The ‘Total Load’ Theory Every Parent Should Know Transcript

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Introduction to Demystifying PANS and PANDAS

Why aren't we studying these end of ones? Why aren't we studying the individuals that are getting better? Why aren't we looking at what helped them? What got them better?

And we know all children are different and they're bio individual. So it's not going to be maybe the same exact thing for your diagnosis, even though you've got the same diagnosis as the person next to you or their child, yours might be coming from a different place.

It might be coming from a deficiency. It might be coming from an exposure. It might be coming from a genetic vulnerability that made that exposure more detrimental to you.

So bringing that awareness to parents that have had to kind of create and earn their own wisdom about that. It's like rather than reinventing the wheel for each child, how do you give a foundation for the parents of all those perspectives?

As Beth said with the flight study, we tried to make that more simplified as not acting as the clinicians, but bringing a group of clinicians together to help to facilitate their collaboration around this child.

Welcome to Demystifying Pans and Pandas, the podcast where we uncover the mysteries, breakthroughs, and hope behind these life-altering conditions. I'm Dr.

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

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

If you've ever wondered what's possible for your child, or how to find answers, this is the place to start. Let's dive in. Hi, everybody. It's Dr. Nancy O'Hara, and I am thrilled to invite two wonderful people from Documenting Hope.

One is Dr. Heather Room, a wonderful physician who has dedicated so much time to this group and to our children with autism. And the other is Beth Lambert, who many, many years ago, my old conventional group called me to say, we're referring you a patient.

And she's crazy and good luck. And that person was Beth Lambert and her wonderful children. And Beth is anything but crazy and has taken everything she learned in the functional medicine world for her own family and taken it to so many new heights with documenting hope and all of the work that they are doing.

So I'm thrilled to welcome both of you guys. Thank you Nancy. So can you just introduce yourselves and how you got here to what you're doing today?

Beth Lambert and Heather Room Introduce Documenting Hope

Sure, I'll start. So Beth Lambert, I'm the founder and executive director of Documenting Hope. And as Nancy mentioned, I started this whole journey because I had a child who had health issues, actually two children that had health issues, and I landed in your office, right?

And that's how the whole journey began where I was introduced to the idea that many of these conditions that we believe are you know, intractable, that there's nothing you can do or actually treatable.

So from that moment over 15 years ago, I think now, I have been on a quest to try and bring some of the solutions that you all are doing in your practices and that these families are doing on their own out into the world and letting parents know that there is hope and that there are things that you can do.

So now Documenting Hope provides a lot of those resources to parents, educational resources, connection to the practitioners like yourselves who are doing the good work, of helping these families and trying to do some original research to point to why our kids are so sick and also what we can do to help them.

I'll lead it to Heather to do her intro. Yeah. Thanks, Beth. It's wonderful to have Beth as our our director and the vision kept alive that there are people that really need to hear that there's hope for their children and that they can be a part of the hope for other people's children as well.

So that has been an underlying thread that has really driven all of us in that mission in our work at Documenting Hope. I'm a family physician trained in Western medicine, medical doctors, so I have seen all ages throughout my career and I stumbled upon in some ways the pediatric world of biomedicine or the bioregulatory medicine or whatever we called it, biologic medicine at the time before that was a bit co-opted by the pharmaceutical companies as a form of drug.

But looking at the reversibility of, as Beth said, symptomatology in children with chronic illness, autism and otherwise. So the early movements with people like you speaking, Nancy, and I remember visiting your office probably 15 years ago as well when you were delving in deeply to other means of looking into what is disrupting this child's life and how do we go about regulating that or setting that straight for them.

So that movement of doctors who were seeing and other practitioners and researchers that were seeing children have their health and lives reversed in a positive direction.

And as Beth said, was sometimes what we think of as irretractable conditions really led me deep into that as a lens to medicine, not just for children, but for adults as well, that across the board, the things that were impacting our children were having impact also on our adults.

And so it not only gave hope in the world of pediatrics, but in the world of all ages, you know, so many things that we kind of took for granted that you're just a bad luck diagnosis.

So in my practice, I really leaned into all the things I was learning through this movement of people like yourself who were teaching out there and saying, this is something we can do something about.

We can address all the different systems of the body because they're all interfacing. We can look at the intestinal tract as affecting the mental health.

We can look at toxins in the environment and or our diets, that kind of thing as how they're impacting our functionality. So that to me became like a blue book or a model for how I saw medicine.

Beth came into my life when she wrote her book, A Compromised Generation. And I said, oh my gosh, she's writing about this very thing that I'm seeing as well.

And I support her work. I think what she's doing is amazing. So I was always on the sidelines supporting it as an advisor, as you have over the years too.

And then formally joined as the medical director when we kind of got deeper into the science of what's happening with our kids. Yeah, and it's so important.

And so just the name documenting hope is so impactful and I think so important. And you're doing so much to maybe uncover the root causes for more people.

So let's start by talking a little bit about the CHIRP study and its potential for uncovering root causes, contributing

factors, even in pans pandas and autoimmune encephalitis.

Yeah, I'll dive in on that. So there is so much medical literature, as you know, that points to various environmental factors that are related to, correlated with, precipitating all these diagnoses, autism, pan-spandas, autoimmune conditions, what have you.

Um, but no one's really looking at kind of the total picture. They might be looking at like, okay, what, what do antibiotics do and how that affects health outcomes?

What does BPA do or, you know, in terms of somebody developing autism? So it's like this really singular, you know, one cause one effect kind of mentality.

And we've all known for a long time that it's not really about one thing. It's about many things. It's a cumulative and synergistic effect of living in the modern world that's creating an entire generation of sick people, but most importantly, sick children like nothing we've ever seen.

And so we designed a study called the CHIRP study, which stands for Child Health Inventory for Resilience and Prevention. And what this study was meant to do was survey how families are living in the modern world.

It's really actually focused just on in the United States because each country has its own cultural way of living.

The CHIRP Study and Total Load Theory

So we're starting in the United States. And it's the most comprehensive environmental health survey that I know of that asks parents to fill out. It takes several hours.

It's a survey that asks about preconception health of the family. It talks about prenatal health. It talks about the neonatal period and what kinds of exposures might the child have?

Was the child in the NICU? Did the child get, you know, skin-to-skin contact after birth, like all the little minutiae of daily life and potential exposures, it takes a broad survey.

And then we take that data, we've been running that study since 2018, and we've gotten some preliminary data, not enough to publish on yet, but we're hoping to enroll as many people as possible so that we can have enough to publish on.

But we've taken that preliminary data to say, okay, well, what is it that causes autism? What is it that causes ADHD and what's the difference? And one thing I think we can say, again, preliminarily is that it truly is the total load of modern living that is creating this epidemic of chronic health conditions in our kids.

So we have a lot of work to do on the CHIRP study, but it does get us closer to understanding the root causes. And it really allows us to lean into this understanding that it isn't one thing, it's many things.

and sort of the combination of those many things will manifest in some kind of disease diagnosis, symptoms, et cetera. So lots of work to do there, but it's a really exciting platform that we're gonna continue to build on.

Yeah, and I think it's so important because you're right, especially in conventional medicine, we look for one-to-one, if this, then this, but in our bodies, in our world, It is a total load theory.

I mean, in our kids with pans pandas, it's not just strep. It's their gut health, their immune health, their lack of immune tolerance that leads to that strep infection causing the neuropsychiatric symptoms.

But we have to understand that total load because if it's an immune intolerance, well, they're not going to do well with the mold in their basement or the pollen or the horrible diet that they may have fallen into.

So I think that that study is so vital to getting at all that little, what may seem like minutiae when people are filling out all of this data, but it's really important in uncovering all the contributing factors.

Technically, it's a questionnaire. It's over 1,000 questions right now as it stands. We're doing some revision to make it even more streamlined for data purposes.

But it's so mixed together. It's creating an opportunity to collect as much data as possible and then start to find patterns within that data as opposed to, like you said, that very linear form of research.

And probably, practically speaking, that type of linear research is much easier. It's hard to do something that doesn't throw the noise out in the background.

We know from science, you start to throw the noise out and you actually might be missing part of the patterns that are so important. Like we used to throw the junk DNA out because that's not functional DNA and then we realized that's actually DNA that's informing the rest of the DNA.

The other thing that you don't often see is this kind of research in pediatrics. And so a lot of what we need to know about our children isn't really looked into because we're dealing with these precious little things that we won't do studies on or trials on.

So that more of an epidemiologic perspective is probably one of the more useful ways to go about understanding and seeing what kind of floats to the surface in terms of what are the synergies, what are the collective things.

And it also just reinforces that it's valuable to care a lot about EMFs or it's valuable to care a lot about whatever it is that you care a lot about mold and learn a lot about that and learn from the experts that have really delved into that.

But it's even more important to just say, everything matters some and so how do we take the the total load down and give this body a chance to breathe a little bit because it has the fundamental components to be an amazing human body.

It really you know we come with the fundamental components so how do we in you know in a way it's the uh Michelangelo quote you know when when asked How did you ever create the David out of that block of marble?

And I think Michelangelo said, you know, well, David was always in there. I just chipped away the excess. So if you kind of the total load is the excess is how do we unburden our children of this total burden so that they're David, so to speak, can come forth in the marble.

Sorry, go ahead. I know you see that in your practice, the beauty of what we didn't know was possible in the healing of these children. Absolutely. And it reminds me as you're talking of the whale watch.

Back in the old defeat autism nowadays, we were always accused of whale watching, which just means we're all on the boat. Wait, the whale's over there.

That's what's going to cure our kid. Nope, the whale's over there. Nope, the whale's over there. And the boat's about to sink because we keep looking for the answer.

And I think the total load is so important. And I also want to talk a little bit about the flight study that you're doing as a way to test this total load theory.

Can you talk about that a little bit? Yeah, so the flight study is building on the chirp study. So if we know that there's many, many variables out there that are contributing to the symptoms and diagnoses of our children, what happens if we remove many of those environmental variables, the ones that are toxic, the ones that are stressing the immune system or stressing the body?

and do that in a bio-individual way. What happens if we change the lifestyle of these children? What happens if we

change and make everything supportive of their health rather than detracting from their health?

So we actually piloted this study in two children. um to test this hypothesis like what happens if you reduce a child's total load um one child had autism one child had uh alopecia universalis which no hair on this body anywhere is on immune condition um and we ran them through a program of 18 months where we tried to give them bio individual assessment of what the stresses were in their in their environment so the church study actually is a requirement to participate in the flight study, where they take this questionnaire and they get a personalized report back that highlights or flags or tags all the things that are considered stressors to their health.

And so that's sort of a blueprint for where do we even begin? We take out the toothpaste with fluoride. We take out the artificial colorings. We take out the mold in the environment.

That's just how you start kind of peeling back the layers of the onion. And then these children each got a set of functional assessments and Heather could talk more about that and to see where the amounts are.

Right. And then we walked them through this program where they were supported as the family attempted to make some of the changes and adjustments to the life.

We're responding to the test, the lab tests they have to see if we could move the needle in terms of symptoms and diagnoses. We have brought that pilot to a conclusion and we are now in the process of redesigning the study to make it more accessible and easier for families to participate in so that our objective with this study is to scale this, which is to say, we want to be able to teach the families how to identify the total load factors.

We want to teach the families how to remove those total load factors. And we want to teach the families how to support their children in a bio individual way.

So our new version of the flight study, which will be launching later this year, will enroll 12 children who have an autism diagnosis. So we're really going to focus in on autism.

And the central intervention in the flight study is a parent education program and health coaching support. So again, really emphasizing what's going on in your life, your specific life that might be contributing to your child's symptoms and what can we do to mitigate that.

So that study will, like I said, be launched later this year. It will be nationwide and we will be enrolling up to 12 children.

The FLIGHT Study and Parent-Practitioner Collaboration

Our hope is to do another version of this study after we conclude this one, after we demonstrate that these total load, moving the needle here, addressing the total load factors actually makes a difference in the children's symptoms.

And then we hope to enroll a much larger cohort in the future to really, again, see, can we scale this? Can we bring this learning? Can we bring this health coaching support out in a realistic way to the community of people that need it?

Right. Right. Go ahead. No, go ahead, Heather. Well, I was just thinking, no, really, it started. Beth, wouldn't you say that there were after you wrote your book, there were many parents who had been on these long journeys and seen great results with their children.

And you said, we've got to capture this. Why aren't we studying these N of ones? Why aren't we studying the individuals that are getting better? Why aren't we looking at what helped them?

What got them better? And we know all children are different and they're bio individual. So it's not going to be maybe the same exact thing for your diagnosis, even though you've got the same diagnosis as the person next to

you or their child, yours might be coming from a different place.

It might be coming from a deficiency. It might be coming from an exposure. It might be coming from a genetic vulnerability that made that exposure more detrimental to you.

So bringing that awareness to parents that have had to kind of and earn their own wisdom about that. It's kind of like, rather than reinventing the wheel for each child, how do you give a foundation for the parents to, of all those perspectives?

And as Beth said, with the flight study, we tried to make that more simplified as not acting as the clinicians, but bringing a group of clinicians together to help to facilitate their collaboration around this child.

And now it's a bit different focus. And it's like, how do we, help the parents bring that. And yes, you're very involved with the MAPS organization. How do we connect those parents with MAPS type physicians who have been trained with a broader, more functional, more integrative, holistic, whole systems biology that it's not just a specialist in one field, but how to bring that all together.

So that's played out in the first flight study and then the second flight study is just a different way that we're hoping to go about that by empowering the parents and also helping the practitioners that they work with have more easy access to those things.

We kind of hand delivered it for the first two, like here's this amazing group of practitioners in the area that can look at you from 360, can look at your reflexes, can look at your neural development, can look at your brain waves, can look at your diet, all this wonderful group of people around you, that 360 support group.

And now it's more, how do we help parents see what's possible and navigate that without overwhelm because as you know as well, how many people do you get in your office that say, you're my last resort or I've tried everything or I didn't know there was a possibility when their child is 32 that they could have done that at age seven.

So it's as Beth said, scaling what you're doing in your curriculum and educating physicians and practitioners. And, you know, I think we're all learning that you can't support one without the other.

The practitioners need to be supported. The parents need to be supported. The teachers need to be supported. You know, there's just It takes a village set up.

Yeah. And I think the flight study sort of encapsulates what we see as the vision of how this problem gets solved, how this epidemic gets turned around.

And it is not like there's these magic doctors out there. They're going to fix it all for you. It's not like the parents can navigate this totally on their own.

It's a partnership between the parents and the practitioners. That's where the magic happens, because the parents have the biggest stake here. They also know their child better than anyone else.

And they should be in the driver's seat really tuning into what their child's needs are. But they need the help and support of the educated practitioners who have been pattern recognizing for decades, who have the training to understand how to help them correct these imbalances.

So the partnership there is how I think this needs to happen in the future. And it would be amazing if we could prevent all these conditions. But we know we have a tidal wave of kids coming down the pike who have all these imbalances.

So let's create something where the parents and practitioners can work in collaboration to help reverse it. Yeah, yeah. And the collaboration is so important.

I mean, people have been watching and listening to this podcast know that I always call myself a GPS, you know, because I'm not driving the car. I may help the families to see the best route to go down, but they're on the front lines.

We have to work together and the families have to know my kid can't do this. I can't do this. I can't do it financially. I can't wrap my head around this.

But to empower them with the knowledge is just so important in reducing this this total load, as we're calling it, that each kid goes through. Because the other thing that comes to mind as you're both talking is, you know one kid with Panzer Pandas, you know one kid with Panzer Pandas, you know one kid with autism, you know one kid with autism.

And that's always been the problem in the training. There isn't, and in my opinion, shouldn't be a protocol Yet, I love what you're trying to do and help give guidelines, you know, of bringing to these families the things that may help their child, their N of 1, get better.

Yeah. And you know, so much of the issue is cultural, right? Like the way that we live in the modern world. So, you know, the people that are best poised to change the way we're living are the people.

We just have to learn a new way of living that's different from what we grew up doing. You know, we're a generation of people that grew up with you know, synthetic consumer driven society where everything was like shiny and plastic and pretty colors and all that's how we grew up.

We don't know any different. It was an educational gap, which we have to close. And I think that the parents are thirsty for that information. They're looking for that information.

So that's where we're hoping to fill in is give them that information. And beyond the information is the practicality. I think there's a couple things.

One is people need to know they're not alone because there's like in the siloed way that we've kind of even handled medicine, you know, you go off to this specialist and that specialist and there's not crosstalk between them, but just like there isn't an understanding of the crosstalk in the body between different systems.

So one is to have a lens to see that, but to bring the conversations together into a community and know that you're not alone and that there are actionable steps.

So it's one thing to have knowledge. But great, I can't access that specialist. It's not that. There are concrete things. We wrote a paper not too long ago, and you see the way that it was just a case report.

It wasn't a study, but it was looking at what parents in and of themselves, how much they moved the dial by the steps they took. practical steps into their diet and lifestyle primarily.

Those practical steps we can all do that aren't out of reach. There's a place to start and you're not alone. And I don't think people get either of those messages.

Where do I start? And I'm the only one that's You get a diagnosis, I just had a parent in the other day and it was like, I got the diagnosis, your child has autism and then they closed the door because they didn't have anything else to tell them.

They just said, sure enough, see ya. So that's rough when no navigation, no guide as you said. And so it isn't that you're guiding them all to one way of doing it.

It's you're just opening up that there are possibilities and think so much that we can take into our own hands. And we're putting our belief in that in this study because it's not about making sure that they do see this kind of specialist or that kind of specialist.

That may or may not happen with all of these kids, but we're trusting the hypothesis that if you get that support around the lens of what resources are available to you and think of them in the context of your whole child and your family.

And that's one other point that I wanted to make is that that child is not isolation. You know, they're part of their parents' regulation. And as you know, maybe there's a propensity or a vulnerability built in even before.

And some of these parents trying to navigate that are trying to navigate modern life themselves. You know, most of them, all of them. So it's not just the child-centric.

It is. It's the family unit. It's the community unit. There's a ripple effect. There's a financial effect. Beth could probably speak to a lot of the statistics around where we're headed if we don't make a change.

Absolutely. And I think the other thing is that 360 approach, that providing them with the lens that there is support, whether it be other parents, other practitioners.

I mean, one of the things in my own practice as I started using health coaches and where I was thinking, you know, I know everything there is about mold.

I mean, I don't mean it that way. I don't know everything there is about anything. But I thought, you know, through my work with Jill Christen, Neil Nathan, I pretty much, and my own homes, you know, three of which I've had to remediate or sell for the land.

Documenting Healing Stories and Case Reports

But once I started working with a health coach who could help that family and sort of spend more time figuring out the intricacies of their own home, it was a game changer.

It made a huge difference for not just the index case, not just that child with pans, that that total load of mold was part of this, but also for the grandfather that was living with them with advancing Alzheimer's, which all of a sudden got a little bit better, and the other child with asthma and allergies that also got a little bit better or a lot better.

So it is the whole family and it is the whole 360, it takes a village. Yeah, the ripple effect too, like you said, like even just, you know, Beth has been very strong since she's been with this, or created this organization of documenting with testimonials and granted, you know, their testimonial isn't your testimonial, but it does give hope.

and so many stories come back to us. You know, I saw that that parent could do it and I knew my child was in there. I knew I could do this too, but I didn't know how.

And I saw that that mother or that father persevered and that that child got to be its full potential. Bailey, my daughter's name, Beth and I are speaking with a group in England and it's about It's about optimizing the health of individuals, not changing whatever that…

It's optimizing the health of the individual, regardless of their diagnosis, regardless of their… Neuro difference, you know, it's optimizing function in their life so that they can enjoy it so that they are not suffering, so to speak.

It's relieving that it's, it's giving, you know, we all have the kind of birthright to live the best life. And you brought up the importance of documenting and that's something else that you guys are doing so much of is the importance of documenting these healing stories and research collaborations and research papers that you're publishing.

Can you talk a little bit about that too? Yeah, that's such an important piece because I think the experience of so many families is they'll, you know, like Heather, you described, they go and they get their autism diagnosis and that's it, like, see you later.

And then sometimes the families will come back and say, well, I heard that the symptoms of autism were reversible

or I heard about this childhood who did a gluten-free, casein-free diet and overcame autism.

They have these things to share with the doctors and then typically the doctors will say, you know, the more conventionally trained doctors will say, well, I don't, there's no evidence to support that.

Which isn't totally true. I mean, Uniancy published a paper in 2008, we're talking about. There's a handful of papers. I mean, a couple of people have published on the reversal of autism.

We just published a paper last year on the reversal of autism in a set of twins who are level three or severe autism. And this is really important to us that we build this body of evidence, whether it's through case reports or whatever we can do to try and really make sure that what's actually happening in the field is getting into the medical literature.

But even it doesn't have to be just in the medical literature. We have been documenting on our website for 15 years, the stories of people who have overcome all kinds of conditions, not just autism or pans pandas, but life threatening food allergies and rheumatoid arthritis and MS and like all these things that everybody hears that there's nothing you can do about other than take some biologics or take some kind of pharmaceutical symptom suppressive therapy.

And we know that's not true. And when these stories are out there, if you look at our website analytics, for instance, you can see that that's one of the places people go to, they want to hear the stories of people who've already been there.

What did they do? Is this really possible? So that feels like an important piece. of what we can do in the world while we're working on getting more case reports published.

We have a second paper about autism reversal that we're trying to put into peer review right now. And it's about a boy who used specific carbohydrate diet as one of his primary interventions.

So the gut healing and all those pieces. It's never one thing, right? It's not like the specific carbohydrate diet is the trick. But in particular family, this was an important part of their journey.

So we're going to continue to push those kinds of case reports into the literature and do what we can to document what's happening in the offices of practitioners.

But at the same time, we're also going to keep collecting these success stories. They don't even have to be success stories. They can be healing wins.

A child had a tic that was debilitating, and maybe all the symptoms didn't go away, but the tic did. That's a win. That's huge. So that's an important.

And I think that's an important piece for families to keep in mind, too, that that, you know, we've talked a lot in this podcast about documenting some of the symptoms, you know, about the the plethora of questionnaires that people have to fill out and all of that.

But but why that's important is sometimes when you're stuck in the mud with it, when you're in the the throes of the disease, pans, pandas, autism, horrible food allergies, whatever it may be, you don't see the little wins, the little successes.

The ticks are much better, yes, there's still a lot of OCD and they're still not healthy, they're not totally healed, but documenting those little successes and building it up.

We often talk about, it's just a little turd, it's just a little thing, A big pile of turds is a big pile of, you know, SHI, you know, and we need to do the same thing in the other direction is reminding ourselves that we are taking steps when we do this hard work.

Yeah. And when you document things like, let's say you're documenting your child's symptoms, when you document that and you note that, you know, symptoms go away, it gives you that, you know, that that power to keep going.

It gives you the motivation and the incentive. I was actually we were on a call this morning. We have a a membership community where parents can come in and get support and they can join live calls, Heather hosts one once a month.

And then we have health coaches that host live calls with parents, parents who are going through their healing journey. And one of the parents was like, we're stuck, we're not making any progress, we're not making any progress.

And then as we sort of unpacked what this child was doing, the parent all of a sudden self-reflected and was like, oh, actually, yeah, he no longer has that symptom anymore.

So it was like, if you were documenting these things, you would be aware of the little wins and then you'd see the trajectory you're on and you'll see you're going up, you're going on the right path.

So it's important for documentation in terms of gathering evidence for posterity, for publications, all that, putting the science behind this work, but it's important for your own motivation and your own inspiration.

If you can see that you're making changes, it keeps you going. Exactly. The other aspect of that, Beth, is the patterns, because just like the CHIRP questionnaire is for us to look at all of this information in context and see patterns.

And as you, I know, did with your own children, you log their diet and their diet changes and things like that, and you log what other symptomatology they're having.

Nancy knows this also from being a doctor that people forget what went away that wasn't pleasant, even if that's what they came to you for in the first place.

It's because now there's something else that's bothering them and maybe they've already taken care of the first thing. Yes, to keep track of the winds, but also to start to look at patterns.

I would have never thought of that, but every time we go to grandparents, the symptoms are lower is it because grandparents are relaxed or they're getting a different diet or there's no mold there you know like there's a pattern that starts to emerge it's like that's so strange every time or I notice if this happens first or it's when we're in that car you know like you start not that you have to you know we had one one person at our conference say I stopped writing everything down because I'm such a type A person that I was documenting so much that it was making me crazy.

So you have to find the balance of keeping track of some things that are changing, like symptom list, intervention list, change of medications or supplements, or bringing in a new modality.

So those big shifts, if you can capture that, Even that smiley face, brown face, how did they wake up this morning? And a scale of 0 to 10 or 0 to 5 or a check mark, an X, something simple that helps.

Because when we're talking about children, for instance, with pans and pandas, when they fill out the questionnaires or or talking about the disease, they often don't realize, well, yeah, he started bedwetting at the same time that these ticks started, or yeah, all of a sudden he wouldn't go to sleep at night, and they didn't even realize they were related.

And then when the ticks aren't better yet, but they're sleeping better, reminding our families that this is a marathon. Right, and this isn't a sprint.

And sometimes that infection that happened six months ago. Yeah. Just we, yes, yes. Yeah, it's all impactful.

Parent Support, Resources, and Community Programs

And I think it is that balance between getting mired down in all the details and getting to type A or OCD about it, which I am very guilty of, versus not even thinking about all the factors.

And I think that that you guys are doing such a great job of that and helping families to both document and to share their stories. Can you, I mean, you've mentioned sort of briefly, you know, the chirp and the flight, but there are other ways, like the webinars you guys give, the support that you give to families.

Can you talk a little bit about that from documenting hope's perspective? Yeah, so we're a platform, an educational platform that's kind of like, come and get what you need.

So if you're like, I don't really have a lot of time for this, I just want to read an article here or tune into a webinar there. We have free webinars with people like you, Nancy.

Sometimes we'll do them with Heather or whoever's got the latest kind of information we want to share with parents. We bring that to our families at a live webinar.

We have a practitioner directory. So if you're looking for a practitioner, we have a health coach program where we teach health coaches how to support families as they walk through their diet and lifestyle changes.

And one of my favorite Aspects of what we do is this membership community. I mentioned called healing together. So this is for families who want to be a little more involved.

They want a little bit more support or a little bit more of a community so they can join our membership community and then they can get access to a lot more detailed kind of process-oriented materials that help them make those changes.

So like, you know, guidebooks on how to change your diet, guidebooks on how to get your child to poop, guidebooks on how to detoxify your home. And then we do live calls as a community.

So parents could come on and be like, you know, I'm interested in pursuing mold as a possible factor in my home. How do I do that? We have health coaches that will be there for that.

And then Heather and Dr. Medea Saeed host a live call once a month, which is such an unbelievable opportunity for these families. I think Heather used to do like a radio show, right, where people could call in and ask questions.

And it's kind of that. And it's really, it's really lovely. I mean, I just seen such people just feeling so supported and heard in these communities. And so what we're trying to do is build more of that.

So we're kind of like building as we can, and we're a nonprofit organization, and we're trying to raise money to put more supports in place. And our goal is to help have the full spectrum of like, a la carte, come get some resources at your own speed too, like very concierge, meaning you need a lot of support, here we are.

So that's kind of where we're building. That's great. That made me think of the Khan Academy of Pediatrics. I need a little help with my algebra. Do you have a webinar on that?

Right. No, but it is. It's the Khan Academy of Healing Our Children. Exactly. It really is. And great resource for families with any types of issues. And then you also have what you call documenting your own hope.

Can you just mention about that too? Yeah, so, you know, it's interesting when we published this paper last year of the twin girls who had overcome their autism.

This was a family who was very good about documenting everything, kept all their labs super organized, you know, did food journaling just on top of it in terms of documenting everything they did for interventions and the outcomes they saw from the interventions, etc.

And so that really inspired us to create a template that we have on our website where parents can or are encouraged to document their own hope. In other words, did you take an ATEC as soon after your child got diagnosed or has your child had the ADOS done and what are those numbers?

And do you have, here's some ways that you can keep track of your labs and are you keeping track of any kind of symptom changes? So it sort of provides a way for parents to document their own hope.

Our dream is that parents will do this and then come back to us after. 18 months, two years, seven years, whatever their journey is, and say, I've documented my child's journey.

I'd like you guys to turn this into a case report so we can put this into the medical literature. We want to partner more with practitioners who are doing this work, but it's not getting done.

You know how many physicians see this kind of miracle or these kinds of transformations happen in their practice, but then a lot of times the families don't want to talk about it later because of the stigma.

you know, or they're like, that's fucked up. We don't wanna do that. But we know we need to document this stuff so that future generations have something to stand on and have guidance.

So that's a super important part, documenting your own hope. Yeah. Chronology is really important, so order of things. Even that family that did such a tremendous job of keeping track of all the things they did, it was still a great deal of work to put it in a chronological order.

I would encourage that as well. It's like a journal that you keep a chronological, because the chronology and the context is so key. Just like as we learn about the total load, it's the whole milieu of the human body.

It's the mitochondria, it's the intestine, it's the neurologic system, it's the immune system. They're all just branches of the same big system. They're one big system of systems.

In that same way, it's really important to keep a context of the milieu of the child. What is the bigger milieu? What is the bigger environment that they're in?

What goes in? what their exposures are. So kind of like, you know, we don't expect anyone to keep the kind of detail that the questionnaire asks in CHIRP.

We're asking a lot to have parents remember those things. But some level of kind of sequencing is very helpful because it's like, Oh, I don't remember when they had that antibiotic relative to when they started to wet the bed, you know, but when you just, Oh, kind of keep a journal that has some kind of order to it will be really helpful.

And a replica. But there are also ways to get that information. And I also, I really want to put out a plea to the practitioners that may be watching or listening that if you have these cases to work together with somebody to get them reported, to get it into the literature.

And yeah, I wrote one in 2008 and one again last summer. So I try to walk the walk as much as possible rather than just talk the talk. But we all need to document more and to put these case reports out there to really let more and more people know that healing is possible.

whether it's pans, pandas, other autoimmune conditions, autism, whatever it is, healing is possible. Even artificial intelligence, you can only be as intelligent as what's fed into that.

If we haven't fed into the literature, then of course it's not going to auto-feed and recreate or bring together these

different things that seem disparate, you know, we need more, more.

And there's some hurdles, you know, for getting into the journals and their costs and things like that. So that's something that needs more love as well is that ability to facilitate because we don't go into medicine necessarily to publish.

We're maybe not even good at that. Some may, those MD-PhDs, but not those of the ilk of you and I. And it takes a lot of time and effort to do those publications.

It costs money to put those publications. It's like $3,000 or $4,000 just to put it in to be reviewed. And that's actually, we're raising money so that we can do more of that.

So we can partner with those practitioners who do want to publish. And our scientific director, Dr. Chris Dodomo, he's published over 100 papers. And he knows sort of how this whole process works.

And if there are practitioners out there who have good case reports they'd like to do, we're trying to raise money to make that happen. And Chris Dodomo can certainly help facilitate that process.

Yeah, and that's so important too. And we're also, Nancy, reaching into government data like CDC and NHANES.

Final Advice, Hope, and Closing Remarks

And so there's a lot of data collected that is not being utilized for the use of knowledge or moving medicine forward. It's just because nobody's tapping into it and taking a look at it, what kind of patterns are happening there.

So we're very excited about that possibility and exploring what's these large amounts of data that aren't generated by us that have already been captured and just haven't been looked at through the lens of total load, for instance.

People are a little bit terrified of doing research around children. There's tons of government data, like you're saying, Heather, on children's health and environmental factors.

But it's a little bit dicey. So I feel like people need to take the lead on that. And we want to do that because it feels like there's a giant void. People aren't doing the research on that government data the way they should be.

So that's something we're trying to raise money to do as well. That's great. So if people wanted to donate, if people wanted to document their own hope, if people wanted to find out about the CHIRP study, the flight study, or anything else, the website is, it's all on the website documentinghope.com.

You got it, documentinghope.com, yeah. And also people follow us on like Instagram or X or Facebook, they'll get a lot of, you know, new things that are coming out too.

Yeah, you do a great job on those social media platforms too, Beth. So are there any last words of hope, of wisdom, anything you want to leave our families with?

Leave the families and the practitioners. We weren't trained in this, none of us. But just as the families, there is hope for you to take steps toward understanding and helping your child.

As practitioners who went through Western training and didn't get this, there are steps you can take. Yeah. The last thing I would say for any parents that are listening is believe in your child and believe in your child's capacity to heal and your family's capacity to heal.

And believe in yourselves. Yeah. Yeah. Yeah. And as you're believing, also care for yourself. Put your oxygen on. Yeah. And know this can get better, but every day find that one little inkling of gratitude too.

As I was talking to Gabriella True of aspire.care and as she was saying, you know, some days it's, you know, I

stubbed my toe, but at least I didn't break it, you know, or I broke one toe, at least I didn't break 10. There's something for us to be grateful for and to hope for every day, whether our child is still deep in the mud or whether they really are getting better.

So thank you both. I heard someone say today, if you're making the habit of flossing your teeth, just even if you can get two teeth done, just start. Call it a win.

Exactly. I agree. I agree. I get the bottom four. I get that. I got it. Start. Well, you two are both such incredible and wonderful women and so powerful in all of you that you do.

So I really appreciate you being on the podcast and appreciate all that you both do. Likewise, we appreciate it. Thank you. And a mentor and an example.

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

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And 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 time on Demystifying Pan's Pandas.