does cause symptoms.

And do you want to talk a little bit about that? Because I love that blog, by the way. Oh, I think, yeah. I mean, I think It's just so fascinating to me because I think we, as humans, we like our stories, right?

We want to make up stories about why these things happen. Why is it so much worse? I mean, we are in the middle of a mental health crisis. We're in multiple crises, so chronic absentee crisis and mental health crises.

You know, the, the pandemic absolutely provided a silver lining I mean we have 30 to 40% of all covert cases the research says is. is neuropsychiatric, right?

I mean, that's huge. But then also, like, I also think the other part to it is that people are really scared and the fear piece of being scared and having your amygdala and your brain kind of mapping down that fear, you know, the more research I've done, the more understanding I have is that stress response can also be a trigger, right?

Yes. It can also light up the immune system and the body thinks it's being chased by a lion. So it's going to send out, I mean, you're a doctor, I'm not, But you know, but it's true.

Right. And, and so was stress a trigger of the pandemic, you have COVID, which had 30 to 40% neuropsychiatric issues, but then you had just chronic stress.

And that actually does unhinge the immune system. So it's it in a lot of ways, it has highlighted a lot of different amazing things, like, even just we're talking about mental health more, right?

We're talking about the crisis. We're talking about medical, we're going and getting this research and COVID. And so it is amazing that we're met as we are.

Yeah, and that response, that stress response also applies to our caregivers.

Pandemic Lessons and the Stress Response

I mean, I know we've talked about this a little bit, but we have to remember that as caregivers that when we're under stress and we are exuding that stress to our child, we're also increasing their stress.

Yes. And that vicious cycle. So I always go back to that tried and true, put your oxygen mask on first. I think, and I'm often asked by grandmothers or whatever, what can I do?

And do you have ideas about caregiver family support, caregiver trauma, any of that? Yeah. Yes. I know. I love talking about that. Yep. Yeah, I think it's really the caregiver stress and trauma.

I think what's really sneaky about it is that we're all kind of told we're parenting, right? Or we feel like we're parenting. We're doing the next right thing for our children.

And I think it's so sneaky. When I do a lot of trainings, we actually have a lot of caregiver support at Dearborn. We have a caregiver trauma group we run.

And, um, when I present to caregivers, like it's, it's often talking about it as it's almost like you're a frog in a pot of boiling water. You know that, um, and now, right.

Like where you're just, the heat keeps getting turned up and before you know it, you're, you're boiling, but you don't even know you are because. Like, there's, there is more caregiver index burden understanding for pans pandas which is amazing, like it's amazing that we have the, the understanding that it's equivalent to caretaking someone with Alzheimer's right like we know that.

Yeah. you understand your stress response or what's happening. I think we become so almost fused with the stress state because it's all we do. I mean, and you know, I know when I've talked to caregivers, you know, some of the stories caregivers have, right?

Like whether it's like they're hiding knives at night, you know, they're locking up pill bottles, like that's not typical parenting. And that's, Right.

Like, I mean, who has knives and lock up medicine so that your child will survive. Right. So I think it's so sneaky and it becomes kind of so fused with yourself that I know for me, it took a long time, like the presentations that I've

developed.

I've developed like basically Because I lived it right and felt it and I was like I don't know what's happening for me like I feel frozen, I do not want you know when my kids want to go back to their community high school I will never forget the feeling of just being stuck.

I'm not signing any paperwork. I do not want to go through any more stress. I can't handle it. But I didn't understand why was I feeling so stuck? Because it's unlike me.

And just going back and understanding that stress response in your body. And I feel it in myself. And sometimes you don't even know you're feeling it.

You're holding on so tight. Until you relax, you don't even realize how tight you were. And I see it now with the measles cases we've seen in Texas and a couple in New Jersey and a couple of other places.

There's this panic within the parents that I've got to go home. I've got to bring my kid home. They can't go to school. I've got to lock down all over again.

And I find myself spending a lot of time, either in writing or in talking to family, saying, let's look at this realistically. Let's look at your child has immunity to this disease already.

We know that. We have things in place that we can give him or her to prevent him from getting sick. What are the pros and cons of staying home versus going to school?

And I think so much of this locking down is caregiver stress. No, absolutely. And I think one of the things at one point when I was doing some research on caregiver trauma and trying to figure out like, why does this feel so different?

Like I've worked in trauma pretty much my whole career. I started out in residential treatment centers. I worked with children with complex trauma. I understand trauma.

And this just felt different to me. And I had sat with a friend of mine who's a trauma therapist and kind of had a long conversation around it.

Caregiver Trauma and Support Strategies

And one of the things I realized I was missing for myself was, A, it was sneaky. It was that kind of sneaky, you miss it, that like you're just in stress hormones all day long, right?

Because you're terrified. Like, I mean, even now I'm like, I'm keeping my phone over here, because if one of my kids calls, you better believe. I'm like, it's literally just an innate reaction, right?

Like, right there with you. Pick up the phone. Yeah. And my father said that till the day he died. And it was so funny. In my father's eulogy, his best friend got up and said, you know, in the middle of every crisis, he was the CEO of a hospital.

He was dealing with 50 different people. His phone was always on beside him in case one of us was in crisis. And I think as a parent, You live that and pulling yourself away from it takes a lot of work.

It does. And the thing that I missed when I was talking to my friends, and we were kind of going over like, well, what is trauma? One of the things that I had forgotten about is trauma causes cognitive distortions, right?

So cognitive kind of changes the lens that you see the world through. And the level of stress that caregivers with Children with Pans Pandas are undergoing all the time, literally, I mean, because your one job is to keep your child safe as a parent, right?

But the level of stress that you're under, it's also causing these cognitive distortions, which are that all or nothing thinking. very black and white thinking, thinking you can mind read other people.

I had that all the time. I know exactly what you're thinking, Nancy. No, I don't. But I was so hypervigilant all the time that I had a million stories and I had a million cognitive, not a million, but I had many cognitive distortions.

And it really does change the way you see the world. It's important to name. Yeah, and acknowledging that and for our caregivers, getting the help that you may not even know you need.

Totally. Whether it be a friend you can talk to, a therapist, a support group, you know, it really is important. Yeah, I mean, I feel like once I met my fellow Pan's moms, honestly, and dads, but I That was life-changing for me.

Like, and truthfully, that's the way I found the path through for my kids, right? That's how I found providers. That's how I found, that's how people woke me up.

I mean, and said like, Sheila, I think you have to do something else. And I was so tired. I didn't want to do anything else, right? But it was the other PANS caregivers.

It's really just an amazing group of people that, you know, really lift each other up and help each other, so. And speaking of groups of people, you're also done a lot with legislative groups as well as nonprofits, the legislative groups.

Do you want to talk at all about Napa or the Massachusetts Coalition for Pans Pandas? Yeah, so I joined forces with a bunch of amazing caregivers in Massachusetts.

And we formed the mass coalition for PANS-PANDAS legislation and we got the insurance mandate passed and the advisory council established. And we have two new bills, first in the country out for a screening bill to have providers be screening for PANS-PANDAS when children present with new onsets of symptoms.

And yeah, it's really exciting. It's in its second session. It just got brought forward again and a prevalence study. So looking at the Department of Mental Health and the Department of Ed and understanding the children who have been in more restrictive settings and have found pans pandas, like what was missed before?

Like, why wasn't it found sooner? And understanding the prevalence in kind of these more acute or treatment resistant cases. So that's really exciting.

And then some of the mass caregivers. So Amanda Crowley is the executive director of NAPA and she and I, and another amazing caregiver, Blake, kind of joined forces with some other caregivers across the nation and established the National Alliance for Pans Pandas Action, which is a national kind of advocacy I'm losing my words on.

Nope, I'm not going to be able to find it, but it's an advocacy group. Right. And so we're really kind of working at the national level to ensure that languages in the appropriations bill at the national level to make sure that NIH is really addressing pants pandas research.

And we don't have money earmarked yet, but we're really advocating for that. So, yeah, I really find the legislative work to be really powerful and exciting.

That's amazing and so necessary. I mean, we really need more research as evidenced by the AAP report that came out recently that was really pretty incomplete and not including any research since 2017 or any of the things we really know about the evidence-based information on these diseases.

Yeah, incredibly disappointing. Yeah. So, and, and then you're also on a couple of nonprofit boards which I of course have have such love for both the look foundation and the Alex man full fun Do you want to mention anything about either one of those.

Yeah, I just, I think that. I am so honored to be on those boards. I first joined the Alex man full fund I was so grateful Susan asked me to join and just the work that were that I'm able to be part of the the research funding for Dartmouth for Georgetown.

is just really amazing it's just amazing group of people really doing amazing work and the look foundation. With Jennifer vitale who's the executive director and just that whole group being able to give grants and provide support to caregivers is.

Advocacy, Legislation, and Nonprofit Work

Amazing. So it's kind of like bookends, you know, being able to support with the research piece and then also with the caregiver support is really important.

Yeah, and the grants. I mean, I think the the grants that that look is doing because this can be very expensive. I mean, often. Sorry. It's so inequitable.

It's just inequitable, right? Like, I don't know how anyone sustains it. Like, even doing this work at Dearborn and helping people get the medical rule-outs that they should have, right?

You then kind of turn and realize, oh, gosh, where are the treaters? Because, I mean, you treaters are such heroes, you know, and there aren't enough.

Yeah, it's hard. And we're expensive. I mean, as much as I try to give discounts and grants and everything else to everybody, it's still, it's tough. Yeah, no, it's hard.

I mean, it's just, it's a challenging space right now, so yeah. Yeah, yeah. And anything else you wanted to mention about Dearborn or anything else you're doing there that we haven't talked about?

No, I just I love the team I work with here. They're amazing. I mean, our caregiver support like we definitely we actually ended up bridging in with the Stanford group to get an understanding of that trauma group that they put forward Dr.

Margaret Theumann and She, they did such an amazing job understanding the caregiver index burden for pans pandas and really it's so relevant for mental health globally so we we kind of run a caregiver trauma group here and and then just lots of supports for caregivers we just think it's so important.

So, yeah, yeah. Well, we've mentioned a lot of stuff, and Sheila, you are such a plethora of information, and we'll have the information on how people can find Look, how they can find the Alex Manfill Fund to donate, because that is important if you can do that, as well as the information on Napa and what you're doing in Massachusetts if somebody's fortunate enough to live there.

So, and how do people find you or find Dearborn or find any of these that you want to mention? Well, Dearborn has a website for sure. And I have a LinkedIn page and I actually, I just had, it was another Pans adult that I've become friendly with.

She actually helped me set up an Instagram, a professional Instagram page. So I am on Instagram now. You can find me there. I'll have to find you. Yeah, I know it's exciting.

I haven't posted anything because I haven't had any time, but you know. But it's exciting. And I have to give a shout out to Elise for helping me out because she was like, you need a professional page.

I'm like, I probably do. And you could easily put some of the information from the blogs that are on psychology today. I mean, there is some really good information there.

If anybody hasn't read that, I really like the blogs. The most recent one was the one on school avoidance and

anxiety. And then the Panda's blog last year, really good stuff.

Yeah, thank you. Thanks, Nancy. Yeah. And what is your new tagline on Instagram so I can add you when you do finally post? What is it? Oh, I think it's just Sheila Gouch.

It is. It's just Sheila Gouch. You can find me. I'm easy. Yeah. Okay. All right. All right. That's so funny. I don't even remember that. Yeah, I hear you.

I hear you. Well, Sheila, thank you so much for all you do. Thanks for being here. Thanks. Thanks for being on this journey, you know, and thanks to your kids for helping you get on this journey.

Yeah. And for them allowing me to share parts of their story. They're very, you know, it's hard. Like you said, it's a challenging, challenging illness to wanna.

talk about, to be honest. Well, we appreciate everything you do, and thanks for being here today. Thank you so much, Nancy. Thanks for having me. All right.

Take care. Thank you. Thank you for tuning in to Doctor Talks. We hope today's episode has enlightened and inspired you on your path to optimal health.

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