Introduction and guest welcome

practitioners. You're going to need to support the parents PTSD as much as the child's PTSD, because it is something that has just taken their child away, stolen their child out from underneath them.

And, there's they'll talk about it, you know, oh, it's Covid that's come back. So we have to get them to the point where they don't fear the coming back This is doctor talks.

Real talk from real doctors. Only issues that matter to you most. Hi everybody, and welcome back to Demystifying Pans Pandas. I cannot tell you how honored I am to have doctor Sue sweet with us today.

Although Sue needs no introduction. She has authored hundreds of publications, including the seminal paper on the first 50 children with pandas 27 years ago.

She's a former chief of the pediatric branch at the NiMH, and so much more than that. You know, some of us are lucky enough to have several role models and mentors in my life, and many of you know that my parents, both physicians, were role models for me.

Doctor Sydney Baker, Bob Navajo are two of my role models and mentors, and I feel very fortunate that I've gotten to know Sue work with Sue and she is indeed one of my biggest role models.

Not just for her intellectual acumen, her her capacity for research and clinical clinical support, but really for her passion and or her humility. Sue, it is such an honor.

Thank you so much for joining us today. Oh, thank you for letting me be here. And I don't think mentor and role model as much as friend and colleague.

I have valued so much our relationship. Nancy. Well, I appreciate that. So but, you know, I've heard you talk about how this all got started, you know, over 30 years ago.

Origins of PANS and PANDAS research

Can you just tell us a little bit about that for the listeners and viewers? Sure. It was, 1986 when Henrietta Leonard and I joined the National Institute of Mental Health and our, boss and our mentor, Doctor Judy Rappaport, was well known for her research on ADHD and obsessive compulsive disorder.

And she was looking for a medical model of OCD because even Freud had said, this is not just an anxiety disorder, this is something brain based. And so she had focused in on the basal ganglia as the site of sort of coordinating ation of a lot of the abnormalities that were seen in children with obsessive compulsive disorder.

And so she sent me, the pediatrician to the library to investigate the relationship. Excuse me, between Sid and him, Korea and, obsessive compulsive disorder.

And it was fascinating to to read those reports from the 1890s and the early 1900s, including work that was published in The Lancet in Jama describing very clear onset of obsessive compulsive symptomatology.

So we reached out to three sites in the United States that had still had rheumatic fever outbreaks and did a little retrospective study looking at, obsessive compulsive symptoms in children who had either rheumatic heart disease alone or didn't have Korea with or with that rheumatic heart disease, and were frankly blown away to discover that

two thirds of the children had obsessions and compulsions for about 2 to 4 weeks before the Korea began.

So it was real. It was very tightly linked to the Sydenham, Korea. And from there we just launched a sort of a two parallel lines of research, one looking at children, Whitsett and Hem, Korea, and the other one looking at children with acute onset obsessive compulsive disorder.

Well, it is such an important paper and all the other ones since then. But but, you know, I think everybody that's watching this or listening knows or thinks they know what pens and pandas are.

But if you could just go through that in your words and also what they're not very importantly what they're not. Yes. I think right now, I just close my private practice, but I was seeing about a third of the children who had a diagnosis of pans, and that wasn't what they needed to be treated for. So.

Yeah. Excuse me. Pediatric acute onset neuropsychiatric syndrome is a syndrome. And at any time you have a syndrome, you are not making any suppositions about.

Cause, all you know is how it presents and how the clinical course tends to go and pans presents incredibly abruptly and if it isn't within 24 to 48 hours, please don't think about pans.

Think about other sources, including autoimmune and self-reliance of other types, because that tends to be more subacute, maybe over a week or two, or even over a month.

Or is it less pans and is sort of the umbrella? It was actually described later? Almost two decades, but a decade and a half later. And the reason for that was we couldn't get kids treated for pandas because controversy had erupted around the diagnosis.

What PANS and PANDAS are

And pandas stands for pediatric autoimmune Neuropsychiatric Disorder associated with streptococcal infections. And we worked on that acronym a long time.

It is anti-viral, antibody mediated neuropsychiatric disorders of childhood. Again, if I could live my life over, that's what it would still be called today.

And it would just be recognized as one of the forms about, oh, municipalities. And people wouldn't hate us. But we went through petitions, pediatric infection triggered autoimmune neuropsychiatric disorder, and I don't like spit.

And it sounded very much like spittoons. We got rid of that one. And the other reason, more seriously was that we were focusing on the strep rather than viruses or, other causes.

And although we know that that strep triggers pandas, pandas is really an immune mediated illness, not an infectious illness. Can you talk a little bit about that? Sure.

Excuse me. So you describe it perfectly and it's. That's exactly. Well, I just want to hear your words. So I think the infection starts the process. And even in our patients with Sydenham, Korea, there was clearly a difference in the bacteria that was causing the neurologic.

So coli from those that caused only heart disease. And the fact that sometimes they overlap was significant. But even for Sydenham Korea, the American Heart Association thought for a long time about whether or not pure cases of Sydenham should be included in rheumatic heart disease, or whether they should be put to the side, like post streptococcal arthritis and I think if you think of this as post streptococcal, neuropsychiatric inflammation or neuroinflammation, that's probably the best description of it requires the wrong bug in an unlucky child.

And usually there's a family history of OCD, tick disorders, rheumatic fever, Hashimoto's very itis in the mom a lot of autoimmunity in the parents. The children may even have an early history of some relative immunodeficiency,

because we know that early immunodeficiency, increases greatly the risk of oral inflammatory disorders later in life.

And then, that combined because of the the nature of the strep bacteria, which puts antigens on its cell wall that mimic its human host. So this is all the fault of the strep, but it may not even be there by the time the symptoms come.

The strep bacteria hides from the immune system by putting these antigens on its cell wall, but eventually the recognized in foreign. And so those cross-reactive.

And if those antibodies can enter the central nervous system, they can set up an inflammatory response. And that's what's key. And I it kind of mad at pediatricians who don't remember that strep is the classic bacteria to break down the blood brain barrier.

Right. That's why the kids get that will present with just headache and fever rather than any kind of pharyngitis. But it does. It produces exo toxins that open the blood brain barrier, allowing those cross-reactive antibodies to go in.

And then you kind of get a self-perpetuating situation where blood brain barrier may heal, but you still have those antibodies in place. The inflammation is continuing because it's got a ready, source of replication.

So that's how it starts. And that comes on relatively quickly. And if you catch it fast, you can abort it quickly. So I just treated a little boy for my church with antibiotics and, ibuprofen.

And you know, two weeks later he's back playing and having a great time. Yeah, yeah, we miss him. And it takes a lot longer. Absolutely. And and I do want to address that for one minute because you and I agree.

And it is the the moniker of this disease that it is abrupt onset. But I would say in those kids that are missed in those kids that may get it very early on at age three and then, you know, get treated because they also have an ear infection.

They may not have gotten that strep culture, but they got the Omicron.

How infection triggers neuroinflammation

So then they get better and they say, oh, that was, you know, the terrible threes or whatever. I do find that the second, third, fourth later on may be more subacute because they already have that inflammation that may not have been fully treated.

But somewhere in that history there has to be that abrupt onset. Would you agree with that? Absolutely. Absolutely. Okay. And and we we don't want to cheat on that.

It's exactly as you said, Nancy. It's the child who falls apart. I think a classic one is the kindergartner who had absolutely no separation anxiety until maybe, a month after Christmas vacation, if it happened right after Christmas vacation, you might say, oh, well, that's just because they're worried about coming back to school, not staying home and playing with mommy.

But it's a month later, and all of a sudden they just can't get to school, and that lasts for a month or even six weeks, and then it kind of disappears over time.

Or they might have bad tics early on, and then those disappear. And you're right, later it can be a more subacute presentation. And at that point, you actually have to almost stop thinking about it as just a nice clean pans and start thinking about, okay, this child has neuroinflammation, and we need to look harder and broader for the cause because lots of time that one's not going to respond to antibiotics and NSAIDs.

You're going to have to be a little more aggressive in your in immunomodulatory treatments. Right, right. And and speaking of treatment, you know, we all we say and as you so eloquently posted, you know, in your publications,

it's a three pronged approach.

It's treating the underlying trigger. It's treating the immune system providing immune modulatory support and also treating the symptoms. I think sometimes, you know, especially in functional medicine, you know, in conventional medicine, I feel like we treat the symptoms and we forget about the trigger.

We forget about the neuroinflammation. But I think sometimes in functional medicine we forget about treating the symptoms. And we put them on an antibiotic or maybe an herbal for those who can't prescribe, you know, and and we don't do that.

So I think that's a very key piece to. Absolutely, absolutely. And I think you identified that dichotomy very well. I get sad on both sides. Right, exactly.

On the for the children who've been treated with a number of psychoactive medications all at the same time, sort of each one targeting one of the multiple symptoms that came on at the same time and haven't looked at the source.

But then there's also the children who've been on, and it's just an exhausting array of things, including repeated IVIg and have never been on psychoactive medications.

And you're asking that child to suffer needlessly. None of us would, you know, sort of try to treat the cause of the migraine without actually trying to get rid of the pain.

So, right, if we think about it, that way, this is psychic pain. It is incredibly disruptive to that child's life. And it's it isn't just a three pronged approach.

It's a throw everything you have to it to make them better as quickly as possible. I have to say, in the realm of always only starting one thing at a time.

And also you and I both talk a lot about, the importance of therapy, cognitive behavioral therapy, CBT, DVT. And I think it's really important for the parents because one of the things I think we both say is that we don't call it I think you've called it tough love.

I call it not feeding the beast of the disease. And either way, I think therapy, even a parent often will tell me my child isn't in a place they can do that, you know, but they can do it.

And I think it can be so important because you often get the secondary gains, even though the child has recovered from the infection and the immune issue, there may now be many years later, the secondary gains of the disease.

And I also think that OCD, does have a lot of secondary gain. It also just has a lot of, generalizability. So if you've been doing something because you've been forced by this, you know, aberrant signal in your brain and the aberrant signal is gone, but it's become so habituated that you don't have it.

And I've actually had kids more with traditional OCD even than with pans pandas. But some of our pans pandas children will say, I don't know what I'll do when I get well, and they're afraid of not having these rituals to feel so relaxed, so cognitive behavior therapy is huge.

For that. I think your your caveat about helping the parents really understand the disease and not accommodate it is absolutely crucial. We saw too many times in our drug treatment trials because we had to use a placebo arm.

Clinical presentation and abrupt onset

The during the placebo arm, children were getting worse and they were getting worse because the parents were doing what they had to to be able to live life, including, you know, a contaminated dad moving out of the hall, and leaving the mom with the sick child for hours so it can be incredibly disruptive.

Yeah. And speaking of that, I want to address something that I find very interesting. I had a young man who, had classic pandas improved with antibiotics.

Immunomodulatory therapy was actually getting IVIg. But every time dad came home, the child got worse again. Dad traveled a lot for work and for many months we were pushing CBT, getting everybody the whole family in therapy.

You know, really working on that. And then remember to check dad and dad. Right. And dad was positive for strep. Once dad got treated he was actually positive for strep.

And mycoplasma. Once dad got treated, the kid never flared again when he came home. A little sample because that would I think Freud would have loved that example.

If he would have been like, yes, we're building this whole construct around this father and what the role is now on the other side. I actually, when I was still doing ICU medicine, had a girl who had psychogenic, Strider. She had psychogenic, complete collapse of her, trachea.

And it was all because she had been abused by an uncle. And so he would come in the room. And so we do have to think both ways, but I love your. Absolutely, absolutely.

Yeah. And I think that's very important. I mean, so much we can rule out by history. And you know, we we've both heard each other lecture many, many times.

I drill home again and again and again. This is a clinical diagnosis. I hate when somebody tell me they had high strep titers. So it might be pandas or the strep Tigers were totally normal right.

And it's so it's not. So I addressed that a little bit too soon. Oh my gosh I have come to hate strep titers. And just this morning I was thinking why can't we resurrect doctor I you into carbohydrate antibody.

Because at least that was able to differentiate these kids that. Yeah. So an anti strip DNA b are a one step worse than useless because. Because of exactly what you discussed.

Right. We we think that they're telling us something. If it's high it must be associated with it. If it's low, can't possibly be. So what you have to know is that if you do both of them and you, you know, sort of have a throw culture to show that that child had an referring pharyngitis, you still have only about a 50 to 60% chance of catching the titer, right?

If you do serial titers. Right. So low titers mean nothing except that there were not those particular epitopes on that particular strip. High titers also mean nothing because they just indicate you've had an infection sometime in the past.

If you're a grade school age child, you have on average three strep infections a year. So in the past you may have had as many as nine, ten, 11 or 12.

And those didn't seem to trigger these symptoms. So we can't use strep titers. I think they can be useful in that child who sort of you're trying to say, this looks like it could be, but you're especially that when you talked about where the early onset was years ago, they they got over that quickly.

And this one's subacute. And you're trying to decide what's going on. Yeah I think I might do serial titers get two if I'm close enough to the onset of the symptoms and try and catch a rise as well.

Is an antinuclear antibody titers. Right. So that you sort of have an evidence of immuno reactivity, which is all that tells us. And our critics would be quick to tell you that 10% of healthy children will have a positive titer.

To which I replied, and do they also have ticks? And post-Brexit. But they rate so that we can't make that argument

with them. All we can tell you is that over 55% of our children had positive titers against, and when they were sick, and that they were better when they then it tires went down when they got well.

So it actually tracks a little more temporarily than the the anti strep Tigers do. But we're just returning to the start of this this section, I think that the, the real issue is was what you said.

This is a clinical diagnosis. If it looks like an elephant and it feels like an elephant, it is an elephant in this case. And you proceed remembering that if you're going to call it pandas, that's kind of the same as calling it cancer or calling it dementia or calling it, I don't know what pneumonia.

And you really do then have to dive down and figure out why is this child having this particular syndrome? And that's where other tests may be helpful to seeing if there is active mycoplasma, seeing, Covid and, you know, I, I am always looking for silver linings of things.

And I took one of the silver linings of Covid in that we saw more physicians accept that there was a post acute infectious syndrome. I mean, the papers that were coming out almost never talked about pandas, but they talked about other, other things.

You know, where we've seen that in history, other viruses, tick borne diseases, etc.

Treatment approach and CBT

but, you know, it did maybe help a few more people see that infections can trigger neuropsychiatric issues. Yeah. And I think I like that you've seen it as a silver lining.

I'm trying I just continue to find it extremely frustrating that we jumped on long Covid and the psychiatric sequelae of Covid so quickly, and ignored it for strep, which is much more of a problem for our children.

And also the sort of recommendations around vaccination and boosters and the rest for pediatric patients. Weren't necessarily geared towards children, they were geared towards adult recipients.

And I think that we saw a number of our children who have been in full recovery, get the Covid vaccine and and fall apart. The good news was we knew from other, you know, literature on Covid that how to treat that.

And if you could get them back very quickly with some high dose steroids. So I think we learned many important lessons out of Covid and and not the least of which is if you isolate children and they're not getting strep pandas goes away.

It was it was just amazing. And if we had, you know, if it was a reportable disease, I think our evidence would have been there. And then that year and a half coming out of Covid, where we, the children were just so sick all the time.

So, you know, sort of saw the uptick again in, in Pandas and Pans and there's so much more with Covid, there are very few silver linings, but there's so many other ways that it so negatively impacted our kids, especially those who were already suffering with anxiety, and OCD.

Absolutely. The contamination fears went through the roof. Of course they did. Yeah, we were promoting it. Yeah. In a five minute reinforcement. Yep. Yeah.

But I do want to mention one other thing that that I think we agree on. When we're talking about blood testing, so many of my colleagues want to look for every virus, you know, and get every viral titer for coxsackie and parvo.

And and again, just like those strep titers, I find them very unhelpful and in fact injurious in some ways, because then you go down a rabbit hole of something that the child was just previously exposed to.

So I you're shaking your head. So I think and I frankly, I have never, ever checked a viral titer to get my kids. So if

you want to practice it the way we do, don't check viral titers because as you said, it isn't going to give you helpful information.

The viruses that we can treat with antiviral medications have very clear symptoms. And you would know if that had been the triggering factor. It is not very common, compared to the number that are triggered by strep and even mycoplasma.

But we do see it after influenza, particularly H1n1. We saw it after Covid, we saw it, after varicella. And in theory, some of the, broader vaccines might be able to, to trigger the episodes.

But again, I think that it, it never is it cause it's just going to, perhaps provoke an exacerbation. And vaccines are to do that. I mean, they're supposed to promote immune activation.

And if you're already immune activated, it makes sense that that would exacerbate that immune activation. Right. So we we know well, I almost said required, but I guess that's actually true.

We should require all of our children to get the flu vaccine every year. But we protected them with three days of inserts ahead of time, the day of the, the, vaccine and for three days afterwards and ask parents to give it like on a Friday so that they could sort of have their little explosion at home.

And more importantly, make sure that the child knew that they might have a little bit coming back and that they could use their behavior therapy techniques to tamp it down.

Yeah. And when I was in my best coaching mode, I would say, okay, this is going to be a chance to really test how well your CBT is working. And it's it's a good, good reminder that you're in control of this disease.

Yeah, yeah. Very true. And I want to address the you know, we're talking about it being a clinical diagnosis, not doing these titers. All of that. And you've you've said that that about two thirds of pans is pandas.

Is that correct? I think, Jenny Frankovic is actually looking at it in her clinic in Stanford. And it's kind of there's at least two thirds, maybe as much as, three quarters of the case. Wow.

They can find strip. So you do treat as a strep has been there and straight. Work by Pat Cleary and others has shown that the strep can lose its cell wall, and it actually can hide in the cells of the mucosal tissues, particularly the tonsils.

So that finally gives us a beautiful explanation for the kids who respond wonderfully right to that initial course of amoxicillin. And you stop it in two days later their symptoms are back.

Well, that's that is actually why the, consortium recommended a full month of antibiotics, because that allows those infected cells to be shed and in the process of shedding of the bacteria is expelled, as effectively as if it was being attacked by the antibiotics.

Family accommodation and relapse triggers

So because you brought up tonsil and adenoid ectomy also, you know, I think we have a lot of our colleagues that may be doing CNAs on every child that walks in the door, and then there are others that don't want to ever consider it.

And and I think the literature is very clear in that it's unclear. Meaning, you know, I there just isn't a consensus. Certainly, if there are the other reasons like sleep apnea and recurrent strep infections, then it should be done.

Certainly, if an EMT is seeing very cryptic tonsils, adenoids absolutely should be done. Are there other cases where where you say absolutely a CNA is is worthwhile or very individualized?

I think it is completely individualized. But I think if you follow the rules of for anti, it includes frequent infections. So if this is a child that you just cannot get into remission because they keep getting infected, you know their brother breathes on them in the back seat of the car the day before he comes down with pharyngitis and your child flares.

That might be an indication. The problem with that is when we looked at our data, because we hadn't thought about doing tonsillectomy on these kids, it was sort of a natural experiment, and some of them had had it and some of them hadn't.

And in reality, those who had had had tonsillectomy tended to have more recurrences, because then the tonsils weren't there to become inflamed and the kid didn't know that they had pharyngitis.

So it goes both ways. All I will say is, if you're going to recommend tonsillectomy, take advantage of getting those adenoids out. Because I work for the Columbia Group is just beautiful in the demonstration that the infections in the nasal associated lymphoid tissue of the mouse, which is the mouse equivalent of the adenoid, just sit there and actually grab a form plate, and those activate the T cells which go.

And then they just that one really is self-perpetuating, because now the T cells that are, really actively promoting the inflammation at the basal ganglia.

So if you're going to use tonsils out, good idea to take the adenoids out. And a lot of scientists don't know that or would not do that. So that might be a contribution the practitioner could make.

Yeah. And the other thing I've been seeing is a shavings that, that, you know, that's another one that really gets me. Yeah. It's not so helpful. Yeah.

I mean I suppose it is if you're doing obstructive sleep apnea and get it down, and there is probably immunologic reasons why you would do it that way, but not in an overly inflamed child.

So I think the other thing we found, and I didn't write anything on this because we never did a control study, but I think just good oral hygiene is really important.

So that may be a reason why some of the special needs kids have such trouble, right? Is you have difficulty keeping their oral hygiene and keeping their plaque down into a reasonable thing.

Don't get it to sort of swish and not swallow the plaques, or act or any of those rinses that may be sufficient, because you can get rid of the oral and some of the nasal pharyngeal just decrease the LM.

Right. And I've had very good success with nasal sprays, even natural ones like like xylitol containing nasal sprays, which is a good anti-microbial, especially for kids with braces, things like that, where they're not really brushing well, squirting that in the mouth can really help that.

Also. And then the the strep Calaveras probiotic, I've had very good success with that. You know they're chewing it again decreasing that buildup in the mouth.

I found that to be helpful. So, going back to the clinical, because I think it's important that we mention the somatic symptoms because in the criteria of Pans is the, the piece where it's OCD or restrictive eating disorder and two of the other symptoms.

And there are a few that are on this path. Mnemonic. And could you talk about that a little bit too. So absolutely, I think, in the psychiatric world, we would have to say acute onset of separation anxiety, emotional ability with aggressiveness.

Obviously in some of our special needs kids, that can be tough, but it's just as clear in them as it is in the neurotypical children that there is a huge change.

So it isn't just an escalation of previously present aggressive behavior, but much more convincing is the somatic symptoms and acute onset of sleep disruptions huge.

Strep titers, viral testing, and diagnosis

And if you have the luxury of getting a sleep study in your patient over 80%, you're going to see abnormalities of REM sleep. That is pattern pneumonic and objective.

Nobody can question the reality of that one. And then the second and probably more clinically useful one is, acute onset of urinary urgency frequency and your risk new onset increases and daytime accidents where they sort of just drip a little, urine in there in their underwear.

It's it's it's definitely related to the, neurochemical control and duration of urination. And I used to think it was internal sphincter versus external sphincter.

I still think that that plays a key role because they are differential, differentially innervated so that you don't have continence of your internal sphincter and you're trying to maintain it with the external.

That's the child that voids. And just, you know, a few seconds or a minute later feels like they have to go back and try to pee again. And so what you see is them going to the bathroom 30, 40 times an hour trying to get that urethra clean.

But there's also ones where they just literally lose the ability to hold their urine. Yeah. The parents. Excuse me. So you might just ask a child about whether what they're feeling.

Right, right. And then the other one that that you've so eloquently presented on many times, and that we use quite frequently is the handwriting change not a somatic symptom, but that handwriting change, that motor abnormality can be, you know, when you have that child that was writing fine on February 12th and then February 15th, it looks like they're ten years younger than they are.

You got your diagnosis. Absolutely. And it can be very useful retrospectively. You just go through that child's school records or the, you know, the journal that they keep or every day.

And the sibling had a strip in their hand ready to be. Yeah. Yeah. So, so classic. So, Sue, I do want to, give you a second to, to, catch your breath, but but also, I do want to address the AARP's, March 2025, report on pancreas, that we so, patiently but anxiously waited for, for so many years and came out basically saying that it exists, but there's nothing we can do about it.

Well, it was the way I interpreted the many, many, many pages. And I would like you to, to address that if you could, please. Yeah. So it actually came in December of 2024, and we kind of tried to ignore it for a little while, hoping it would go away, and instead it became the industry standard, which I thought was very sad.

It had been many years in the process and over a decade actually, on you. Murphy and I did a webinar at the IPS request for their senior leadership in 2014 June of 2014, and, presented the same stuff that Tanya and Jim Lachman from Yale and I had presented at the Pediatric Academic Society meetings where Fann Tate, who is the medical director of AARP, has said, I don't understand why there's a controversy.

This seems clear as this day to me. So she had wanted to share that information with the AARP. Unfortunately, Doctor Tate retired a few years later, as did I.

And then Covid happened. And so this supposed rapid process of taking it outside of the committees, because the thing that happened at that webinar we were presenting to all of the section heads section in neurology, infectious disease, developmental Behavioral Community, PDS, blah, blah, and not unexpectedly, some of our naysayers were heads of those committees and just dismissed the entire thing the same way they always have by saying, I don't believe it.

Rather than let's look at the evidence. So Tanya and I gathered the articles that we had at that time continue to add to them until about 2017, when they finally got the media together.

But they were doing supposedly doing the literature review in the meantime. And literature review is actually quite compelling. Yes. The only negative things that say pandas isn't what we've always found it to be.

Our editorials, and one very badly done study by Roger Curlin, and a second paper published by Jim Lichtman. And when you dive into those which we had done for them, you see that they actually separated the sample so they wouldn't have significance because they had they taken all of the children together, even they found the relationship between strip and OCD tics.

So it's real. We go into complete radio silence because those of us who had seen or treated patients were considered to be contaminated. Supposedly the opponents of Pans Pandas were also contaminated.

But when Doctor Tait retired, it moved out of the special study section into the general population.

Tonsils, adenoids, and oral hygiene

And that's what took the next five years, was sending it around and sending it around. And you can see that in the report. The introduction is pretty not great.

It's very clear that whoever did the literature review didn't understand how to review literature. They literally went to the most recent publications, which were tended to be review articles and some of them are really bad, and didn't go back to primary source.

So we again, we didn't know it was coming, so there was no opportunity to rebut that. And then what happened is it went out to the committee's introduction pretty good.

They at least acknowledged that it exists, which was a huge step forward up until the most recent book, Pediatric Infectious Disease. The literal, official position of the American Academy of Pediatrics in the Red book was the pandas does not exist.

There is no role for doing a strep throat culture and no role for treating strep in these kids. They kind of went back to that in their recommendations.

I found it personally. Okay. It made me quite angry. Yes, but they went piece by piece through every negative editorial that had ever been written and literally repeated it in the response that Tony Murphy and I submitted, which may never get to see the light of day.

We pointed out how the arguments being made in this 2024 had been already made in 2004 by Kurland and Kaplan in exactly the same words, actually, that a lot more than 200 articles had been published since then.

And as you know, the bottom line was not just to not do anything, but just treat with standard psychopharmacology and behavior therapy and keep it in the medical home.

To which you have to say, you haven't allowed pediatricians to be educated on this for more than a decade. How is the medical home supposed to care for these children?

You can't just send them off to a child psychiatrist state there aren't enough of them to treat these children. And besides waiting for three months to get into that child psychiatrist or get on to the, you know, get off the waitlist for the behavior therapy, the child is suffering and you're missing an opportunity to help abort this illness.

The the Pants Canada's clinical research consortium, is writing an article where just the state of the state of the science article where we actually quote the papers that should have included in this one provide guidelines.

And and we are we don't recognize our vulnerability. Right. Because in order to get children treated, we have to recommend treatment of pants as if it's all pandas.

Right. And that's why your comment, that reminder that up to three quarters of these children are pandas because has been stripped reared is so important, because that means there's a quarter that are probably not going to respond to that.

Traditional use antibiotics use immune modulatory therapy as, as, conservative as you can based on how sick this child is and use the tools that we have for treatment of symptoms, which is psychoactive medications and behavior therapy.

Use them all. Don't just depend on administration of an assistant. Right. Which even if you start low, go slow, taper up so the child doesn't have too many adverse effects.

You have to get the maximum dose and be there for 8 to 12 weeks before you see real benefits. And that's just too low. Right? Right. And and the other thing is it really was an even recommending a strep culture, you know, a throat culture, you know, and, and and that is a simple do one.

It was crazy crap. And then I pointed out how in their own articles and in the Red book, they actually equate it to Sydenham, Korea, which has mandatory prophylaxis, not just with treatment of the acute infection.

And as you said, there's so many articles there is so much research in support of this diagnosis. And you talk about a lot, you know, but you mentioned Jenny Frankovic Pittenger, the, the lovely, research by Drayton Igloo.

You know, maybe we're on the verge of a biomarker if our clinics don't all get shut down, you know, and, you know, the evidence is really there. There's no question about it.

We actually know now because we gave up our studies, as in him, Korea, and nobody else was doing them. We know more about the pathophysiology, etiology, and treatment of Pandas than we do about Sydenham, Korea.

AAP report controversy and evidence review

And so I just I just kind of that does amuse me at this point rather than irritate me because I just look at at the recommendations. Plasmapheresis is a first line treatment for severe Sydenham, Korea, based on our one study, which was actually smaller than the study that we first did, showing that IVIg and, plasmapheresis were superior to placebo.

And yet ours didn't count if a done in pandas because the countries. So the controversy is clearly impacted the interpretation of study results. And it's made me so jaded about all of science.

You know, how do you find truth. So I really appreciate you doing this podcast and trying to get the truth out there. Nancy. Yeah, because the the controversy so impacts so many of our children and families.

You know, being unseen, minimized, undiagnosed, misdiagnosed, having the stigma of mental illness, all of that. I mean, it breaks our hearts. Yeah. And then they go in with the evidence and it's, you know, it's an affront to the pediatrician because they're confronting their lack of knowledge, and the parent does no more in this case than the pediatrician.

So they have to have the humility to be able to say, wow. Yeah, I think I heard about that. Yeah. Because early onset, early early diagnosis equals better outcomes.

I think I think one of the most interesting articles that's out there is an article by 11, medical professional parents about their experience with their child's pants, pants and how even they, within their own hospital systems were, denigrated and the symptoms denied because pandas couldn't exist.

And they're sort of like, I've watched it. Yeah, I I'm one of them. And I watched him get better right in it. So he, I always said if every practice had one classic pandas patient and they did the right thing.

Nobody. This controversy would disappear because it's actually the most rewarding experience of your life to take a child who has this debilitating mental illness where they cannot get out of bed because contamination is so severe and treated with augmentin?

I'm sorry, that doesn't happen. Yeah, yeah. So so your recommendation for any practitioners who may be listening or watching or parents in responding to the AAP report, do you encourage practitioners to write a report?

What's your recommendation? I would love to see the I think that the AP report, because the editors seem to be based on our experience, that our response still hasn't been posted.

I think they are censoring some. So I had originally thought, oh, we'll just flood them with responses, but they're not being posted, so that may not be as effective.

I think if practitioners would start working through their local and regional chapters, we could turn this around because the chapters and the, you know, the sort of the grassroots has more impact than the sections at the to the leadership.

But they're not hearing because pediatricians are too busy. Right? So what practitioners could do that would probably be the very most helpful is just go ahead and send their response, citing a case where they had a child, what they look like, how they treated him, how they responded, how they were cured.

If we could get even a dozen of those, I think that people would have to start paying attention to this. And if they won't publish it, if we send the letters, a letter to the editor, to one of the other journals, this lists, you know, one of the online journals.

I think that that just those kind of testimonies and, and and deniability of case response is what's going to have to happen. Absolutely. Because what's the cost of inaction?

Right. Well, the cost of inaction is we've had 25 years of controversy. If we would have been much more aggressive in our response to that first editorial in 1999 by Harvey Singer that accompanied our treatment, paper, I think a lot of this could have gone away because we didn't we were the NIH and couldn't respond to the fact that he literally outlined all the reasons the study shouldn't have worked, but it did.

And so you can't, you know, and then his colleague actually accused us of fraud. So we should have, been much more aggressive about calling him out for just being a liar and libel, slander, whatever it is.

Well, I actually did write. You did it verbally and in writing, so. Right, right. Well, well, I always say is if you had a greater ego, it would have been the, the veto disorder.

Or maybe this veto Rappaport. I mean, I'll give her that, but but, you know, and then the, the controversy might not have been a straight, you know, it is kind of interesting, isn't it?

You have it really is. Got NMDA receptor antibody, mediated disorder accepted in a heartbeat. And I think you could not have more of an antithesis of personalities than Joe Doe and I.

Yeah. Very true, very true, very true. Fitzhugh, I, you know, you and I could talk for hours. This disease is probably as close to my heart and soul as it is to yours.

Hope, outcomes, and closing message

Maybe just not as long lived, as yours, but, What words, would you like to leave our families, our practitioners, anybody that's listening or watching with.

I would say that, the secret to a good outcome with patterns is recognizing it as it's happening. So I started by telling you about the little boy, my church, who, you know, sort of mom wrote what I did, and she said he just had had this kind of funny.

So we cultured the whole family, got him treated and saw a beautiful result. And I think that that's the same. It is a disease of incredible hope. And I know that you have written I love your book and and I love the fact that you continue to see the patients and are in with them for the long haul.

So yes, it's a disease of incredible hope. Our 10 to 15 year follow up on these kids was superb. They had less mental illness than the average population.

They did not have pans pandas anymore, but it sometimes was kind of rough getting there. So you're in for a bit of a the long haul practitioners. You're going to need to support the parents PTSD as much as the child's PTSD, because it is something that has just taken their child away, stolen their child out from underneath them.

And, there's they'll talk about it, you know, oh, it's Covid that's come back. So we have to get them to the point where they don't fear the coming back because fearing the coming back leads to an action that then accommodates the illness and all the rest of the stuff we've talked about. But I think, I have yet to see a pants pin this child that we couldn't get into remission.

Wow. There may be tougher, but you can do it. I agree, I agree there is hope and that hope is so much. Thanks to you. So thank you for your your diligence, your unwavering support of the science, but also support of the families and support of the rest of us in this community.

We are so lucky to have you. And, I hope, the controversy subsides. But I we're getting closer. We're so much closer in the last couple of years than they than we were in the previous 25.

And it is coming. So hopefully we'll both live long enough to see it. But thank you again. So appreciate you being here and and for being you know it's been an honor.

Thank you so much Nancy. 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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