Introduction to PANS and PANDAS

Welcome to another episode of Mycotoxins, Mold and Chronic Illness Summit. I'm your host, Dr. Ann Shippy, and today we get to talk to Dr. Scott Antoine.

He is board certified in emergency medicine, integrative medicine, certified in functional Medicine and a forum. And he is an expert in many things that especially pans pandas.

And I think this is just such an important topic for us to be covering on a mold summit because it's affecting so many children and I think also overlapping into adulthood.

So thank you so much, Scott, for joining us. Oh, it's my pleasure. Always great to see you. And oh, well, thank you. I know this has really been quite a journey for you and your family to become an expert in this, because we're not taught this in medical school.

In fact, I think still in medical school, it's really hardly getting covered at all, even though it's been well-established now that it is a very important clinical diagnosis.

So if you'd like to start out with just telling us how you became an expert and how it affected your family. Sure. So we have a daughter, my wife, Ellen, who's also a physician, and I, we practice together.

We have a daughter named Emma. She is 21 now. When she was 12. She got some fast. And so when she was 12, she came to us one day and said, I don't think I'm a good person.

I don't think God likes me. And, you know, we had a talk with her. Being a parent can hear, Right? Right. And so we had a talk with her and we thought maybe it's just like pre teenage sort of stuff.

And then a few days later, we noticed her hands were just raw and chapped. She was washing them multiple times a day. She lost the ability to get herself to sleep and just to it's one once really compliant.

Our most compliant of our five children, once compliant sweet girl just became a terror. She kicked the door off the hinges twice to our bedroom and she was about like £85 and just a total overnight change crippling OCD.

She couldn't eat anything we made for her. She thought the food was raw and just absolutely it was it was a mess. And so we called a pediatrician, of course, and never got a call back.

And the reason we called was so Ellen started searching and searching the medical literature and figuring what what is wrong with our neurologic exam is otherwise normal.

There's something strange going on and I came across the diagnosis of pandas, which is pediatric acute onset Neuropsychiatric syndrome. So that point, it was really hard to even find anything about it.

What it was. And so it's it's a disorder associated with strep. And in this case, these kids will get a strep infection and then a period of time afterward, it can be weeks, it can even be months.

They will develop antibodies to strep, which will then attack their brain and give them all of the symptoms Emma had and more. And so there's also a related phenomenon, PANS, which is pediatric acute onset neuropsychiatric syndrome, when it's not associated with strep.

So we know that it can happen for multiple other tick borne infections, mycoplasma and other things. And she had some of each of those when we did testing on her, but we initially didn't get a callback.

And so we looked and looked and looked and finally found a physician in New York who got on a plane with Emma in the midst of her terrible OCD and took Emma to the physician.

Emmau2019s Sudden Onset and Diagnosis

And he took one look at her and said, This is a pandas and she needs IVIG. So they came home and we thought, Oh, great, we will at least be like knowing what to do now. And I called a physician, neurologist here, pediatric neurologist here where we live and said, look, this is the deal with my daughter.

This is what's going on. And we think it's pandas and she's having all these symptoms. Can you help us get IVIG? And he said she just needs to be on anti-psychotic medicine and put in a psychiatric ward.

And we. Just cried. That's so upsetting. And we just said, not not our daughter. That just doesn't none of this makes sense. This was immediate onset.

So we got an MRI and got multiple other things and got other people involved in the care plan, found a physician in a nearby state who did IVIG for PAND AS, she and I.

And four days later her symptoms were gone. So it was an incredible journey. And at that point, due to this struggle that we had, even as physicians within the medical community getting someone to believe us or to investigate or to figure it out on this potentially reversible cause of what looked like psychiatric illness, I just knew my specialty had found me.

And I said, This is what I need to do and I need to also make it more friendly. I need to make it easier for people and I need to make it a more complete, you know, once I got into treating these children, there were parts of this that I had to change and modify and tweak, because even within the community of physicians treating pandas, there's sort of a limited amount of treatment options.

And fortunately, through study and and and clinical experience, we've been able to expand that to a point where we've been very successful in treating these kids.

That's that's life, you know, just life changing for individuals and for their families to be so aware and so adept at this treatment. So for those people that are not that familiar with PANS PANDAS, I'd love it if you if we just step back for a moment and if you could talk about the most common symptoms that you see and the things that make you most suspicious, that that's really a diagnosis.

Sure. So the classic criteria and I always say classic because we see lots of kids that don't quite fit the classic criteria, but still something's up.

So the classic criteria that were developed by the National Institute of Health in about 2014 or so said that children had to have either sudden onset severe OCD or eating restriction.

And the eating restriction doesn't look like a kid that's picky. It looks like these kids will say, I feel like I'm going to choke. I can't eat, I can't swallow.

They can actually end up hospitalized with a feeding tube needing feeding and or nutrition. So one or both of those OCD or restrictive eating, plus at least two of the following seven categories.

So the seven categories are things like anxiety, particularly separation anxiety, labial mood or depression, school changes, school deterioration in performance for some reason, and I don't know why a lot of these kids that come to us and they were originally gifted children and then ended up it's it's a they ultimately can't do math, which was our daughter's case.

They will also end up with somatic signs and symptoms. So very frequent urination like wetting their pants in the daytime, wetting the bed at night. And children are previously potty trained.

They also develop physical signs and symptoms, including text. So motor tics, movements of their fingers of their hand. Most common are tics involving their face to their head, so they will squint.

I'll never forget my daughter when when she was sick, she would come to us and in the midst of this flare, she would kind of do this with her eyes. And I kept saying to her, You're a teenager.

You're supposed to be better at rolling your eyes at your parents than that. And I was embarrassed later to figure out that this was a tic. A lot of these kids will have like a mouth opening or they'll clear their throat and then they will see the doctor and they're told you have, you know, allergies.

But the kids will or they'll sniff. But when I say it's it's multiple times in an hour, it's over and over and over again. So ticks they will also a lot of times have issues with coordination.

So they all have issues with their kid once riding a bike and now they can't where they trip or they're falling, they suddenly become extremely clumsy.

So these symptoms in this in this other group, what I'll tell parents is, you know, these kids, when you see them, they all look alike. In other words, they all present severe.

It's a severe sudden change. It's not mild. And initially the criteria were to be applied to children between three and 13. It turns out that distinction was made sort of four to get an identical group so that they could study and whatever.

But it turns out we've seen children that have had an onset in their late teens. I've seen a few adults that either represent missed cases as a kid or that developed this later on in life.

The classic story is, of course, the reporter from the York Post who wrote Brain on Fire about her experience developing autoimmune encephalitis as an adult.

So we've seen older cases, so age, there's really no age restriction. I find that below the age of four or so, it's really difficult to tell. Kids at that point have a hard time telling you that they're having intrusive thoughts or OCD.

You just see a big behavioral change. But, you know, we have children who come to our practice and the parents say, you know, it wasn't a sudden onset.

What do I do? And that's a thing that it's been studied since the criteria made it maybe up to 40% of kids, that it's not sudden. In our case, it seemed sudden with their daughter.

Recognizing Symptoms and Clinical Criteria

But when we then look back, we we found that over the six months preceding, when we would sit down and, you know, say a prayer before we ate, she was progressively praying longer and longer.

We'd all start eating and she'd still be sitting there with her eyes closed, new lips moving, praying. After we were all finished. And we initially thought it was not nice, but it ultimately ended up being part of a religious obsession.

A lot of these kids will have a religious obsession. A lot of times you can see obsession with sexual topics as well. They will they will begin to be very upset about sexuality or they will have sexual thoughts sometimes about siblings or a parent or even a teacher at school, which is really alarming to parents because they start thinking, gosh, did something happen to them somewhere terrifying?

So those are the criteria. But as I said, you know, they're to be loosely applied because if you had a child with like three of those things, but they didn't have OCD, that it's still something's up.

So that could still be at a time that parents will come to us and treat us. And fortunately, the comprehensive nature

of the way that we treat children tends to help give us victories in those areas, too.

But you'll notice I didn't mention lab tests, radiology tests. It's a clinical diagnosis alone. So one of those. Is some clinical testing sometimes to confirm the diagnosis or do you just go based on clinical.

So the diagnosis itself is just based on the clinical presentation and we do test. And the reason we use the test is, number one, to rule out other things.

One of the things that I should mention when you have these criteria is there's a little asterisk at the bottom of the criteria. And I tell people this every time that says not better explained by another neurologic disorder. So there are times when these children will need an MRI to look for a structural lesion to make sure that we're not seeing behavior from a brain tumor.

There are times in severe cases where they may need a spinal tap to look for an infection, encephalitis of some type, viral or bacterial and stuff like this, or meningitis.

There are other. Parents who don't want to miss those things for sure. Yeah. Right. And that's the thing. You don't you don't want to say, Well, I have a hammer, Does everything look like a nail?

And so on. So we use tests that way and then the other way that we use tests is to give us a signpost of which direction to go. Right. So if we have a child and we believe that it's pan-European is many times we may start them on a course of antibiotics using our best clinical judgment as to do we think this is more of a strep presentation or does it sound like mycoplasma or does it sound like could it be a tick borne illness?

And that determines which antibiotic we may start with. But then if we get an infectious disease test that points in some other direction, then you change speed.

A lot of this is really like playing chess, kind of make a move, you get additional information you might have to adjust course, and that's why it's really personalized medicine.

That's beautiful. So why, you know, you've got five kids, right? So and one of you, I'm sure the strep is going around family right. So why do you think one child over another is affected by pandas?

Pandas? That's a great question. That's a great question. We could do c times where we will have a sibling in a family affected that. It did not, fortunately, happen in our family, although today when you have this type of drama going on in your house and both of your parents are falling apart at a time because of it, it's affected all of our other kids for sure.

But what we tend to see in our practice, like any autoimmune disease, there tends to be a genetic predisposition. And as I know, you know, as a mild expert, you know, you'll have a house that we're a house happens to be moldy and one person's super sick and everybody else seems fine.

And that's what tends to make people doubt that it's a thing. But, you know, there seems to be a genetic predisposition in these kids. And then also, if you then add to that increased intestinal permeability and then immune dysregulation, once that sort of starts, that sets the stage.

So That's right. I mean, why would strep do this to one kid? And millions of children get strep every single day and it doesn't tend to do it to them, although we think the prevalence of of autoimmune encephalitis, post infectious autoimmunity epilators maybe as many as one in 200 children now that it's kind of started looking for it, but it's a great question.

And I think that it has to do with genetics for sure. And then obviously the environment and everybody processes things a little bit differently. And so you use the word immune dysregulation and can you just elaborate on that for our audience so they understand why you're.

Absolutely. So your immune system, you know, has the job of testing everything that you come in contact with, whether it's something you put in your mouth or touch or breathe in or whatever else, whatever other way it gets into your body.

Your body tests that your immune system tests it and determines whether it thinks it's harmful. Sometimes it gets that right, sometimes it doesn't. But if it believes that there's something harmful than it mounts, some type of a response or cell response sends white blood cells there to either eat or dismantle it, or it may make antibodies to things.

We're sort of all familiar the last few years with the concept of antibodies being a protein that recognizes that thing when you're introduced to it and fights against it.

And so autoimmunity in the body occurs when your immune system mistakenly attacks your own tissues. And so what happens in these cases? It would be in patterns and pandas.

We know there's experimental evidence for both showing that in the case of pandas with strep, the same antibodies that attack the strep bacteria there are similar the outside of the strep bacteria.

It has proteins and little peculiarities about it that actually resemble a certain portion of your brain. And so if those antibodies cross the blood brain barrier into your brain, they then attack that specific type called the basal ganglia of your brain region of your brain, and then produce these exact symptoms.

We've seen it in mice and dogs and people. It's that autoimmune attack is the same. And so you would look at that and say, well, I guess these people just have autoimmunity.

So their immune system's like way out on overdrive. Absolutely true. However, we also have found a significant proportion of these kids have low immune globulin.

Those are proteins that make antibodies and they also don't tend to make antibodies to immunizations, for example, that other kids get making antibodies to without a problem.

So the problem is twofold. You know, your immune system should just kind of sitting idle when you're exposed to something. It should turn up the heat and take care of business, and then it should go back down and idle in these kids.

That system's not regulated. So at times their immune system's on overdrive and attacking their body in their brain and other times the immune system's sort of asleep at the switch.

And so they're susceptible to some of these illnesses. Look, a lot of these kids will, you know, strep in general. Lot of people probably get strep, never get treated, not my recommendation, but they never get treated and they recover fine because they don't have this immune dysregulation in these kids, whether it's strep or mycoplasma.

Also not a particularly bad actor. Even Lyme disease in some people probably doesn't produce clinical symptoms. But in these kids, when there's an immune dysregulation, it goes haywire and it causes this big, huge immune response.

So it's an issue of immune regulation getting that dial set right so that you can respond when you need to. But at other times, chill. That's a great explanation of the immune system.

I think people can really get a good feel for how their immune system should be responding and what goes awry. You mentioned that the Ivy League, which is kind of been the standard care and and the allopathic physicians that recognize patterns.

Pandas, if you could explain with the Ivy ideas and why you think it works. And then next, we'll get into how you're helping patients without even needing that, because it's very expensive and it's it's not an easy treatment, right?

Isn't so Ivy League is it is an intravenous treatment. It's an infusion. It takes about 6 hours or so a day, two days in a row. And so what IVIG is, is it is immune globulin.

So it is a protein that your body makes that it makes antibodies out of. And what they do to make IVIG is they actually take proteins, blood from thousands of donors Between 1010 thousand donors are pooled to make one infusion, lot of IVIG.

And so what they're taking is they're taking that small proportion of your blood. The red blood cells are taken away, the white cells are taken away. They're just filtering out to get to that immunoglobulin G called IgG.

They take that.

Testing, Immune Dysregulation, and IVIG

It also contains some other immunoglobulins, but the main one is stage and then that's purified and put into a solution. Very safe. It's so filtered. They really haven't been many reported cases of of transfusion infections that you might imagine with blood or other blood products, but that intravenous immunoglobulin is given to people as an infusion.

And we don't know exactly how it works, but it's given for a lot of autoimmune diseases. And how we think it works is twofold, really. It seems to help remove abnormal antibodies from the circulation.

It also when you are getting IVIG, because it's from so many different people, you have the benefit of getting their immunoglobulins to whatever they've been exposed to, whether it's mycoplasma or strep or whatever.

And so if you are a person where that immune to IL is turned down and you're not making antibodies to things, there's a benefit to getting antibodies from the environment to other people who've been exposed to the exact same things you're being exposed to.

So we don't know exactly how it works. It also seems to have an anti-inflammatory capability. They tested IVIG a few years ago. They did a study and found that most of the IGG contains active antibodies against strep and mycoplasma and Epstein-Barr virus.

So there's a benefit there to it. But as you said, it's very expensive. A single infusion, two days of infusion or IVIG averages around 20 to $25000. So it's expensive.

It also. Noting that most people can. It's. Not it's pretty tricky to get through insurance. It is so insurance companies have basically a blanket policy in many, many ways to to restrict coverage against IVIG.

They almost always initially deny it. Fortunately, due to the plethora of studies that have come out in the last few years, I've been able to successfully appeal and get it approved many times.

Because to say that it's to say it's experimental or it doesn't, it's not been proven to be effective, is not evidence based medicine. And I point that out when I send letters back or I do an on phone, peer to peer with them and say to deny this and say there's no evidence when I'm giving you the evidence from the professional medical journals, not evidence based medicine.

So I've had pretty good success, probably 85 or 90% success getting that approved. And then in Indiana in 2019, I was part of an effort that lobbied the state Senate here.

And we are able to get a law passed that in Indiana insurance companies can't deny IVIG for patients and pandas. So I didn't realize that. That's impressive.

So we're one of about seven states now. Many other states are going and it was an effort started by moms of children with panels and pandas. So they railroaded and stampeded their way into the Capitol in Indianapolis and

started the ball rolling.

And then I came in and testified and we were able to get the law passed. Great job. That's thank you. So important. And obviously, now you've gotten really good at not needing the IVIG.

I think you had said like only 10% of your patients actually need it because you find other ways to help get their immune system balance. So I'd love it if you'd talk a little bit about that and what some of the other ways of helping to get get children treated.

Sure. So there's initial barrier, obviously, right to fans and Pandas is sort of a whisper down the lane. People have said in the conventional medical community and I'm a conventional medical doctor, but people have said, you know, these things don't exist really, I think because it makes you forces you to look at mental health an entirely new way and say maybe this isn't a case of a medicine deficiency.

And I'm you know, I'm all for psychiatric medications in their proper context. But gosh, if there's a reversible cause, we don't need to get there. If you look at the folks that actually do believe in panels and panels and and work with panels and pandas, they basically do about four things.

They'll do antibiotics for infections. And even then, they don't always consider other infections, tick borne infections, mycoplasma and other things they'll treat for strep.

Maybe, but they'll do antibiotics. They may do IVIG, they may do steroids occasionally. And then also they will do, you know, medications to help behaviorally, psychiatric medications.

And that does work for people. IVIG was basically curative for my daughter. But a lot of our patients, it is not. And so Dr. Ellen Antoine, my wife in our functional medicine practice, came up with a protocol we called a fully functional protocol.

And when we went through this, we sort of modified it. And then in the in the ten years following that, we've continued to refine it and got it to a point.

Now we're only about 10% of our patients end up needing IVIG. So the timeline of times when I'll order it immediately is if I have the kid that's just absolutely so out of control.

I think they're either going to hurt someone else or hurt themselves, or if the child's not eating, if they're not eating, they're losing weight, they're about to be hospitalized.

It's time for IVIG now. So. Yeah. So but generally what we'll do in these cases is I always tell parents it's four things. You've got to identify and treat infections.

You've got to identify and remove toxins. You have to reregulate the immune system, and then you have to deal with neurologic loops, which are OCD, magical thoughts, behaviors, anxiety, things like that. So identifying and treating infections, you have to know the right infection you're looking for based on what the patient looks like.

You have to know the right infection based on the testing you do and what the testing you do mean. So we test for strep, we test for mycoplasma. We also test for tick borne illnesses by far the highest things that we're seeing in terms of tick borne illness with patterns are Bartonella.

We also see quite a bit of abuse here. Duncan Recently, I don't know why, but in the Midwest where I live, it tends to be very prevalent. We do see Lyme, we see beryllium.

Miyamoto I was sort of related to line but won't be picked up on any conventional Lyme testing. Where you're using for that. So the testing we use, we either use I Gen-X testing or I tend to use a lot of in fact the lab testing and I like infective lab because it gives you interleukin two and interferon gamma.

Those are chemicals, inflammatory chemicals that your body releases when you're actively fighting that particular thing. So if you do antibody testing, even through a really good company like I Gen-X, sometimes it's hard to know whether if it's just one of the antibodies, if you're seeing an old infection or a current infection.

And so in fact a lab will show you it will be elevated. It's a perfect test, I think, especially in kids, because if it's elevated, your immune system's finding it.

And then we will treat these kids with the appropriate antibiotics and or herbals and the infection will get better. Their symptoms will go away and we'll retest the infected lab and it's negative.

So like, how do you test that will be really helpful. And so we also do the conventional testing. We do not do a Cunningham panel. Lot of people ask me about that.

A Cunningham panel is a commercial autoimmune. It's a flight panel available. The reason I don't do it is because it really doesn't change my my treatment at all.

So the one time I might do it is if I'm trying to get IVIG approved, an insurance is really being a pain, then I can do it and say, Look, this child has an antibodies to their brain.

They have autoimmune and stuff like this. You have to prove ADHD. And I've gotten away with that a few times. So strategy. So testing for infections and then picking the appropriate treatment.

Many of the times we see these kids right off the bat, they're so severe, we'll start antibiotics. And the question is always, well, how do you decide what you're treating?

Because the treatment for tick borne illness and mycoplasma is one thing, one group, and then the treatment for strep tends to be penicillin based, cephalosporin based antibiotics. So what do you do?

And so actually we designed a table panda's initial antibiotic selection chart that we use, and we grade it based on clinical factors that might tip the balance one toward the other.

For example, if they've had a penicillin based antibiotic in the past and they got remarkably better behaviorally, that kind of puts one in that category.

If they have a history of asthma, you might think of mycoplasma, and so they might put a hash mark in the other category. And then we totaled that up and whichever one seems more likely, then we might start that class of antibiotics initially after that.

But so we use a lot of herbals in our practice as well. We found, especially with Babesia, the uncanny crypto lapis, which is an herbal, is amazing. It's where we used to have to use an antibiotic in an eight over one, which is an anti-parasitic we're now just having to use is a thrice and plus crypto app and getting a lot more bang for the buck doesn't taste great, so you have to work kids up to it.

But crypto has just been really a changing thing just recently, a life changing thing for us in our practice. But treating the infection then toxin wise.

I just love how you're plowing new ground with us. Like just, you know, your your brilliant mind, your big heart. You're really solving some great problems.

So, you know, just hard out there in other ways. So I just have to interrupt you to say, hey, this is really amazing. Well, it's what's enjoyable, right?

It's it's it's an investigation. It's it's just like your practice. It's medical detective work. So it tends to stimulate your brain. Unfortunately. It also makes me sometimes lay in bed at night and I'll, like, awake and I'll be like, I know exactly what Sally has, and I'll run in the other room and write a note so I don't forget it.

By the time the morning comes and you know those little bits of things. But, you know, I do find time to relax and downtime. But so toxin wise, by far and away the most common toxin that we see in these kids are mycotoxins from mold exposure.

It is in we've been keeping data for about two years now.

Treatment Approach: Infections, Toxins, and Immune Support

There's probably 200 children's data in there. Over the last two years, 100% have been positive for urine mycotoxins and the vast majority of those. Have had.

100% of 200 or so children that we've tested. It totally makes sense. And based on what we know about Mycotoxins and how they cause that immune dysregulation. Absolutely.

And so I think our theory and I just wrote it a section in a book I'm composing on this on Pins and Pandas. Is that based on the experimental literature?

And also what we've seen in our practice, our theory is that the initial tipping point is that immune dysregulation. And because the mycotoxins, as you know, cause defects in cell mediated immunity, they affect bone marrow antibody production.

They also block detox pathways that other toxins get out of. So they're like a poison that poisons you further by making other poisons poison you like.

Blocks that escape routes for the other time. That's exactly right. And so that immune dysregulation seems to be where it starts. And so we make a timeline for our patients, as a lot of folks do.

And as I'm going through it, I'll say, when did the symptoms start? And then I'll say, When did you move into your house? And I'll say, well, like a year earlier, I'll say, okay, let's talk about that later.

Let's keep going. But that toxin exposure, I've also we've also seen children with heavy metal, elevated heavy metal levels. We've seen some children where in the atrazine belt here in Indiana.

So we've seen some children that grew up on a farm. They were exposed to lots of chemicals that I feel like that was the area of of immune dysregulation for them.

So finding and removing toxins through all the things that you would do good if I owned binders, moving someone out of that, out of that environment, remediating a home, all those things.

I'm sure you guys will be talking about a bunch during the summit, giving people that great things now immune reregulation So find and treat infections fine and remove toxins fix immune dysregulation.

Well now what how do you fix the dysregulation? And so there's several sort of tiers to that. So the first most common thing that we'll start with is low dose naltrexone.

Low dose naltrexone is a drug. It is made at a compounding pharmacy. And what we know, low dose naltrexone does is it releases natural endorphins which which help with pain.

A lot of these children will have joint pain, muscle pain, something called M4 situs, which is like an arthritis like condition. So to help with pain, it also has been shown to modulate behavior quite well.

There's some studies with autistic children with low dose naltrexone been shown to be beneficial and it also tends to, if you can imagine if there's autoimmunity, it tends to bring that down, bring that level down.

If there's decreased immunity, it tends to bring that up. Bingo, You've got it. You've got the thing that's regulating

the immune system. Now, not everyone responds to low dose naltrexone.

Sometimes we give it at night because it tends to chill people out. And night is a hard time for kids with fans and pandas, but sometimes it stimulates them or it'll give them some night terrors or things.

So either have to move it to the morning or reduce the dose. Other things you can use for immunity regulation, the ultimate immunity regulator, IVIG. But not everybody needs that.

But IVIG is the ultimate immunity regulator, right in between kind of our steroids. So things like prednisone and steroids aren't my favorite. I give them sometimes if I've been treating a child a while and I'm trying to kind of make a move and play that chess game and figure out what's the best next step.

Usually if I'm trying to deal with inflammation, I'll use non-steroidal medications, things like ibuprofen or naproxen or things like that. But steroids have indications.

My concern with steroids is, you know, you can't be on them long term. It's bad for your adrenal glands, it's bad for your cortisol, your stress hormone.

It's also bad for your bones, eats up your stomach lining. So short courses are probably okay, although I'll tell you, it's probably 30 or 40% of the kids.

We use steroids and get worse because of the steroid. They get really aggressive or they'll be up all night and unable to sleep, even if they take it in the morning.

So not my favorite, not something I commonly use. Occasionally it will find its way into the armamentarium. So infections, toxins, immune dysregulation.

The last thing we work on are neurologic loops, OCD, the most effective treatment for OCD in children worldwide, no matter what you read, is exposure, response, prevention.

And that is a type of cognitive behavioral therapy. It's a type of therapy where children with OCD are exposed to a stimulant, something that may bother them in a supportive environment and then allowed to kind of sit in the discomfort without performing the ritual.

And then over time, what that does is it weakens the ritual. It's kind of like if you had a superstition about something and you kept doing it until the superstition went away because you knew that it just didn't have any power on you, you know, you're lucky, Penny.

You left it at home. You still had a great day when Penny's not so lucky. So do this CBT therapy in your office, or do you work with a psychologist? Or how do you generally. We have several.

Yeah, we have several psychologists in the area. One tip for anybody that might be watching or a tip you can give your friends is there's a great online OCD program that does exposure response.

It's called their methods called No CDD and OCD, but treatmyOCD.com is the website and a lot of our children have found benefit because they do it via zoom in your home so you don't have to take this child who's got these behavioral issues or might have fears of contamination out of that environment.

You can do it right from the comfort of your own home. Right now. We we actually have something we call the point system. I didn't invent it. They used it with my daughter when she did a partial outpatient hospitalization program before she got IVIG in Chicago.

She did a partial outpatient program. And the point system is actually pretty interesting. It's a form of exposure, response, traditionally exposure response, if you phobic of spiders, I would kind of sit you in a chair and I'd show you a picture of a spider and you might feel a little uneasy with that.

And then over course of a period of treatment, I might eventually bring a spider in a box. And then ultimately we'd want you to like, be able to have the spider right next to you, maybe, or even touch the spider, whatever.

But to get over phobic behavior and it takes a long time and it's uncomfortable while you're doing it. So you have to take tiny steps and each step you have to kind of say, okay, what's your stress level?

On the personal, say it's an eight, it's an eight. And then you say, okay, let's just sit here for a minute. You keep asking them and eventually they start saying, okay, it's a two, I'm better. It's a one.

Now I feel okay. And then you wear that, you kind of wear the the the OCD down over a period of time and then it tends to go away. The problem is it's pretty uncomfortable.

Children don't understand it. They don't do well with it. So we have a modification of that that we learned in Chicago. I have a video that I send to all the parents, which is called the Point System.

And basically you make points for behaviors that they're doing that you want a lot of the behaviors you would be doing would be exposures. So let's say you have a child who is washing their hand ten times a day, you're all tapped and you want to get that and work on that behavior.

So what you would do is you you'd say to them, okay, the parent would sit down with them and say, okay, you're going to get 20 points if you don't wash your hands for four, you're going to get ten points.

If you don't wash your hands for 2 hours, you're only going to get five points if you wait an hour to wash your hands. And then what you do then is you make a separate list of things that the children child has to use points to buy.

And I tell the parent, any pleasurable activity has to be on that list. For example, it might cost them 20 points to watch TV for an hour. It might cost them 20 points to be able to go outside on their bike, whatever it is.

So all of those behaviors and what it does is it takes the parent out of the adversary role and the parent ends up being the coach and saying to them, All right, I want to see you get these points.

I really want to see you be able to go outside and play with your friends. So let's work on this. You only have 20 more minutes. Let's wait to wash your hands till the 20 minutes.

And what happens? It's very interesting. If I sat in that same scenario and said to you, okay, you're phobic of spiders, we want to desensitize you to exposure, response, prevention, therapy, ERP.

And I could do it. Just keep exposing into the spider until you could live with it and then maybe got okay and could like not be petrified. But imagine if I said to you, All right, I'm going to take this spider, I'm going to put it right in your lap, You'd say, No, no, no, no, no, no.

You're not going to do that because you would panic and run out the door. And if I said, okay, I'll give you ten bucks, you'd say, No, I'd start upping the ante, but I'd get to some number.

Maybe it would be $1,000,000, maybe it would be $5 million, At which point you would a little switch would go off in your mind and you'd say, I'll try it, and then you would do it and you would get your money.

And almost immediately right after that, what you would say is, Can I do it again for another $10 million? So what had happened at that point is a fundamental changes occurred in your brain where you've associated.

The thing I thought that was so scary actually wasn't, and it gave me this enormous benefit, this reward. And so that is a great way to do exposure response with children.

And so we have a video. We give our patients parents and show them how to do that. And we've had remarkable success with that, where talk therapy hasn't helped or when they where they've had sort of a militaristic exposure

response where they're like, I'm never going back there again type of thing.

But it was a technique they used with my daughter when she was in treatment that was remarkably successful. She would not touch the floor. She felt the floor was contaminated.

She wouldn't touch her phone, she wouldn't do anything. So she would literally do anything to end up not being on the floor wherever we were. And so the first day she was in treatment at the treatment center, they found that she was an athlete and she's super competitive.

And so she came into the room and two of the male therapists got down on the floor and started doing pushups. And she said, What are you doing? And they said, You're doing pushups.

And she said, I can do a lot of pushups. And they said, Oh, you can't do pushups. You're a. And they just kept doing pushups. And so after about two or 3 minutes, she got down and did pushups and legit beat these 20 year old kids.

She would. Love. Oh. She's like a ninja warrior, really. But she's in such great shape. She now plays Division one soccer for our local college, and so she beat and then a few days later, they same thing.

She came in there doing sit ups on the floor. And so this happened and she beat them several times. And ultimately they sat down in group and said something along the lines of, well, Emma, we're going to have you talk in a minute.

But I just want to point out to everybody that Emma's not afraid of the ground anymore. And she just looked at them and they said, you know, the push ups, the sit up thing, that's all it's over. It's in your past.

And then they just went on nonchalantly talking about things. So that's cemented that in her brain. And then she thought, Well, I guess I was wrong about the ground and it took it away. So beautiful.

I mean, so that's really how it and I think Europe's great. If you look at the studies in kids, it's the antidepressants SSRI, These are not as effective.

And if you have someone who's on an SSRI, about 40 to 60% of people don't get relief from OCD with an SSRI, sometimes they work. Absolutely. In fact, I've seen a few cases where SSRI has made kids start eating again.

So if I have a severely restricted food restricted child, I'll order IVIG and almost always start some, probably some Prozac or something similar to that, because I've seen a few kids that just turned a switch and they've started eating.

So I'm a firm believer of any port in a storm.

OCD Therapy, ERP, NLP, and Hypnosis

You do what you have to do and then you can always taper the person off that later. But so that's the surviving. You got to get them eating and. Absolutely.

Doing, at least doing the basics. What else do you do to help with the neuro loops? So some exciting things just in the last year, go started investigating neuro linguistic programing and hypnosis.

And so in NLP neuro linguistic programing is was developed in the seventies. And it's a system. It uses linguistics, it uses the way we talk to ourselves and the way we talk to others and uses the message, the messages that we tell ourselves, which a lot of times aren't real or aren't reality.

And so it's almost like we help people adjust the lens with which they view the world. And so NLP is really, really helpful for removing phobias almost instantly within 10 minutes.

That's sort of the party trick have been NLP. The neuro linguistic programing can help a lot of these kids reframe the situation that's going on and it can help them.

So sometimes what I'll do is I'll bring the children in and they'll say, There's nothing wrong with me. This is what our daughter said in their parent.

I'll start listing off what's going on. And the kids just sitting there looking at them and I'll say, Are they telling the truth? And they'll say no. And I'll say, Oh, you're a liar.

Brought you in here today. Your parents a liar. Well, I'm gonna have to have a talk with them. So I don't like when people lie to me. I really appreciate you for letting me know.

And almost always, that's enough to flip something, and then I'll look back in them and I'll say. Or are they saying something? That's the truth. Are they just exaggerating?

Yes. Okay. So what they're saying is the truth. Yes. So there's little bits of hypnotic language. And during the mystic program you can doing. But hypnosis has been a big the biggest surprise to me.

So I started working with hypnosis to help some of our patients with chronic pain, to help patients who couldn't sleep or who had severe anxiety. It was super effective.

And then I started doing it with some of these children and I had one particular girl that had severe contamination, OCD, and I had done everything to get the house remediated.

We gave her binders to remove mold. We treated infections, everything you can think of. I had her on low dose naltrexone. The only thing I hadn't done was IVIG, and I think I ordered that and I told her, Mom, bring her in, I want to do something with her.

And so I did a hypnosis session with her and she walked out of the out of the office without contamination, OCD, I've never seen anything like it. And same girl, two weeks later, she also had selective mutism, hadn't talked to anybody for a few years.

Two weeks later, I brought her back in and I told her mom, like, I just I don't know that this is going to work, so I'm not going to charge you, but I need you to bring her back in.

And I did hypnosis and she started talking to me that very same day. And I nearly, like, I wept. I was just overcome by that so that the ability and hypnosis really works.

I think Erikson celebrated the Milton Erikson, one of the most famous hypnotist, said, you know, you have boundless capabilities, you just don't know it.

And hypnosis really helps you understand what capabilities you have. And a lot of times in hypnosis, what I talk about is taking a capability. You had some other time in your life and transferring it to now.

So people will tell themselves a lot of I can't messages. So I could never go to I could never go to college, I could never do that. And I'll say, you know, under hypnosis, I'll talk to them about a journey of remember when you learn to walk and it was impossible and you were imbalanced and you were top heavy.

You had a big melon on your head and fell over and your feet were flat and you didn't have balance and your cerebellum wasn't developed and all those things that now allow you to walk.

But now you're an expert at walking. You could walk with the blindfold on. You can hop over things, you can ride a bike, you can jump, you can do a cartwheel.

Like, that's incredible. That's so much harder than going to college. And so bringing those capabilities over, A lot of

times you can bring those capabilities over and then people will when they come out of trance.

So all hypnosis is self-hypnosis. There's no sort of spell I put on people and. I was going to just ask you to leave. You give a little bit of because I think it is a lot of people, it sounds like something scary and.

It sounds weird, right? So we've all stage hypnosis where people have hypnotized someone to make them act like a chicken. And then and I'm not saying there's no hypnosis going on there, but the folks that get up on stage to do stage hypnosis, there's a specific process by which they're selected.

There's books written about it, how to pick a good candidate. Those are sort of the folks that you've known throughout your life that would sing loud karaoke or get up and dance on a table in the college when they were drunk.

Those are sort of exhibitionist people. They really want to be up on stage. They want to see something funny happen. They've seen hypnosis before where people's someone's asleep and they suddenly go out. You know, they've seen those things.

They've kind of have an expectation. So I'm not saying no hypnosis going on like this. I think there's some of that. But hypnosis is just a state in which you are really suggestible.

So are in trance multiple times. When you daydream, you're in a trance when you're driving down the highway and you're just thinking about nonsense and you miss your exit.

You're in a trance when you're in a really good book and someone's calling your name, you're in a trance. Most people walk around now with their phone in a trance.

You're talking and they don't hear you. They walk into a pool, they fall into a lake, they have a car crash because they're texting. So that's all trance.

So what we do in hypnosis is we just get people super relaxed. Lots of ways to do it. You know, think about your hair, think about your body. There's confusion, multiple different types of inductions.

Once people are super relaxed, we just talk to them about their their goals ahead of time. And then we talk about that and tell them stories, usually link things together and help them almost 100% of the time when they kind of bring them back up.

They've never been asleep, but we bring them back up and they almost always can remember everything that was said during hypnosis. There's no way for me to hypnotize you to go rob a bank and bring me the money.

So it's not mind control people will think about, but it's very pleasant experience. It's been shown to be work for pain. I've also have some stories about that.

I used hypnosis to be able to do natural childbirth, and then after that I it was so good that when I had to have some dental work, I just use the same techniques because I don't like the way the cane sheds.

And it's amazing for pain. Well written, well written in the and you mentioned childbirth. They've also shown shorter times in the hospital for women that have used it after childbirth or during childbirth, and they've used it in pediatric emergency rooms where they did not have the ability to sedate children, to set form fractures and had good experience with that.

That's all in the literature. So it's fascinating. You learn to do the hypnosis. So I took a few certification courses. I'm also a member of the American Society for Clinical Hypnosis.

I read a lot, a lot of trial and error, and I took several hypnosis and several neuro linguistic programing courses, both in-person and online, and ultimately ended up getting certified in both and now have practiced both.

And for whatever reason, it's just one of the most fulfilling things I do because it maybe I always wanted to be a magician because when you do it, it looks like magic, but it's really the own person fixing themself.

And I guess I like that part of it too, because I don't like to think, you know, I like to get out of the way so people can help themselves. And that's what really hypnosis is about.

It puts things, you know, in these these neurological trenches, you know, the way we think about things, how we're thinking about things, what we're thinking about and the way you describe.

I love your stories about working with these kids because it feels like you're helping them. Just very quickly get out of the trench that they're in and how they're thinking and then get it in a new groove.

Absolutely. It's it really is about getting into difference, about changing something about your environment. And so we've had some severely affected children, one I can think of in our practice where the parents ultimately took them to do an type of a well controlled wilderness therapy experience, multiple counselors.

But it was in a very rural setting where the children had to kind of get up and do chores and do things. And it was a such a total different, you know, no cell phone, no media and nothing else.

And it was life saving for this child that we tried everything else for. And so one of the things I'll tell parents a lot of times about themselves or children is, you know, if people are having a hard time sleeping in one spot, I'll tell them, go to another bedroom and sleep or go sleep on the couch.

Sometimes changing that little something about it changes the pattern in your brain, and it's in hypnosis. We call it a pattern interrupt. It's kind of what happens when someone pickpocketed you, right?

They bump into you and sort of gets you jarred for a minute in that second that you're jarred your that's the most vulnerable time to not being able to be in control of your senses or your environment.

And so that's a great time to take someone's wallet. So it's a pattern interrupt. So a lot of times I'll have parents also with those CD. I'll have parents use a pattern interrupt for OCD at home.

So if you have a child that's continually asking for reassurance or my hands clean, are my hands clean, are my hands clean, parents will instinctively either keep answering Yes, they're clean.

Yes, they're clean, yes, they're clean. Or I get really frustrated like I used to get with my daughter and be like, I'm not answering you. Stop asking me questions. You're driving me crazy.

What's the matter with you? Of course your hands are clean and so have parents. But the problem is both of those instances, if you answer them, it will seem like a placate to them.

But it strengthens the OCD. If you say I will not answer you, you're leaving them in a super anxious position. They have nowhere to go. So their anxiety builds and then they lash out and they're screaming and it gets worse.

So I'll have parents do a pattern interrupt, simple pattern, interrupt for reassurance. OCD, a lot of these kids have is if a child is continually asking you and they say, are my hands clean, do I need to wash my hands of parents say, you know, the one thing I really admire about you is the fact that you are always concerned with your health.

And a lot of children in your age aren't. And I really admire that. That's awesome. So you've taken them to a difference, but they've taken them out of the loop.

They're no longer in the loop. They're in this other place you've complement to them and left them with this positive feeling. And you can do it in a way that's not frustrated.

You're going in a completely different direction or to not say the same thing every time. The other thing you can do

is a big pattern or two is I'll tell parents to say, Oh, I think I left the dishwasher on or something and get up and move to another room.

Just that setting because you know, any of us, if we were in the midst of an OCD flare or an anxiety or anything else, if the house suddenly caught on fire, we wouldn't have any trouble shutting that down and moving outside for our own safety.

So there's something about a pattern. Interrupt that kind of like moves your cheese and gets you a little bit out of that state. And a lot of times with these kids, it will do that.

As you're talking about it. I was thinking about the loop kind of being one of those roundabout traffic. Right. Things like finding an exit with with the dishwasher or the complement or whatever.

That's such a great, great approach. So I'll help with that. I know you you're coming up on the completion of this labor of love that you have with your new book on this topic that's going to be coming out.

I'd love it if you just tell the audience a little bit about what that book is going to be, because I know some people really do want to have access to the textbook kind of level of information on this.

And so I saw a few just talk about that a little bit. Right? So I started about a year and a half ago writing a book, and my idea was to write a book to parents based on the experiences I had with these children of Pens and Pandas.

And I got several months into it, and I one of these late night moments, like I sat up in bed and said, This is all wrong. This is not the right audience.

A lot of what I do is geared at parents. Every blog on my website, speaking engagements many times are geared to parent groups. I make videos and send them to parents.

We have a whole online Pans and PANDAS program that we made a few years ago that were in process of revamping. But we give all of our parents that it's multiple modules with worksheets and whatever.

But I thought to myself, I can't think of a single parent that's ever come to my office, their child. That that said, I just don't know what's wrong with my child and what they all come in and say, No one will listen to me.

Book, Resources, and Closing Remarks

I look this all up. I think my child is pants and pants. And they're right, like every time. So I said, the the link here is we have to help our fellow physicians understand this condition.

And first of all, understand it from an evidence based standpoint. So the book's got about 1200 references and I decided to write it as a textbook. It's I made the thing that I would have wanted back when I started because I needed someone to really take me through it and say, okay, what works and what tests I be doing and when do I do IVIG and which antibiotic do I pick and how do I know and how long do I use it?

How do herbs work? Does that thing make any sense? And so the idea was I also didn't write anything that was adversarial because physicians operate on what they operate based on how they were trained.

And I think we're all train well. And I think physicians in this country do a fantastic job that you're, you know, subject to your toolbox and how big your toolboxes.

So my goal was to make this textbook to give to physicians as a tool to put in their toolbox so that they can use or and certainly anybody can buy the book, obviously, but it's written to a physician audience. It's written there's a lot of science in it and there's a lot of helpful tips and things in it as well.

But it will really help a lot of times I get calls from parents who say my child's too sick to travel and we really legally

have to see people at least once in the office to examine them.

A good physical exam is a huge part of PANS/PANDAS, and so it's hard If parents see my child has such severe OCD, they can't travel to you by airplane or by car or by anything where I've had people call from foreign countries and say, no one where I live knows anything about this.

So I figured, you know, this is the audience. We've got to produce something that allows physicians to learn about this and to look at the science behind it, behind mold and behind Lyme.

And, you know, is Lyme a big deal? Is mold the big deal? They are. And here are all the references. So here's 300 references on mold. Here's 150 references online.

Bartonella Babesia to give you to help you understand things so that you look at this and don't think, Well, that's all kind of sounds weird to me. Here's the overwhelm because they don't know.

They act like, right? Where do you. Go? Because we're not trained to treat it. So I can see patients buying your book and taking it to their doctors and saying, this is what my this is what my child has.

And then, you know, here's here's what we need to do to help. Right. And I think that would be that's one thing I'd thought of. I would actually take a step further and say, you know, take it to your doctor and say to your doctor, you don't have to accept it if you don't want to.

But if you take it and you like it, you have to pay me back. And I would accept that if I were a physician. And I think I hate to have the patients buying that book for the physicians, but I think that's the thing.

And also just really to have something that's that makes sense, that's written in a language from by doctors for doctors to to help that information trickle down to the rest of the health care system and, you know, help doctors get IVIG approved.

Here's the data. Put this into a letter and you really can't argue with it. So that's great. Well, I before we conclude, is there anything else you'd like the audience to hear today?

And then, of course, I would love for you to share your website, where to find you a private online program that you have all these tools that will really help people get even more information.

Absolutely. Of I think what I would say is there's always hope is sort of my my mantra for these patients when they come in and my message for physicians is be curious.

Right. And I think that that's something that you and I have both shared in our clinical is just the concept of, you know, when people present with a complaint, even if part of their story is anxiety, that anxieties a lot of times because no one's believed you or you've you're told you just need this medication when it's actually something entirely different.

So I don't fault the physicians, I don't fault anything. It's sort of the system. But be curious is what I tell physicians and have hope is what I tell patients.

And so you can find us. Our website is fullyfunctional.com Our practice is the Center for Fully Functional Health, but on our website you'll find contact details.

You can call our office and talk to anyone there about our PANS and PANDAS program. We have that that we've made available to people as well. The book will be on the website eventually.

I don't have any preorder details yet, but it'll also be in bookstores and in Amazon on Social media. We are the PANDAS Docs on both Facebook and Instagram, so you can find us there as well.

Thank you so much, Scott. And I just I love how you're bringing all this information together and really helping patients and their families. It's such a such a great journey that you're on.

And I'm so glad that your daughter is doing so great, So awesome. Thank you. Know, I really appreciate it as well. And I really am so thankful that this summit is coming to be it's it's too long.

It should have happened years ago. And the fact that you're bringing it and have all these folks on that are just idols of fun that I like look up to these folks.

And so I'm so happy to hear all of the talks and have access. Nice. We think that's fantastic. Thank you so much. Scott. We'll talk to you soon.