

Transcript: #346 Could Your Child Have PANDAS? Symptoms and Solutions with Dr. Scott Antoine

Wendy Myers: Hello. My name is Wendy Myers. Welcome to *The Myers Detox Podcast*. You can

learn more about my site at <u>myersdetox.com</u>. There and on this show, we talk about every topic related to heavy metal and chemical toxicity, as well as some

of the health issues that underlie that toxicity.

Wendy Myers: Today we're talking to my colleague, Dr. Scott Antoine. We'll be talking about

what you need to know about children with PANS and PANDAS. These are neuropsychiatric inflammation disorders that have a number of underlying root causes. It's something that is affecting a lot of our children today and they're

being misdiagnosed with psychiatric disorders. They are being put on

medications and getting other protocols and medications that are inappropriate for them. They are not really addressing the underlying root cause and resolving all the symptoms, the scary symptoms that children exhibit that have these

diagnoses. Today we'll talk about that.

Wendy Myers: We're going to be discussing the symptoms related to this issue. What are the

protocols that actually work to address the health issues and resolve these symptoms in these children? What are some of the symptoms, especially the early warning signs that a child may be dealing with, with this type of health

issue.

Wendy Myers: We'll also talk about the kind of success that Dr. Scott Antoine has seen in his

practice, with the protocols that he's developed after dealing with PANDAS with his own child and not being able to get help. We'll discuss why PANDAS and PANS are not recognized more in the medical community. We'll talk about why that is and what you can do if you suspect that your child has PANS or PANDAS.

All that and more is on the show today.

Wendy Myers:

Wendy Myers:

Our guest today is Dr. Scott Antoine. He is a DO, FACEP, FMNFM, ABOIM and is also known as the "PANDAS Doc". He completed his undergraduate training at the University of Scranton in Scranton, Pennsylvania, after which he completed his doctorate at the Philadelphia College of Osteopathic Medicine. Following medical school, he completed an emergency medicine residency and an emergency medical services fellowship at Albert Einstein Medical School in Philadelphia.

Wendy Myers:

He then served seven years of active duty with the United States Army as an emergency physician, serving as both the emergency department director and the chief of the department of medicine at Fort Knox, Kentucky.

Wendy Myers:

Upon completing his term of service, he moved to Indianapolis in 2005 and worked as an emergency physician at St. Francis Hospital where he also trained students from both the Indiana University School of Medicine and the Marian University College of Osteopathic Medicine.

Wendy Myers:

In addition to his board certification in emergency medicine, Dr. Antoine completed a fellowship in metabolic, nutritional and functional medicine through the Metabolic Medical Institute, which is affiliated with the George Washington University and the University of South Florida.

Wendy Myers:

In 2016, he was one of only 121 physicians nationwide to achieve board certification in integrated medicine through the newly formed American Board of Integrative Medicine. He also holds a certification in functional medicine through the Institute for Functional Medicine.

Wendy Myers:

He and his wife Ellen, who also is a PCOM graduate, currently run a busy functional and integrative medicine practice in Carmel, Indiana, where they focus on environmentally acquired illnesses, such as PANDAS. They have five children and two dogs. In his spare time, what little there is I presume, Dr. Antoine enjoys playing the bass guitar.

Wendy Myers: You can learn more about Dr. Antoine and his work with PANS and PANDAS at

vinehealthcare.com.

Wendy Myers: Dr. Antoine, thank you so much for coming on the show.

Dr. Antoine: Thank you. I'm glad to be here.

Wendy Myers: Tell me a bit about yourself, your daughter, and how her illness motivated you

to practice the type of medicine that you do.

Dr. Antoine: I have a daughter. She's 18 and her name is Emma. When she was about 12, she

came to me and my wife Ellen, who's also a physician, and told us that she was having some troubling thoughts, that God didn't like her and she's a bad person. She also started washing her hands until they bled. She developed severe insomnia and some loss of bladder control. We really weren't sure what the cause was. I hit the books. My wife came to me one night and said, "I think

Emma has PANDAS." I said, "I don't know what that is." She showed me the

diagnostic criteria and, sure enough, she met every one.

Dr. Antoine: So PANDAS is pediatric autoimmune neuropsychiatric disorder associated with

strep. These kids will get a strep infection. Their body does what it's supposed to do, which is it makes an antibody to fight the infection. But then, the antibody crosses their blood-brain barrier for various reasons I can elaborate on later, but it then attacks parts of their brain and produces this very similar response in

these kids.

Dr. Antoine: My big problem was I started calling around once we figured it out. I called a

pediatric infectious disease doctor in my community, for help, and he said, "PANDAS doesn't exist." That really left us with nowhere to go. We remembered hearing about a doctor in New York who took care of kids with autism and ADHD, and my wife even remembered that he had talked about PANDAS once.

So I sent Ellen and Emma to New York. They saw him. He said, "Yes. It's PANDAS," and he said, "She needs IV immunoglobulin, IVIG." That's a blood product, but when you give it, it reverses some of these antibodies and helps. When they came back, I called another colleague who said, "Why don't you just give her antipsychotic medicine and put her in the hospital? It sounds like she's

crazy."

Wendy Myers: Great solution!

Dr. Antoine: I said, "Not our daughter."

Dr. Antoine: So we kept looking and found someone in Illinois who treated these kids. He

gave her IVIG and four days later her symptoms were gone.

Dr. Antoine: It was a big catalyst for me that I didn't want this to happen to anyone else.

Sadly, the parents, usually the moms, come to me and they've been told 58% by

studies that they're crazy and that there's nothing wrong with their child. It's terrible. It's very hard on the family. Our doctor was good and gave Emma IVIG, but it was very allopathically minded. "We'll do steroids. We'll do antibiotics. We'll do IVIG." We really take things from a different perspective. We look at toxins in the house, in the child and in the diet. We look at trying to enhance detoxification and really treat things as best we can naturally, but there are clearly times for antibiotics, steroids and IVIG.

Wendy Myers:

Nothing gets me more inflamed than when someone goes to their general practitioner or their doctor and is told, after trying desperately to find out what's wrong with them or their child, that they need to see a psychiatrist or are told they are crazy. They're told that there's nothing wrong, they're a hypochondriac or what have you. It's just infuriating when that doctor is dealing with a limited tool set. I think you always have to look at that. One person does not know everything, it's not possible. You have to seek answers. If you're not getting the answer you're looking for, keep looking.

Wendy Myers:

Let's talk about what causes PANDAS. I know, certainly, environmental toxins are a contributor. Can you talk to us about the whole spectrum of the underlying root causes of PANDAS?

Dr. Antoine:

Absolutely. Initially, PANDAS was described as being associated with a strep infection. After a few years, the same large group of investigators at the National Institute of Mental Health in Washington, DC, discovered that with some of these kids, even if they were caught them right at the beginning of the illness, while they still had a fever and their behavior had changed, they couldn't find strep. They started finding other pathogens, like mycoplasma, which can also cause pneumonia. Some of them were found to have Lyme disease and some Bartonella.

Dr. Antoine:

What's really interesting to me is that we've taken it a step forward, in that, why does this weird immune reaction happen? A lot of kids get strep. Why is this not super common? The reason seems to be that the kids that we see with this, a lot of times, have an abnormal immune system. They'll have low immunoglobulins. They're the kids that get sick all the time. They get unusual infections, like my daughter. She had various unusual infections as a young child.

Dr. Antoine:

What we've begun to figure out in our own practice is, we've started really looking at the environment. An awful lot of these kids have mold issues in their home. One of the mycotoxins that we commonly see in them is called mycophenolic acid. It's a strong immune suppressant. My personal theory from all the children we've seen is that these environmental toxins, heavy metals, mold and mycotoxins from molds can depress the immune system and then cause the immune system to be a bit haywire. I say haywire because they both have an immune deficiency and about 40% of them have a positive antinuclear antibody. They actually have autoimmunity or thyroid antibodies. They have autoimmunity at the same time as they have an immune deficiency. Things are really off.

When you don't find strep, it's called Pediatric Acute Onset Neuropsychiatric Syndrome. We now recognize other microbes as well, as likely toxins. That's not in the mainstream medical literature yet. I can tell you I had at least one child that we tested for every infection under the sun, bacterial, viral. Nothing came up, but he was living in a terribly moldy house. When he got out of that house and we used some binders and some glutathione, there was a complete reversal in his behavior. His facial tics went away. It was remarkable. The environment has so much to do with this. We talk about strep. We talk about these infections, but the actual root cause may be this toxin-induced change in the immune system.

Wendy Myers:

You mentioned tics. Can you talk about that symptom in particular?

Dr. Antoine:

Sure, when my daughter got sick, there was one point at which she was having an argument with my wife, I think she was probably 13 or almost 14 at this point, and she was looking up with her eyes. I said, "Now, you're a teenage girl. You're really bad at rolling your eyes. You're supposed to be able to do that when you're arguing." Sure enough, it was probably a facial tic.

Dr. Antoine:

Sometimes they'll get squinting or eye-closing tics. They'll commonly get lip smacking or a lot of clearing the throat tics. They don't tend to get what children with Tourette's Syndrome get where you get the barking or being really loud or the profanity. They may have profanity because they're defiant. That's a separate issue. But they don't tend to get a similar presentation. It's mild, but it's there. Sometimes when you have them stand with their arm out to their side, you will get almost a piano playing motion. When you're asking them to stand still, they'll almost get a piano playing tic. These tics can be really troublesome.

Dr. Antoine:

To make the diagnosis of PANS or PANDAS, it's a uniform criteria. You'll get either sudden onset or severe OCD, and that typically looks a lot like separation anxiety, counting things, lining things up, refusing to eat things. My daughter would not eat any of the meat I made. She was convinced it was raw and she was going to get sick. You'll have contamination worries. A lot of times you'll either have OCD and/or restrictive food eating. I'm not a huge fan of either type of PANS, but restrictive food eating is problematic because a lot of times these kids will feel as if they're going to choke. They'll say, "I can't eat food with sharp edges," like potato chips or pretzels, not that I would want them to eat that anyway. They'll develop one of those two things, and then at least two of seven additional criteria.

Dr. Antoine:

The additional criteria are anxiety, labile mood, meaning they're sitting eating popcorn watching a movie and suddenly throw the popcorn and are in a rage about nothing that anyone can figure out. They'll have this really labile mood. Sometimes they get very depressed. An interesting symptom I've seen a few times is children will unbuckle their seatbelt, open the door and try to jump out of the car. Praise God, we've never had any child complete that act, but that's

been something I've seen in a few kids and it's unusual. Then you can also have tics as we mentioned, physical signs and symptoms like tics; losing control of the bladder, either bed-wetting or sudden urgency during the day. If the school is not super understanding, these children wet their pants, which is socially terrible when they're 12; then they can also have deterioration in school performance. When I give a lecture to physicians, I actually have pictures of handwriting and drawing from before and after, and it's rather alarming. These children get this brain inflammation and it's really alarming the changes you'll see.

Dr. Antoine:

Those are some of the minor criteria, but the initial starting criteria between the ages of 3 and 13, are either severe sudden onset OCD or restrictive food eating or both. My daughter had both. Then the additional symptoms on top of that.

Dr. Antoine:

It's uncommon to see a child with a really mild case. By the time that parent brings them to you, the average delay in diagnosis is between one and three years. Typically they're sent from place to place and nothing seems to help. A lot of times they're placed on psychiatric medications. I think all medicine has its place, but those don't seem to work. They're discontinued about 25% of the time due to side effects.

Dr. Antoine:

These children also develop multiple chemical sensitivities. They can tolerate very few drugs. They seem to do okay with antibiotics and sometimes a short course of steroids. They seem to actually tolerate IVIG okay, but beyond that, they can react. They do okay with supplements if you do targeted supplements for brain inflammation, curcumin or whatever. They react pretty strongly and negatively to almost all the psychiatric medications.

Dr. Antoine:

Sometimes it's the right thing for the mom to take them to the hospital if they're in danger or endangering others, but I am always wary to say that, because I don't know other than pharmacology what's going to happen to the child in the hospital. They're probably not going to get a good, definitive answer, and no one's going to think to use IVIG or even steroids or antibiotics at that point.

Wendy Myers:

It's just heartbreaking when so many of our children are on psychiatric medications without really any kind of formal medical diagnosis or brain imaging to see if that's actually what they need. It's just really problematic.

Wendy Myers:

Can you talk about some of the early onset symptoms? You talked about a whole rash of symptoms that your patients come in with, that they're presenting with one to three years in, looking for answers. Are there any indications early on as to this could be PANDAS?

Dr. Antoine:

The most common initial symptoms parents will notice is a change in behavior, defiance, not wanting to listen to the parents, and usually, to be honest, that's because of OCD. The child has not confided in the parent, but the parent is telling the child to go upstairs to bed and the child's saying no. The parent is assuming it's a disciplinary issue when actually the child's terrified that

something's going to happen. OCD is probably the overwhelming first symptom, and it can manifest as defiance, but usually it's very sudden, meaning overnight. We'll have children that go to bed and wake up in the morning and refuse to put their socks on. People are in a hurry, trying to get out of the house, get kids to school, and they'll just absolutely refuse and develop almost a sensory "It's not right. I can't do it. Something's going to happen." The children will develop an aversion to going to school. They'll vomit on the way to school. They'll get extreme. You'll see a child in middle school clinging to the parent, not wanting to go into the school.

Dr. Antoine:

Typically, OCD's the very first thing that would clue the parent off. Often, though, they will say, "I just knew something wasn't right for a week or two, and then this sudden behavior started." So OCD's usually the first behavior that you see, then anxiety, then later on you would see tics and wetting the bed, things like that. Defiance usually occurs right away, and it's either due to anxiety or to OCD feelings. I try not to pry too much because it really doesn't matter when there's abnormal behavior, but a lot of the OCD behaviors revolve around "If I do or don't do some certain behavior, my parents will die or my sibling will die." They're very reluctant, sometimes, to tell you what the thought is. Thinking that it's so bizarre or that just by telling someone it will happen.

Wendy Myers:

How are these disorders treated? You mentioned a few things prior. What is your conventional roadmap for addressing these health issues?

Dr. Antoine:

We have a five-step process that we go through for most of our patients, and we see adults as well. The first step is identifying exactly what the issue is. We try and first make the diagnosis and see if the diagnosis fits. We have some very, very, very small proportion of patients come to us where the parents will say, "I think they have PANDAS," and they just have nothing. They may have attentional issues or something else, but really nothing else. The first thing is making sure that this is what it is, and once you've seen these kids, you know that.

Dr. Antoine:

Then typically we will do testing. If the behavior's very bizarre and there are other abnormal findings to a neural exam, we'll do an MRI. We don't always have to do that. Typically, we will do blood testing. We test the typical things you would test; a blood count, chemistry, things like that. We also will check immunoglobulins and see if the child has an immune deficiency. That helps us get IVIG approved if we were to need it. We also check strep antibodies to see if they're elevated. It can be an indication that strep was the thing that incited this. We will do Lyme testing and also check for Bartonella, another tick-borne infection that can cause problems. Those are some of the things that we will test for.

Dr. Antoine:

There are also auto-antibody panels that are very suggestive of PANS or PANDAS. One of them's called the Cunningham Panel. I don't order that a lot because it's about \$900. It doesn't change what I do. I get it sometimes to get IVIG approved. It's helpful to make an argument with the insurance company.

Once we've identified what's going on, the next thing we do is try and reduce anything that's negatively impacting health. That means taking the inflammatory foods, gluten, dairy, preservatives and sugar out of the diet as best we can. We really can't do that well in patients with food restriction. There are kids who sometimes that the mom will come in and say, "All I can get in them is Jell-O and rice pudding," or something. You have to make a decision that you're going to make sure the child doesn't need a feeding tube. It's hard to limit their diet sometimes. Then we say, "Well, if you're going to do things, at least do organic. Do your best."

Wendy Myers: The organic Jell-O.

Dr. Antoine: Right, we try to get them eating good food as soon as we can.

Dr. Antoine: Then we also look at other toxins. We have people test their water to look for heavy metals, and we do sometimes do heavy metal testing in these kids. We're

just really trying to remove everything.

Dr. Antoine: Once we get laboratory tests back, we try and remove it if they have infections or if they have neural inflammation. We'll typically start these kids on curcumin.

You can use non-steroidal drugs like Ibuprofen, but about 10% or 15% of the time these kids have stomach issues with them, so I try not to start there at all.

We reduce those things.

Dr. Antoine: The next thing we try to do is optimize detoxification, so what you would think it

would be like green, leafy vegetables, if you can and things like that. Also, we look at specific supplements that can help unburden or unload the liver for sure,

optimizing detoxification.

Dr. Antoine: The next would be support. We try to support the immune system. We will use

low-dose naltrexone to do that. It's used for a lot of autoimmune things, and it seems to reset the immune system for a lot of these kids. It can really change their behavior. That's a compounded medication. We will also support the immune system if we need to. Sometimes we have to use short courses of steroid medication, also not my favorite, but you do it when you have to. When

the children are in severe flare.

Dr. Antoine: Then, ultimately, either right at the beginning or somewhere along the way if

things aren't really progressing, we'll make the decision about IVIG while talking to parents. There's no absolute rule because it can really be life changing if you need intravenous immunoglobulin. It is a blood product, so we're very careful with that and we only use it in certain cases. Probably, I would say of all the PANDAS kids I see, we use it in maybe 60%. It's probably a little bit higher in a conventional practice where they're not doing a lot of the other things to

address immunity, and things like that.

Then, ultimately, the last part of it is a personalized plan. We do genetics, occasionally, on these kids. Once you get the information and you know what's going on which usually involves testing their home and the child for mold and for mycotoxins. Once you figure that all out, you put together a plan for how you're going to tackle it.

Wendy Myers:

Well, it sounds like based on the underlying root causes, neural inflammation and immunity, that CBD extract would be ideal, because that addresses immunity, inflammation and helps the brain as well.

Dr. Antoine:

We do use CBD as well. It depends on what type of CBD you have and what the taste is for the child. Even the tasteless CBD, to me a lot of them have a little bit of something in there that the children don't respond well to.

Dr. Antoine:

We use phosphatidylcholine, as well, which is great for brain support and for cleaning the cell membranes. We would use phosphatidylcholine and omega-3 fats. Magnesium is a great behavioral modifier which will help make them sleepy at night. We actually have a product in our office that has magnesium in it. It also has some inositol. Inositol works great for children with PANS, up to about a 12 gram dose, and that's not a ton of inositol but it really works well to get behavior in check. You can use small doses of GABA.

Dr. Antoine:

There's some physicians conventionally that will talk about using antipsychotics or benzodiazepines, things like Ativan or Valium. I steer clear from that. That's not something I would do. I don't think it's worth the risk to the child. Benzodiazepines are addictive, and I just don't want to go there. It's going to do the job. You're probably going to have a quiet night, but in my practice, it's not something that we do.

Dr. Antoine:

So we do use CBD. Sometimes these kids really have taste aversions to almost everything, even the tinctures. So we'll either have parents open things up or mix them in something. I've had some good luck with low dose naltrexone as well as glutathione in getting them topically compounded and then putting a topical cream on the child. They usually do okay with that, so might as well do that, because they just won't tolerate anything sweet, as best you can make the syrups and compounded materials and even some of the commercially available things, they just won't tolerate it well.

Dr. Antoine:

It's kind of "any port in storm". This is an emergency. I'm an emergency physician primarily. I've been practicing emergency medicine for 27 years, and the last six or seven years now I've been in functional and integrative medicine. I can tell you that the controversy that came with PANDAS and PANS had to do with the idea that there weren't 50,000 patient studies on what to do with these kids. There also aren't ones for patients in cardiac arrest. There also aren't ones for patients who have dropped a lung in trauma. There just aren't big studies. We just know that works and we know that it's "any port in storm". These kids are in crisis. When you see it, it's terrifying.

I usually tell people, and there are various documentaries about it, but a great film about an adult form of PANDAS is *Brain on Fire*. It's the true story of Sarah Cahalan. She was a New York Post reporter. I would recommend it. It's on Netflix. I don't get a kickback or anything, but I would recommend it. It's a fascinating story about a girl who degraded into, for all intents and purposes, what looked like schizophrenia. Her parents would not rest and got her admitted and ordered testing. I don't want to ruin the ending for anybody, but it's a fascinating film and it's what these kids look like.

Dr. Antoine:

For parents it's particularly hard. One day my daughter was sitting there doing Bible study, in my bed, with my wife. They're constant companions. The next day it's like she's gone. You look into her face and she's vacant. It's just like a different child there. It's terrifying.

Dr. Antoine:

We're in the process of writing a blog. Ellen's actually going to write a blog about the times when you would say that there are certain diseases, when it comes to mental health, where it's almost more advantageous to you to have cancer. That's a strange thing to say. When you have cancer, God forbid, people make a Facebook group. They bring you meals. Everybody knows what to say. When this happens, people scatter. That's what happened to us. Our friends, not our family, but our friends just scattered. There's no support. The medical community doesn't help. We're actually in the process of setting up a supportive atmosphere, both in our office and we're also going to have some online support groups for parents going through this, so they can get scientific results. Sometimes people get online and there's a lot of information. You have to be a bit careful. I'm committed to giving people hope, healing and science.

Wendy Myers:

I've heard some harrowing stories of some people I follow on Facebook, whose child has PANDAS. The child can fly into rages, and then they're screaming and the neighbors call Child Protective Services on them. Or they're screaming on planes, it's just an incredibly difficult situation to deal with.

Dr. Antoine:

It is, and there's no rhyme or reason behind it. You can't always attach "Oh, maybe they're just hungry or overtired." It doesn't work like that. It will be in the middle of "We were having a great day at the park, and suddenly my child pushed another child off the sliding board and flew into a rage and started hurting themselves." It's really hard to deal with.

Dr. Antoine:

One of the things that I encourage parents who are struggling with this, not to do, is try and reason their way out of it. If your child believes that there's an elephant standing next to them that's going to take them out of the house, just distract. Take them somewhere. Say, "Hey, let's go and watch a movie. Hey, let's go and play outside. Let's go do something. Where's the dog? Did you see the dog?" Something to distract them, because you can't reason them out of it. It's just almost impossible to do that.

The caution I usually give dads, from my own heart, because of the apologies I had to give my daughter when I knew better six months later. "Try not to view every defiance as a disciplinary issue. It's usually because these children are terrified." Some of these children will develop selective mutism. They will stop talking. You can imagine how that would get under your collar a little bit if you're giving them a direction or asking them a question, and they wouldn't answer.

Wendy Myers:

What kind of success have you seen since you've been working with this population of children and developing these protocols to help them overcome PANDAS?

Dr. Antoine:

We've seen a lot of success. I can say that sometimes things are difficult for parents if they're in a house with a lot of mold and the child's sick. Especially if a spouse is not particularly supportive or buying into that. It's hard to get that resolved. If these children end up in a toxic environment, like a mold-containing environment, and they're continually exposed or if they won't change the child's diet, a lot of times that stalls. We've had great success when parents have been able to do what we need them to do.

Dr. Antoine:

One of the parents I'm proudest of, she used to work for us and care for our children. She suddenly called us one day. She didn't know what was wrong. She described this classic case of PANDAS, brought her son up, and from the second they got here she was willing to do anything that I suggested. They did everything we suggested. They bought a red light unit for their home and did red light therapy. They bought an infrared sauna for their home and did the infrared sauna. They did counseling. Cognitive behavioral therapy is really helpful in overcoming OCD. All of those things, they were willing to take it to the max. We treated him for a period of time with antibiotics. I think we might have done a course of steroids, and he just completely recovered. They just were "pedal to the metal" all the way. It's hard, they came in very early, because they knew us and knew something really weird was going on. If you have a parent and it's been a while, sometimes it takes longer for their kids to get well.

Dr. Antoine:

But, we've had great success. In any medical endeavor, not everybody gets better, but I can tell you everyone heals. Part of it is healing the family and healing the child.

Dr. Antoine:

In terms of cognitive stuff, there were things my daughter didn't get back. She was a straight "A" student. Now she struggles. Likely that is due to neuro inflammation, which causes some neurological issues that may persist for her. But once she got IVIG and went through cognitive behavioral therapy, her whole life changed. She's now graduating this year. She's going to go on and be a soccer player at Wright State University in Ohio. She really is dedicated to living every day.

Dr. Antoine: Cognitive behavioral therapy is something that I suggest to parents, too. It's

remarkable. They will expose this child to what they're fearful of, in very small

doses, and then gradually work their way up. It really, really helps.

Wendy Myers: You need an expert, someone besides the parent, making suggestions also. I'm

sure that can be very helpful.

Dr. Antoine: Absolutely, because there's a dynamic between the parent and the child. Some

of the times I think the children think the parents are not smart enough to know

what's going on, so the child says there's danger here.

Wendy Myers: The child doesn't respect them.

Dr. Antoine: The worst cases are where a child assumes the parents are trying to hurt them.

It's very rare, but when that happens it's hard to deal with. To get the parent to give the child any kind of supplement, change their diet or take them to an appointment is really difficult. That's super rare. I think I might have seen one or two cases of that, and usually those are cases that we really try to get IVIG in. Sometimes that takes a little bit of bribery and holding and, if you can get it in and convince the child, steroids. That's probably an indication of where we do a little longer steroid taper, and sometimes that can really pull the child back from

the edge and get them to cooperate a little bit.

Wendy Myers: I understand that PANDAS and PANS is really misunderstood and even

discounted by the medical community. Is that still an issue that you run up

against?

Dr. Antoine: Yes, when this first came out, the problem was there were physicians that

looked at it and said, "A lot of kids have strep. Why doesn't this happen all the time?" They also said, "Look, you're talking about case reports." When it comes to IVIG, there were case reports of four children, two children, one child, 12 children, and they said, "Look, in order for us to believe anything, we need evidence-based medicine. We need 10,000 patient studies." What really

happened was that set us up for failure.

Dr. Antoine: When I was in residency, evidence-based medicine as a principle came out, in

1996, and it basically said you should have good experimental evidence for the things you do. It's absolutely true. The other part of the article also said you should never rely solely on evidence without clinical experience and patient preference, and we deleted those two things. So when I hear people that absolutely say, "I am an evidence-based doctor. I won't do anything without a

double-blind, placebo-controlled study," I always say, "There are no

double-blind, placebo-controlled studies for parachutes when you jump out of

an airplane. It's all anecdotal."

Wendy Myers: That's a very good point.

There's really no controlled studies for anything that we do in cardiac resuscitation in the ER. We know epinephrine may help. Virtually no one that's in cardiac arrest for more than 10 minutes, walks out of the hospital. But we do things. We do our CPR. We shock them. We give them epinephrine. We do things on the odd chance that they might be the one that recovers. PANDAS and PANS need to be looked at like the resuscitation. That's my message to physicians. Yes, it's still controversial, despite thousands of kids, thousands of docs like me, tons of literature. There are still people that are so stuck.

Dr. Antoine:

They think "How can neuro inflammation be responsible for psychiatric disorders?" That requires a total change in the way you think about things. One of the interesting comments the PANDAS Consortium made when they wrote their articles in 2014, was they said, "Hey, perhaps some cases of adult OCD may be cases that were missed when they were kids." They just left it there, just that simple one sentence in the article, and I thought, "Hmm. Think about that. Isn't that interesting?"

Dr. Antoine:

The other night Ellen and I were watching a show, of course on Netflix, about Ted Kaczynski, the Unabomber. As we're sitting there, they said that at one point when he was a teenager, he was hospitalized for some type of rash and then his mother said, "He was never the same after that." We both looked at each and we're like, "I wonder what that was. Scarlatina, scarlet fever. Was that from strep? Was it rheumatic fever? What was it?"

Dr. Antoine:

When you think about things in that way, it gives you hope, because you don't have to just say to the person, "You know what? Bad luck. Your child has schizophrenia or OCD. We have these medicines. They're not terribly effective. This is just how your life will be now." Giving them that glimmer of hope and support is what makes it worthwhile for me. Seeing a child recover, every time it happens, it's a miracle. It just makes me happy just to see it.

Wendy Myers:

I love doing shows like this to give people that alternative viewpoint or options. They may not get these when they go to a medical doctor that may not have ever been exposed to this, or heard about it, or poo-pooed it because they don't have the double-blind clinical trials. That's why I love to do shows like this.

Wendy Myers:

What can parents do if they suspect that their child may have PANS or PANDAS?

Dr. Antoine:

We see people from all over the country. Our website, I'm not sure if you're going to give that later, but <u>vinehealthcare.com</u>. It's the name of our practice and we see people from all over.

Dr. Antoine:

It's tough sometimes to get these kids in a car. If there's an issue, you can go to the PANDAS Physician Network website. If you search for that, you'll find it. That has a provider finder. You can find people all over the country, hopefully near you, that can help you. That's one thing you can do.

I think your best thing to do as a parent is not accept a response that does not make sense to you, concerning your child. I was a physician before I had children. When I had children, it made me a much better pediatrician. I should say, I'm not a pediatrician, but it made me take better care of kids because I saw weird things with my kids that didn't fit the textbook. They got bizarre fevers that I couldn't explain and had other illnesses that I couldn't explain. I was able to give other parents a lot of grace. If something's wrong and if someone gives you a silly answer or an answer that you don't think is right, find someone else. Keep looking. I can tell you 90% of the children that come to me, the parents sit down and say, "We think our child has PANS or PANDAS." They figure it out when no one else would for them, and that's something that is really important.

Dr. Antoine:

I had one child, not too long ago, and the parents were told, "Your child is having all these bizarre neurologic symptoms because your marriage is strained." Oh, great. Yeah, there's no guilt there at all.

Wendy Myers:

Yeah. It's all my fault.

Dr. Antoine:

Usually when these parents sit down, especially the moms, I'll say, "None of this is your fault." They usually start crying because they're wondering, "Did I not take a prenatal vitamin? Maybe it's because I ate non organic or drank non organic milk while I was pregnant." All these things that they've had, but this is just one of those things. We live in a toxic world, as I know you talk about quite a bit. Don't accept no for an answer. Find someone that can help you do the tests you need and the treatment you need. We know these kids do better, the earlier they're treated.

Wendy Myers:

Can someone work with you remotely? Where is your practice located?

Dr. Antoine:

Our practice is in Carmel, Indiana, just north of Indianapolis, the easiest airport in the country to get in and out of.

Dr. Antoine:

Typically we need to see the person the first time in the office to do a good physical exam, especially because there are some scarier diagnoses that can sometimes look like PANS or PANDAS, like autoimmune encephalitis or rheumatic fever. Those are all things you need a physical exam on. After working in the ER for 27 years, I'm super concentrated on the physical exam. I found unusual causes of this that were not related to PANS or PANDAS. They'll need to come to see us at least the first time, and we usually can do an appointment all in one day, including a blood draw. We usually get them some cream to put on, in case they need blood drawn when they're here.

Dr. Antoine:

Then follow-ups, we've done over the phone or over Skype. You can do follow-ups after that, but the first visit would be in the office.

Wendy Myers:

Fantastic, is there anything else that you want to share in relation to this topic?

I would say the one thing would be speaking to anybody who knows anybody that this happened to. Whether it's your sister or your grandchildren or whoever it would be. For the parents out there, it's an incredible place of loneliness. Your friends scatter. I don't know if they think it's contagious and their children are going to get it or what it is, but be a friend of those people and just love them through it. There's nothing easy that you can say about it, but just sitting with someone and saying, "I care about you. I'll be here. I'll do whatever I can. I'll take your other kids out for some healthy food. I'll take your other kids out to the bowling alley. I'll watch your challenged child so you and your husband can go to a movie," something like that. I think it's really important to support these folks, and that's absent in a lot of places.

Wendy Myers:

I agree. Like I said, I follow a few people on Facebook, their child they suspected or they had a diagnosis of PANDAS, and my heart just went out to them so much. It just seemed so, so difficult.

Wendy Myers:

Dr. Antoine, thanks so much for coming on the show and imparting your wisdom and insight on this topic. Your wealth of knowledge on this is so appreciated.

Dr. Antoine:

Thank you and if anybody wants to go, we have a ton of blogs, diagnostic criteria, information and support on our website, <u>vinehealthcare.com</u>. Anybody can come there and start reading. We have some introductory material, some more advanced material and just a lot of information, as well as some support for folks that are going through it.

Wendy Myers:

If you suspect, if you identify with any of the symptoms that Dr. Antoine discussed on the show, definitely go check out that resource.

Wendy Myers:

Everyone, thanks for tuning in to the *Myers Detox Podcast* where we discuss every type of topic related to heavy metal and chemical toxicity so that you can discover if you or your child's health issues are related to toxins in your environment. Thanks for tuning in and I'll talk to you guys next week.