Introduction and Dr. Antoineu2019s Background

Welcome back, everybody, to the Lyme summit. I'm joined today by my friend and colleague, Dr. Scott Antoine. And Dr. Antoine is triple board board certified in emergency medicine, integrative medicine.

I want to make sure I get this. All right. Metabolic, nutritional and functional medicine. He's also a Lyme expert, an expert in pans and pandas. So, Scott, I'm really thrilled that you're joining us today.

Oh, I'm so happy to be here. Darren, always good to see you. So if you don't mind, I know you you have a personal story that kind of, you know, led you, I think, to do what you're doing today.

Can you just share a little bit about, you know, how you got involved with, you know, pans and pandas and why kind of what you do? Sure. So about ten years ago now, our daughter Emma came to us.

My wife Ellen and I are both physicians. We have been physicians at this point 20 years or so. And she came to us one day and said, I don't think God likes me.

I think I'm a bad person. She started washing your hands excessively and couldn't sleep or grades tanked and she, you know, was once a really sweet, compliant girl and she just became kind of a monster overnight, just very defiant and just a complete personality change.

And we didn't really know what was going on at the time. We called the pediatrician, didn't get a whole bunch of help there and then ended up hitting the books ourselves.

And a few nights later, Ellen came to me and she said, I think I know what's wrong with him. I think she has pandas. And I said, I don't know what that is, but I took the article and said, Sure enough, she means every one of these criteria.

And so ultimately, we had to fly her several states away to be seen by someone. And they came in and took one look and said, you're exactly right, this is pandas.

And so pandas does pediatric acute onset or a pediatric autoimmune neuropsychiatric disorder associated with strep. And he said she needs antibiotics, which we had already started around at that point, and some additional support and then likely will need I. V.

intravenous immunoglobulin. And so they flew back home and I thought, great, we now have, you know, a direction. And I called a pediatric neurologist here and said, you know, this is what's going on with my daughter.

These are symptoms. I think she has pandas and she needs IVIG. And he said it sounds like she just needs to be locked up and put on some antipsychotics.

And I just kind of said, yeah, that's not my daughter. That's just this isn't right. And so we ended up once again going on a search and found someone in a neighboring state from Indiana that would give her IVIG.

And within four days, her symptoms were gone. And at that point, I realized my specialty had found me. I said, I'm just not going to let this happen anymore.

And there's even among some physicians that were treating pans and pandas at the time, I just didn't feel like the knowledge base was enough to help all of these kids.

And so Ellen and I put together sort of a protocol, which was how am I got better? And we've successfully used it in

a few hundred children at this point and had great success.

So for I mean, you mentioned, you know, pans, pandas, you know what it is. What are some of the other symptoms that someone might experience if they've got this condition?

Right. So the definitions are a little bit loose. They originally came up with definition so that they could identify a treatment group, so they could do studies or see what kind of work did classical definition.

And we'll we'll talk about pans, probably more than pandas here. So Pans Pandas is a type of pans when it's from strep bacteria that there are also other bacteria, mycoplasma, of course, all of the tick borne illnesses we've seen.

And when it's something other than strep, we call it Pan Pans, which is pediatric acute onset neuropsychiatric syndrome. So classically, we would say it typically happens between the ages of three and 13.

We've seen older, we think we've seen younger. It's hard to tell when they're that young, but it would start with either acute onset OCD or restrictive eating.

PANS and PANDAS Symptoms and Diagnosis

Typically, the kids will say, I think I'm going to choke. I can't swallow or won't eat a certain texture or color of food, and then four of seven additional groups of symptoms.

So separation anxiety, anxiety in general about separation anxiety lay by all mood, often with depression and suicidal thoughts and gestures. You will also have neurologic signs and symptoms such as tics, facial tics or vocal tics, kind of throat clearing sort of things.

And you also see deterioration in school performance. You will see regression in behavior, baby talk, things like that. You can also see what are called somatosensory symptoms.

These children sometimes will develop really urgent urination like they began wetting their pants because they can't make it on time to the bathroom or wetting the bed, things like that.

And so those are the additional groups of symptoms. But sometimes we have people come to us and you know, the studies have shown maybe in up to 40% of the cases, it's not sudden onset.

As parents think back, they'll think, well, you know, I saw some changes six months ago. I just didn't think anything of it. In our daughter's case, in the months leading up to her sudden breakdown, she was praying a lot.

So we would sit down to eat for dinner, we would say prayer and we would all be done. And then she would be sitting there with her eyes closed and her hands folded and just continually we would see her lips moving until it became like 15 minutes and we were all kind of eating.

And and it turned out that was a religious obsession that had kind of crept in over a period of time. So, you know, the criteria or the criteria that if I have a child come to me and they have every single other symptoms other than OCD and restrictive eating, I say there's something wrong here.

There's some neuropsychiatric thing here, and we have to investigate it in very much a similar way that we went Pans, Panzer, Pandas. That meets the definition.

You know what's been shocking to me, and I'm sure you probably had similar experiences, the medical community as a whole, it seems, hasn't really embraced the idea of patterns.

And I'm always amazed the number of pediatricians in particular that are very dismissive and gaslight these parents when they come in with these kids exhibiting these kind of symptoms.

And again, the kind of that knee jerk reaction of wanting to put them on antipsychotics, I guess, for, you know, parents who are tuning in here or like you're hearing that you describe this and go, oh, my gosh, this is my my child.

Or again, it's not just children I've seen this with. They know adults, too. Sure. I guess. How do we how do we navigate this this medical landscape when you've got practitioners that are not really paying attention and often dismissive of this diagnosis?

Well, I think the reason that really happens and obviously I can't speak for naturopathy training, but in medical training, you know, we like to think we practice evidence based medicine.

We certainly do as much as we can. But a large amount of your training, there's so much training, you know, you sort of learn on the job. So you'll learn from older physicians.

If someone has hypertension, perhaps you'll start lisinopril or some other antihypertensive medication and you know, you don't really ask questions. And so Pans and pandas became controversial in kind of the mid 2000 when it became apparent that other things were causing it.

So people could kind of go along with strep because pandas had a lot of the features of rheumatic fever. So people are like, okay, I guess they kind of get that.

When we started talking about tick borne illnesses or influenza or mycoplasma or other things, it just became a different way to look at mental health.

So people were uncomfortable. And I can tell you as a physician and in our school, what was sort of emphasized was you were the best physician. If you could diagnose people and so if you're presented with someone you can't diagnose, it's almost a chink in your own armor.

So sometimes it's easier when you don't know what to say rather than saying, I don't know what this is to say. Sounds like anxiety or sounds like depression or sounds like, you know, I've had parents physicians have told them this is because your marriage is troubled or you're too permissive or you're not permissive enough for it.

So how to navigate it? Your original question is find a health care provider that listens to you, that really listens and that's willing to say, I would rather someone who is willing to say, I don't know, but I'll look it up and we'll try and figure it out together.

Then someone that's just sort of standoffish really said, you know, I am a health care practitioner and and I'm going to bestow upon you a diagnosis. I always tell parents, I don't do you a favor if I give you a diagnosis, it's just a list of signs and symptoms and things that doesn't help you in any way.

My job is to help give your child and your family freedom from the limitations that this disease puts upon you. So I want to talk a little bit about testing because again, I guess along with the controversy of the diagnosis, you know, what do you think about testing?

I remember I was at a conference, some psuedo who's at NIH, and I think she's the one who gets credited with sort of coming up with this term pandas. She is.

She kind of said, well, yeah, you can do testing, but it's kind of worthless. You know, she's like, you just need to treat based on symptoms. So do you find value in testing?

So I do. That's a very good point, though. There is no test that establishes a diagnosis of Panzer pandas. It's a clinical diagnosis. So you are basically looking at the list of symptoms I mentioned.

Also, coupled with the physical examination and big proponent of an in-person physical examination, because I found some specific things signs of dehydration.

If the child's restrictive eating or tics can be very subtle and parents won't notice them. But yet, when I see the child there, they may have an ocular direct tick where they kind of roll their eyes up.

So history in the physical is how you establish the diagnosis, where testing helps is first at the bottom of the pants and Penny's criteria. When I present slides, I like to put a little asterisk which says the original paper is produced by Dr.

Sweet Owen, Dr. Frankovich and some of those folks at the NIH said, not better explained by another neurological or psychiatric condition. The idea being, if I'm if I have a hammer, everything can look like a nail.

And so I always tell patients this, they come to me and sometimes it's not Panzer pandas. It may be purely behavioral. And I have tips to help them with those things, too. But, you know, there are children that have a sudden onset change in mental status that need an MRI urgently, or they might need a spinal tap or they might need something else.

So at times testing helps exclude other things. And then the second helpful bit, and I know this is helpful when it comes to tick borne illnesses, it gives you an initial direction to go.

And so of course we start treating empirically and we can talk about that whenever you'd like, but we start treating things typically, empirically, but once we get lab testing back, I think it's very similar to when we test for tick borne illness.

You can sometimes then change directions or at home or perhaps use a different herbal or a different antibiotic or stop an antibiotic. There might be something else that you're seeing.

So for me, it gives you supporting evidence of what you're seeing. So if you happen to get something that confirms a tick borne illness, and if I have a child who's very rageful, very angry, aggressive, suggests Bartonella is you know, when I see that, that's what I'm looking for.

And when I then get a test that gives me positive results, I say, Yeah, as I thought. So the old wise sages will say, You should never at a diagnostic test unless you know what the result is going to be.

So that's how I really look at testing and that's how I use testing in our practice. One of the problems is and there are some pediatricians and physicians and folks starting now to think outside of the box and try to diagnose pandas.

But a few times I've seen kids who went to the pediatrician. The pediatrician said, oh, I'll run an anti strep and ask an an anti DNA antibody. And if they're negative, then it's not pandas.

And if you know how those antibodies to detect whether you've been exposed to strep bacteria, they typically rise a little bit after the infection and then can remain elevated for months and then decrease.

So they may not be elevated in the acute infection or kind of like rheumatic fever, which comes from strep symptoms sometimes can lag because it's an autoimmune process.

Months after the infection. So that's one of the common pitfalls that I'll I'll mention to patients and other physicians that I may consult with is you can't rely on that. It's solely to diagnosis based on symptoms.

Well, and I think it makes it challenging, too, because a lot of these microbes that are triggering patterns like strep, for a lot of people, it's part of your normal flora.

So I think that's right. Yeah.

Navigating Dismissive Medical Care

That you're going to get rid of something that's part of you that presents challenges. And we'll talk a little bit about treatment, but I think that's something that people need to be aware of, that if you're being triggered by, you know, some of the viruses out there like Epstein-Barr virus, which I've seen in practice as well.

Again, once you get exposed to that virus as a child, it's in your body your entire life. So the idea that, you know, we can just wipe it off the face of the earth and, you know, maybe even Lyme to a certain degree, I don't know that we have great evidence that we ever completely eradicate Lyme, but if it's part of us, part of our milieu, how do we modulate your immune system then to better tolerate that microbe?

Oh, that's a great word. Modulate. I talk about immune modulation a lot because it really is the terrain, right? It's not always the bugs, it's the terrain that they're in.

And I think future directions may ultimately provide insight to perhaps how we modulate the gut microbiome since it trains the immune system. And there may come a day when we don't use antibiotics for anything, we just modulate different families in the host, which then train and modulate certain immune chemicals, inflammatory chemical cytokines to rise up and defeat whatever it is, wherever it is in your body.

I think that's a fascinating area for future, future research. So I really want to hear about your approach. I know again, this is your wheelhouse. You're working with a lot of people with patterns, pandas, Lyme disease.

So where do you start with folks? So I usually tell the parents and the kids if they're old enough to understand, but I will usually tell them there's kind of four general concepts for general things that we have to tackle.

And then after that then I will kind of outline my process with them. So the four major things that you have to take care of to get a permanent recovery from from patterns, because one of the other things I like to tell parents and if there are any listening that have a child with bands or pandas is sometimes they're led especially in online groups and social media to believe you have a pandas child, you don't have a pandas child.

You have a child that may be fighting a disorder, an autoimmune battle, an immune dysregulation, whatever, but it's not an identity. And some of these folks are told kind of once your child has this, every time they get the sniffles, they'll have a problem.

It's not true. So the four big things you have to do tackle is, number one, find and treat infections kind of obvious. Number two, find and remove toxins.

Toxins particularly mycotoxins from mold, exposure, heavy metals. Even stress can act as a toxin will depress the immune system, then allow these bugs on board to wreak havoc.

Because as you know, there are some people that get Lyme, they get infected, they never have a symptom. Now, whether they're going to have an issue many years down the road with dementia or something else, but there are other people where it absolutely kind of wrecks their life.

And a lot of that is due to other factors. So find and treat infections, find and remove toxins. The third thing is manage immune dysregulation. So this is really a case of immune dysregulation.

People will say pandas and pans are an autoimmune attack where your immune system, instead of just attacking the infection attacks part of your brain, it's absolutely 100% true.

However, these same children, when you measure lymphocyte subsets or when you measure immunoglobulins, you'll find immune deficiency. So they and if you talk to parents, these are the kids that are sick every other week in preschool, in kindergarten and throughout school.

They have their tonsils out at a young age. So it's both. The immune dial, I always say, is turned way up, way too high sometimes and stuck other times it's way too low.

And these children are susceptible to infection. So and the last thing are neurologic loops, so OCD, those things. And so if you look at those, let's say I have a child who's been well managed in the parent causing back and says, oh my gosh, they're flaring.

So my questions always are the broad general question could they have an infection or have been exposed to an infection? Some of these kids will have strep and not exhibit any symptoms.

So once again and a failure on their immune system to even mount a fever. So do they have an infection? Number two, if they had a new toxin exposure, have they been in a new new school or a new environment where they could have gotten exposed to mold?

Number three, what are we doing to modulate their immune system? And we can talk in a bit about that, different things we do for that. And then lastly is what we are seeing, just a habitual sort of OCD type behavior.

When I first started doing this and a lot of I think physicians, when they start out treating pins and pandas, a child sort of goes off the rails that you've been treating.

They've been doing well. And you think, oh, I guess I need to treat an infection. It's not always the case. Sometimes something has triggered the child that you don't know just to have this neurologic loop behavior.

So sometimes just digging in and asking parents question, you can find your way through that and fix that. So once you know, those are the big kind of categories, explain to parents the process that we use for it.

So first and foremost is the pillar we call identify their five pillars. So identify and that's identifying anything adversely affecting their health.

So that's our huge intake form. That's me meeting with them online for an hour, an hour and a half, me doing a physical exam, blood work that we might need to figure out what's going on.

Testing and Diagnostic Pitfalls

So identifying the second step is reducing things that are negatively impacting their health inflammation, infections, toxins, inflammatory foods. If you have a child who's not restricting and, you know, relationships, things like that, the third step is optimizing their ability to detoxify.

Almost all of these kids have issues with detoxification, almost all of them. And they may be the only one in a moldy house that's sick. Everyone else seems fine, so they have detoxification, etc. there.

So we will enhance and improve that. The next step is support. We like to talk about supporting the central nervous system, supporting the gut and support for the person.

So we have a pretty robust support network in our office. We contact patients. They're all assigned a health coach. We are a team in our office and how we manage the pandas and pandas.

And then lastly, personalization. So no two children are the same. There will never be a protocol book or there shouldn't be a protocol book for pans and pandas, just like there will never be a very strict protocol book for tick borne illness.

Because, as you know, it's like Dr. Moorcroft always says, it's like playing chess, right? You make a move and you see what happens and then you may have to adjust or whatever.

So there's always good things you can get started with, but sometimes you have to adjust on the fly. So let's talk a little bit about antibiotics or antimicrobials.

You know, I know this is often one of the first stops. And again, you talk about that first step being, you know, treat,

identify and treat the infection. Yep.

What is your experience with antibiotics or herbals? Do you have a preference of one or the other? Do you do both? Is there something that people should be thinking about when they're talking with their practitioner about, you know, should I take, you know, an antibiotic?

Should I start with nerve or, you know, what are your thoughts on that? So I think it's always good to get someone with experience to guide you. A lot of times children will have reactions to things, whether it's a prescription or honorable.

And so you need someone kind of with experience to to run the show that knows kind of what's going on and how to deal with any things that happen as a result of a therapy that you might prescribe.

So if you look at the information put out by the Panda's Physicians Network and the folks at the NIH, in the articles that they've written back in, I think about 2014, they kind of say if you have a new case of pens or pandas or a new flare, they would recommend and they have sort of a decision tree and they would recommend either antibiotics or steroids or both, and then have basically specific tests that they might recommend looking at to kind of get an idea, strep, titers, etc., trying to get an idea of where you are.

And so that's the general approach in a lot of places, and that's okay. You know, when you look at the general approach, you kind of advocated by the original research physicians, it was really just antibiotics, steroids, IVIG and psychiatric medications.

It's nothing wrong with any of those. And sometimes they will help. But it's a very narrow approach, sort of like tick borne illness. Right. As you know and I know I've read your book, I see it right behind you.

It's behind me when I work at home today, but it's behind me when I work and I reach for it. But, you know, to open things up, there's so many more treatment modalities.

So when I see a children, typically when they come to me are pretty severely ill. So I will usually start off with a course of antibiotics unless I'm super confused about what's going on with them.

If I'm pretty sure this is Panzer Pandas, I will usually start off with an antibiotic to target strep if I feel like that might be the player. But quite often I will start off with a macrolide antibiotic like is a through mice and or doxy cycling to treat them because it has some strep coverage.

But it also covers, as you know, for tick borne illness. I do do herbals quite a bit. I usually do them in concert with antibiotics based upon my clinical suspicion for what's going on.

There have been some times when I've had children, I may not have started antibiotics. Perhaps their illness when I'm seeing them is mild and I may not want to subject them.

You know, everything is a risk benefit ratio. I may not want to subject them to that and think perhaps I'll get test back. That says they would be easier done, Connie, which seems to be a little bit more responsive to herbs than it does to antibiotics, in my experience.

And so those children, I may start on, I'm on herbals, so I generally it's individualized to the person. Most of my children, when they come to see me, are pretty severe.

So we will usually start an initial course of antibiotics and I always worry about that and not worry about it. It's a concern because, you know, in integrative medicine, we always talk about the gut, the microbiome and the deleterious effects of not only industrial chemicals, but antibiotics and things we put in our body.

And what's really interesting is there's some good data that shows that all antidepressants since our eyes have anti-microbial properties in the gut. So that may be why they work for some people and why they're disastrous wreck for

other people.

And then Pans and Pan has about 25% discontinuation of SSRI antidepressants, which are started for behavior. And so, yes, we worry about that. And, you know, it really is like there are times in medicine where you sometimes have to do something that's not ideal, but it's necessary at that very moment.

Treatment Framework and Root Causes

And so when we do antibiotics, we always use both broad spectrum probiotics plus Saccharomyces and also have just in the last year or so, been adding in Beta eight as a gut protective measure.

We keep people on a shorter period of time as we can, although I will tell you, typically pans and pandas sort of like tick borne disease at times. You have to have children on a little bit longer period of antibiotics.

Sometimes we will sell children who came in, maybe they were put on seven, ten or 14 days worth of Augmentin or things that they're mice in by their pediatrician.

And then they immediately bounce back. So they tend to require antibiotics longer. If you look at rheumatic fever, which shares a lot of the characteristics of pandas, the current recommendation for chronic fever is that people stay on antibiotics till they're 21 or five years, whichever is longer.

So and I don't mean I don't do five years, I think on average the children probably are on antibiotics about three months apart. Some of the children might be six months, very rare to go beyond six months whenever it's at about the six month mark.

And it's not common. I get there, but I'm thinking I'm missing something. Some there's something here that either don't have the right bug. I don't have the right drug, I don't have the right I haven't supported the gut microbiome enough or it's an OCD issue, or they're in a toxic environment that I just haven't figured out yet.

Yeah, I, I agree. It's like and I'm hesitant to use antibiotics, but I've seen kids that are so bad, destructive to themselves, to their friends or family, their siblings, that you have to fight fire with fire sometimes.

And it has its place. I think one of the the clinical things I've seen in a handful of kids I've worked with is when they come off the antibiotics and quite quickly they get this rebound effect.

And it seems like every time we try to cycle them off, they're back to square one. And again, I don't know, is it the wrong bug, wrong drug, wrong approach to something else that we're just overlooking?

But I've had a handful of kids and it's really frustrating because it is we don't want to keep everyone on herbs. I really don't like keeping kids on herbs long term either.

Again, you know, even might be less damaging to the gut microbiome in the mitochondria. I mean, they're, they can still have, you know, a side or so. We want to still minimize that.

I know. I mean, what are your thoughts on these kids? Just they keep rebounding every time they come off. Is that is that just a toxicity that we haven't quite figured out or.

Yeah, yeah. What's going on? It ends up with those same four things. I always go back to, is there an infection I'm missing? Is there? And so, you know I don't commonly off the bat or galaxy lab testing for Bartonella but there are times where I get to that point and I'm like, is this just now?

And I'm just need to add something else in need to add some rifampin or something else or a different herbal and to kind of manage this. And so I'm thinking about the bugs.

I'm thinking about drugs or herbals. I'm also thinking about toxins. You know, I haven't found a great way to ask the

question about parents, about, you know, is does your how could your house possibly have mold?

Because everyone says no. So I've gotten sort of creative and saying, is your house humid? And when you ask most people if they have a water leak, they'll say, oh, absolutely not.

We've never have a water leak in my house. And I'll say, What about the basement while water comes in the basement once in a while? And so it's a hard, hard question to ask.

So I asked that I ask about schools. You know, schools are built by the lowest bidder in every city. So I remember my own high school in Riverside High School in Taylor, Pennsylvania. I'll give a shout out to anybody in northeastern Pennsylvania.

But when it rained, there were big oil barrels in the hallway and it would drip. As you know, I didn't know any better, 17 years old. So one in two homes and industrial buildings have water damage and you don't have to have a big intrusion event and can just be a high humidity environment.

So I'm always looking out for that. And even when people pay ten or $20,000 and have the house remediated, I hate to say it, but there are times where the child just won't get better there.

And one of my index tests is, I'll say, find a new clean hotel now. Doesn't have to be expensive. Take your child there for a week. Don't take any clothes with you.

Stop at Walmart and get some sweaty clothes and just stay there and have people bring your food, do something and see. And a lot of times if you have a child in that setting and they're on glutathione or an AC in binders, you'll see this dramatic change in you go.

All right. Well, we've got something going on. The other good question I like to ask is, how did your child do during the summer or how did they do on Christmas break?

Because if they get better, maybe it's the school. Or I will ask, what about when you went away on vacation and came back to your house? Very common. The kids all kind of get a lot worse.

We do see rebound. You're right about that. We do see rebound as well in our patient population after they come off antibiotics. A lot of times I will manage that with L-Theanine, an amino acid increasing the dose of increasing the dose of an AC and also inositol.

So a lot of folks will use inositol as a carboxylic sugar, but a lot of people use the inositol, unlike adults will use it for polycystic ovarian syndrome, for example.

But Inositol is really good at helping sort of aggressive behavior. You have to use a high enough dose. A lot of times people use a really low dose. Some of these kids will have to get up to 12 grams or 16 grams, depending on their size, to really help with behavior.

So I'll use those things. I also tend to talk to my patients a lot about vagus nerve retraining. I talk to them a lot about mindfulness based practices.

And then in the last year and a half has got into hypnosis. I've done a fair amount of hypnosis with my patients and had really good success. And as strange as it sounds, I recently had an A girl who just came back to me three times for hypnosis sessions and we were able to get her over her cleanliness, OCD, stop washing your hands as much.

She was able to go back to school and then she started talking. She had selective mutism. She had only talked to her mom for the last two years and started talking to everybody.

So it's amazing the mind, body, things that you can do that, you know, and this is, of course, after I had given her

steroids and tried her on antibiotics and done herbals and done all of those other things.

And there's such the power of the mind to heal is just so amazing that it really it makes a difference a lot of times. But it's hard. It's and I can't you know, no one can say they're 100%.

Antibiotics, Herbals, and Rebound Flares

So obviously we have children sometimes that don't improve and you wrack your brain. Sometimes it takes two years, sometimes it takes three years. So it's hard to be a parent.

And I always I always tell parents that there's no magic bullet and I can't guarantee it's going to be six weeks from now or six months from now. Most of the time they're dramatically better by the year point, usually some progress by six months.

But occasionally we have children that we start an antibiotic or in herbal, and four or five days later they're much better. Yeah. Now we always like to see those quick results, but I agree sometimes it takes a little bit of time.

I mean, I always think with patterns it's like being a bullfighter. You got this bull charging at you the whole time. You're trying to dodge it and manipulate it.

And sometimes Galway get in the way and you just have to you just have to stay with it. So, you know, we as your doctor, your practitioner know, looking again globally at all these different things we think are impacting your kid's brain.

But with the understanding that, again, there's so many possibilities that sometimes we just have to keep running down the list. I mean, I don't know if it's practical really to throw the kitchen sink at you.

It gets be horribly expensive. And then we don't really know what's helping you, but if you like, you have you have this very methodical way of working through the case so that we can really kind of pinpoint what's giving the best result.

You know, I really think that, you know, I used to think when I was I can remember when I was in medical school and residency, I used to think that the best doctors were these folks that could tell you, oh, on page 481 of Nellie's emergency medicine that talks about tetanus prophylaxis.

And what I discovered over the years was it was the doctor that was maybe a little forgetful but super curious. And if you are curious and you just won't give up and you do not give up, so we always say 95% isn't good enough.

I just I don't it I'll be off on vacation. I certainly try and reset my my batteries and recharge and all those things go on vacation. But it I remember I was just in Dominican Republic last summer and at one point I sat up from my chair and I said, I know what's wrong with X, one of the little girls I was taking care of.

And I actually called back to the office and said, Call this mother and tell her to get this particular thing and we'll start it and see. And it was helpful. So, so occasionally that happens.

But I think it's just about being curious, not about having all the answers. And I think any time anybody has someone caring for them, that's not curious.

That's when people tend to get dismissed. When people think, you know, a practitioner thinks, I know everything. You can't tell me how to do my job and I'm not.

So I'm happy to listen to people and listen to whatever theory they have of what's going on. And I can say I don't know, I haven't heard about that or that's not been my experience or let's try this.

But I think just being curious collects you, let you not have to have a photographic memory. So in my experience.

Well, and I think the nature of medical practice today, particularly for primary care, if you're a pediatrician, family practice doctor, you know, your volume of patients is generally quite high.

I mean, that's the way you make a living. And I'm sure you experience even in the E. R., right? It's just one slow person coming after another. And the time it takes to really work through complex cases, it's exactly that.

It's time. And as a regular practicing doc, you just don't have that time to really sit and think about it and meditate on it and and do research and do all the things that you and I do in our day to day practice now, but very hard for our medical colleagues on the other side to really be able to do that.

And I think that's where, again, people often get kind of dismissed because some doctors are like, oh my gosh, it's so much work to have to like do all that and we've done it.

But for them, I think that's why they get that wall. So like they'll find someone who's to work with you, who's going to sit with you and wrestle with the case and be willing to be curious and find different solutions.

Right. And there's a lot of burnout. A lot of burnout in medicine. And you're exactly right. You know, generally practitioners, pediatricians, they're seeing 40 patients a day.

You know, a new patient visit might be 15 minutes. An established patient visit might be 7 minutes. They're hours behind. Then they're taking the computer home and charting at night till ten or 11:00 at night. So it it's hard.

And in that milieu, it's hard to learn a new thing or take a little extra time. And so the current state of things, and I wish it weren't this way, but the current state of things is that people do have to rely on specialists, whether it's in the conventional medical field or coming to see you or coming to see me or Dr.

Moorcroft. They have to kind of rely on people that do can take a little bit more time and do a little bit more and figure things out. So I'll tell you moms, you know, dads, too, but moms primarily figure out the children of pandas.

It's very rare for someone to come to me and be like, I don't know what's wrong with my child. I mean, they they call the office and say, I have a child with patterns.

I need to be seen now and and cetera. So, yeah, I which is helpful, too, because I'm not hitting people out of left field with. Let me tell you about the strange disease that goes on, because usually they are they won't have that.

Well, I want to talk a little bit about IVIG. I know you are a champion in Indiana. I believe you actually were successful in getting the Indiana legislator to pass laws to require it right to be covered for bans.

And I know most states in the country and certainly around the world actually, I can just talk a little bit about what is IVIG. And again, why is this potentially helpful for bans?

So intravenous immunoglobulin IVIG is a product that's made by taking actually thousands of pooled human donors. And you would know about this because you were a laboratory technician, exactly how this occurs.

But they spin the serum down and then take the immunoglobulins. Those are immune proteins in your body. It's what makes antibodies. And so they take immunoglobulin G and then spin it down and make it kind of a thick, syrupy substance.

And so then it's administered to people. It's based on your weight. Generally, two grams per kilogram is what we would do for pandas. It's typically split in two.

So you give half on one day, half in the next. It's a little bit complex to give. We have very specific protocol. If you give IVIG to fast, people can get a terrible headache or vomit or get a hypersensitivity like an allergic reaction to it.

So we give certain medicines to prevent that to begin with and then are very controlled in the way we run the IVIG

and then we have medications we give afterwards.

But what we don't know exactly how IVIG works. We do know that it seems to reset the immune system. Some people believe that there are. So for every every antibody immune protein, and we're sort of familiar with antibodies in the last three years.

IVIG, Insurance Battles, and Access

But due to COVID, everybody kind of knows when you get an infection, your body makes an antibody to kind of cling on to it and market so the rest of your immune system can take care of it.

But for every antibody, there's an antigen. And in these kids, they to have high levels of antigens circulating. So some people think that the IVIG, when it goes into the bloodstream, mops all those up like a big mop and that it also takes away some of the antibodies that actually anti neuronal antibodies, they call them that attack the brain, the basal ganglia and so so IVIG tends to be very expensive, 15 to $20000 for a two day infusion.

So, of course, insurers won't give you a problem at all for paying for prednisone because it's five bucks for a five day course. But when it comes to IVIG, they typically will will rebel and deny the IVIG.

And for the longest time, they could basically say panels and panels don't exist. And then they kind of had to acknowledge, okay, they exist. But then they came out with this idea that panels and pandas, it's not effective for panels and panels. That's one that I've had recently dealing with.

So I have a specific letter that I sent with references from the peer reviewed medical literature from the Lancet and National Institute of Health that talks about the effectiveness of IVIG for it.

And I just kind of point out to the insurers, if they deny it, then they're not practicing evidence based medicine. So but, you know, insurers still in a lot of areas just deny.

They say panels and pandas isn't a diagnosis. We approve IVIG for. And so in Indiana, we went to the legislature and I testified and we got a law passed that said insurers in Indiana cannot deny IVIG on the basis of a diagnosis of Panzer pandas.

And so that's what's going on. So when people get IVIG, you can have rapid improvements. Like in our daughter's case, she was basically much better in four days after she got her IVIG.

In some children, it will cause them to have a week of pretty bad, worse maybe behavior than they had. So they'll have sort of an acute immune reaction.

Some children will also and adults will also get a really bad headache, especially if they don't hydrate. So they need to hydrate quite a bit. And sometimes we send them home with a little bit of steroid, some prednisone to help with the headache and some some anti-nausea medicine now.

But that's sort of the deal with IVIG. We've seen it be really helpful in a lot of children. There are some places, mainly kind of conventional physicians, that have started treating pins and pandas where they just give the child every child IVIG.

And it's not wrong. You know, there's a risk and a benefit to everything. And so only about 10% because of our process, only about 10% of our children end up needing IVIG.

So that's sort of, I think, the skinny on IVIG, it's can be really effective. We generally will give a dose once a month for about three months as a trial to start, if you have a child with a severe immune deficiency, common variable immunodeficiency, sometimes they will require IVIG for years, if not for life, just to protect them from additional infections and other things.

But so IVIG is a really good tool. I don't think it's the universal key to unlock every door with pain as I kind of look at it like that with tonsillectomy too.

There's not a ton of good data on tonsillectomy me for PANDAS prevention. There's some unpublished data in different places. I think if I had a child who kept getting who kept flaring and I kept getting high ISO or anti DNA strep titers or getting a persistent positive throat culture, I have no problem at all recommending for tonsillectomy, but I knew there are some physicians that will say I will not treat your child until they get their tonsils out.

Kind of like that's a little paternalistic. I'm not I'm not going to go there. So. Yeah Well, I'm in California. We do not have a law that requires that.

And it is a huge fight to get it covered. And part of the problem, too, is, you know, and when we put in our diagnosis codes, there is a code for pain does there is not a code for patterns.

And so in absence of strep markers, some assurance companies will say, well, you don't have pandas because you don't have high stress titers without this understanding.

This is a much bigger global problem. So. Right, I know for many people, again, outside of Indiana and other states that have passed legislation to require to be covered, it's often a huge fight.

What I'll do in that case, a lot of times is I'll say, because I do use the code B 95.5, which is PANDAS, which also comes up as streptococcus as cause of disease, not otherwise identified or something like that.

So I will use that code and then I would basically do a peer to peer, which is where you kind of argue with the physician or person, pharmacist, whoever at the insurance company and try and get things approved.

And I'll say this, Charles has has pandas and they'll say, well, they don't I'll say, prove it. Because if we know the antibody titers can be negative while they have the disease.

And I'll say to them, you know, what about rheumatic fever? Do you treat SONAM'S Korea from rheumatic fever with IVIG because they don't require titers for that?

And it's the same bug, it's the same autoimmune process. And so, you know, part of why a lot of times we'll talk to practitioners about how do you get IVIG approved?

And a lot of it has to do with establishing rapport with the person you're having a peer to peer with. And the second thing has to do with making them view it like both of your problem that you have to solve.

And so I'll say to them, All right, let's solve this problem today when I talk to them on the phone, if you go out people and say, how could you work for the insurance company?

You're denying this sick child like you're not going to get anywhere. But sometimes if I'll say, hey, look at it, this if you write it this way, it's actually autoimmune encephalitis.

And I see here in paragraph two that you actually cover for autoimmune encephalitis. And so I don't use in a lot of people talk about the Cunningham panel.

Yeah, and it's an autoimmune encephalitis panel. I actually don't usually use it. It's pretty expensive. It's $900 or something and it's not covered by insurance and it doesn't change what you do.

Since panels and panels are clinical, diagnosis doesn't help you, I will use it occasionally if I'm trying to get IVIG approved and I'm running into problems, and then I'll say, Look, this sick child is making antibodies against their brain.

We need to act now and get them on IVIG. And I've been successful doing that a few times, but in general, I won't.

I don't use it in general. So wonderful.

Well, again, it's like everything else. It's a tool in the toolbox. Oh, yeah. I don't think again, it's the first tool we reach for.

Support for Parents and Closing Thoughts

But if we've tried other things and we're not getting the kind of success we want, it's nice to know that that option exists so well. Before we wrap up, is there anything else we haven't talked about that you think people, parents who've been have dealing with parents and their kids that they should know about?

Absolutely. So first, not your fault. I talk to people and this is especially an issue with moms of children, with pans of pandas. They always are looking for something.

In fact, they'll get on my initial console, we typically do online and then I see them next week in person and examine them. But usually we'll do our first consult online.

And as we're talking online, I'll ask them a question. You know, tell me about this or that, and I'll say, Oh, I'm a terrible mother. I forgot to bring that paper.

And there's this sort of pervasive and maybe it's societally induced, but there's this sort of, you know, somehow maybe I missed a prenatal vitamin when I was six months pregnant, and that's what caused this.

Or the moms will say, you know, I have autoimmune disease. Did I pass this on to my child? There's nothing is part of living it. There's nothing that that is your fault about it.

And also, you need to care for yourself. So you got to put your oxygen oxygen mask on before you put it on on your child. You need strength for the long haul.

You need to eat, you need to rest. You need to take a bath. You need to call people to love you, to get help, to watch your child, even if it's so you can walk around the block once for a mile just to get your head about you was very important.

And then finally, pans and pandas is a lonely situation. You know, when your child has cancer or has something like that, people know what to do for that.

They make a Facebook group and they drop meals off, but they don't quite get pans and pandas. They don't know what to do with that. And I don't know if they think it's contagious.

But when our daughter Emma was sick, we had some people from the church, like they pulled it up, dropped them on the driveway and left. Like it was a strange thing and people just stopped calling.

I think, because it was awkward. They didn't know what to say. And so it's a lonely time. So you really need to, you know, to find people, find a group, find a spiritual connection with people that can be in your corner for you and understand what's going on.

And I will drop to you. Our we have a blog site on our website. It's got a ton of blogs about panels and pandas caring for the caretaker, the loneliness of panels and pandas, all sorts of things, including a blog I wrote on Dads of Children with pens and pandas.

Because there are specific things dads need to know. Like it's not a discipline thing. Your child's misbehaving because they're scared of death and have OCD.

It's not because they're just trying to be a little jerky. Well, this has been incredibly helpful. And if people want to connect with you, what's the best way to find you and Ellen?

Sure. So they can go to our Web site, which is WW dot fully functional dot com or they can find us on Instagram at the PANDAS Docs is enough. Well, Scott, I really appreciate you spending time with everyone and sharing your knowledge, your experience.

And we're grateful to have you as part of the summit. Oh, you as well. Great to see you.