

Dr. Nancy: Okay. Hi. This is Dr. Nancy. We're coming somewhat live on Wednesday. Welcome to another lunchtime interview with Dr. Nancy. Today we have Tara Fox. She tells me she's going through her doctorate right now, but right now she's working with patients with PANS and PANDAS. I know it's not a familiar topic to a lot of people, so we wanted to bring this to the forefront because there are a lot of kids with this and you may not really know that they have it.

Dr. Nancy: I want to have Tara introduce herself to you and let us know how she got into this. Welcome, Tara.

Tara Fox: Thank you so much for having me. I really appreciate it.

Dr. Nancy: Oh, you're welcome.

Tara Fox: A little bit about me and how I got into this. I was in infectious disease for seven years. During that time, I started to see patients who seemed to not really fit exactly into infection alone anymore. They seemed to have some neuropsychiatric issues and some changes in their behavior, even post infection. I started to get a fairly large population and was seeing a behavior change with these children. With that, I started to gain a little bit more interest in the area of kind of a broader topic of encephalopathy or inflammation around the brain.

Tara Fox: About seven years, I got more into it. Over the last few years, I've been really interested more in how we can get more providers, more parents, and even the community to know more about this rare, but significant, disorder.

Dr. Nancy: Yeah. You say rare, but I think it's a little more common than people think, really.

Tara Fox: Yeah. Exactly. The new NIMH study suggests that there may be as high as 10% of kids that suffer from OCD or a tick disorder may have one of the encephalopathy type disorders... again, inflammation around the brain... known as PANDAS and PANS.

Tara Fox: PANDAS, which has gotten some notoriety over the last few years, is a disease that we know. It stands for Pediatric Autoimmune Neurologic or Neuropsychiatric Disorder After Strep. A really long title that can be difficult to understand, however, it's usually related to an infection of strep of some kind. I think most of the time we think of strep as a sore throat type of infection. However, there are some studies that suggest it can be associated with infections on the skin too.

Tara Fox: After these infections, approximately two to four weeks later, patients usually between the ages of three and nine... although, recent studies have suggested that a large population fall within that range... tend to develop symptoms in the neuropsychiatric family. Meaning, the start to have really severe OCD, tic disorders. PANDAS is really a very specific disease because we know that it's associated with strep. Usually, it's an abrupt onset and occurs two to four weeks after.

Tara Fox: Along with that, we see other children that may not fit in the strep category and have similar symptoms. PANDAS is uniquely defined because of the strep, but also because it usually doesn't result in the restrictive eating that we see with some of the other types of infections that can result in these symptoms. So, that's where we start to talk about PANS, Pediatric Autoimmune Neuropsychiatric Syndrome. Whereas, kind of just more of a broad... we know that the child had an infection of some kind and that happened, likely, two to four weeks, but we can't say with any certainty. The symptoms usually look very similar to that of PANDAS, but a lot of times, again, they're very remarkably restricted in their eating.

Tara Fox: The restriction is more they're very specific about what they can eat and they become very sensory sensitive. A lot of times it's not that they're unwilling to eat. They're only very specific about what they will eat or how they will eat.

Dr. Nancy: So, like they'll only eat white foods? Things like that? Okay.

Tara Fox: Exactly. In my own practice, I had a child who would only eat potatoes, pretty much in any form, but that was about it. So, nutrition becomes an issue. Along with this, we also see, again, that OCD picture. A lot of times what happens is the family doesn't find out until later that this could even be a process that happens. They see their child completely change and are told that it's a psychiatric or psychological issue. They go and see a psychiatrist or a psychologist and they're put on certain medications or gone through certain therapies that may or may not be effective.

Tara Fox: Usually, with the PANDAS and PANS and encephalopathy picture, we use a very different type of treatment and it really is based on the individual and what kind of diagnosis they have. With somebody who has PANDAS, they may respond better to something like ibuprofen than a neuropsychiatric medication like Prozac for OCD. That's one of the reasons why we need to get more information out there about this disorder.

Dr. Nancy: What are some of the things that parents can look for that would alert them to PANS or PANDAS?

Tara Fox: That's a great question. Let me pull up my screen so we can share and I can show you a picture of the symptoms and how when I explain it to other people how they can remember.

Dr. Nancy: Okay.

Tara Fox: Share my screen around the back.

Tara Fox: Here is just a short explanation of what PANDAS, PANS, and... what we call PAER. Again, post infectious autoimmune encephalopathy, a set of symptoms that occurs after infection, can really be broken into the PANDAS and PANS. So, we'll briefly talk about PANS. I always like to include pictures because it helps me visualize the symptoms and put them in order.

Tara Fox: Abrupt onset of dramatic OCD. A distinct change in your child's behavior is really what you would notice. One patient that I saw, a nine year old for her initial visit, she had a very distinct, abrupt change in her behavior and became very obsessed with the weather. Constantly asking about the weather. Constantly asking about concerns for tornadoes and hurricanes. That was a really interesting picture. In addition to that, she did have severe restrictive food eating, only eating at specific times.

Tara Fox: So, a patient may not always present with just having what types of foods they eat. It may be times that they eat, or how many times they have to chew the food. Or, they may be sensitive to the textures of foods. Like they won't eat soft foods or they won't eat extremely hard foods. In addition to this, there's no obvious, clear explanation, but there's no history of OCD, there's no history of a stressor or an environmental factor that would result in these symptoms.

Tara Fox: Whenever I hear, in clinical practice in any frame, a child that has an onset of OCD or has OCD, I always ask the parents, "Did this seem to come out of nowhere?" Because that helps give me an idea if we need to go down the path of this disorder. In addition to these types of symptoms, a lot of times we'll see at least two forms of other neurologic symptoms. The most common ones I see are behavioral changes. That would be regression, baby talk, changes in behavior, not wanting to hang out with their friends, or having a hard time relating to their peers, and oppositional behavior, where we have a child who may have not necessarily been very argumentative who becomes really resistant to doing any type of activity.

Tara Fox: In addition to this, we also see a lot of stomach issues and a lot of joint pains, usually in the lower extremities. The stomach pains tend to come and go intermittently, but those are the most common signs that I see, overall, when I suspect PANS.

Tara Fox: Again, PANDAS is very similar in a lot of ways. However, it does have its distinction being associated with strep alone. In addition to this, although PANDAS and PANS can both be what we call relapsing and remitting, meaning that it can come and go and the severity can change, PANDAS does tend to worsen with any type of infection. You may see that your child seems to be doing really well, but then they get a cold and all of a sudden their symptoms seem to be "flaring" again. In addition to that, we usually see PANDAS more in the pre-pubertal population. Usually, again, between three and nine. Although, that's pretty common for PANS also. With the onset of PANDAS, we usually see it very much early on. Usually with the first strep infection.

Tara Fox: Obviously, PANDAS can have any of the PANS symptoms. They're very similar, but the distinctions are there and it is important to determine the difference between the two. Overall, if you have a child that has a history of OCD, tick behavior, Tourette's, onset of anxiety, or any abrupt onset of neuropsychiatric changes, it wouldn't be unreasonable to think that this could be in the differentials of diagnosis.

Tara Fox: I'm going to stop sharing my screen now.

Dr. Nancy: Okay. If a parent does see some of these symptoms, is there a test you can run? How do you really know? Is it just based on the history?

Tara Fox: That's a very good question. It's actually fairly difficult. There are some tests that have come out. They're extremely expensive and the studies are still out on whether they really determine the difference between autoimmune encephalopathy, PANDAS, and PANS. The tests, right now that exist, are called the Cunningham panel and it looks for something called autoimmune, or anti-neuronal antibodies. So, antibodies that we're building to our nervous system. But if you've had any type of nervous system issue in the past, or you have a genetic propensity, you may build these without any symptoms at all. Again, even with a positive test, it may not be true, or vice versa.

Dr. Nancy: Go ahead.

Tara Fox: No. So, yeah, the Cunningham panel's out there. It's very expensive, but it is an option. Madeline Cunningham developed it at the University of Oklahoma. Currently, I'm not using it in practice as frequently because, again, when I think about what tests I run, I think to myself, "Is this going to change the plan of care?" If I have a child who comes in with an abrupt onset of symptoms, then I usually like to check other labs to make sure we rule out things of a different etiology. Then also, I usually do like to have a psychologist on board, just to get their input. We do run other tests to just determine any autoimmune players that may play a role. But for the most part, there's no specific test. It is really a clinical and historical diagnosis.

Dr. Nancy: Have they found what child may be susceptible? Is it a genetic connection? Is it an immune compromise? Is it anything like that?

Tara Fox: I'm working with the University of Arizona and what we have found is we do think that there may be some, what we call, epigenetics where you have a genetic predisposition to this and then a gene gets turned on because of infection, but only in the nervous system. So, that makes it a little bit harder to determine. But I do think that there's some interesting studies out there that also suggest that maybe gut flora plays a role in it. It's really a holistic view, in a lot of ways. We're just looking at ways we can lower inflammation in the form of treatment, but also how do we recognize these children earlier on? That's a little bit more difficult, but we do believe genetics and exposure, immune function, and even your own nervous system... how it's chemically wired... may play a role in it too.

Dr. Nancy: Once they are diagnosed with this, does it ever go away? Is this just a childhood disease? Is this something that they'll take on into their adult life? Or, do we know?

Tara Fox: Yeah. I would say, with my experience, I do believe that everybody does take it on in their adult life because the brain chemistry changes. So, even if we treat it early, I do think that we have changed the way that the brain functions. Basically, if we think about it like the brain is an area that's inflamed, so chemicals become more permeable. They can get in and out a little bit easier. Even if we get rid of the infection, you still have that tissue that has to heal. So, the earlier we treat it, the more we can rewire the brain to

function differently. Just like somebody who has anxiety. They don't necessarily grow out of it, we just gain the tactics and treatment to minimize the symptoms of it.

Tara Fox: We do see that, a lot of times, by the age of 20, 21, symptoms can resolve fairly significantly with certain therapies. That may include ibuprofen. That may include cognitive behavioral therapy. That may include probiotics. It's really interesting because each patient presents differently in how they respond to what.

Dr. Nancy: Okay. Also, can you describe what a flare would look like? Is it just going back to how they were, originally? Is that what that is?

Tara Fox: Yeah. Not always. They can present very differently. I have a patient that I see who started off with this really significant change in their school behavior. That's how it started. They had these periods of what I would call almost like brain fog. They were unable to attend school. They couldn't focus. They couldn't function. That has kind of progressed to the point where he just has a difficult time reading. Now, when he has these episodes... this is three years out and he still has, but he recognizes them and we can do some treatments that may help.

Tara Fox: So, I think they can present exactly the same. They can present very differently. But again, knowing that you get familiar with the pattern of behavior and when it can occur.

Dr. Nancy: Okay. That's all the questions I had. Did you have anything before we close? Any tips or any advice you want to share?

Tara Fox: Yeah. I think the biggest thing is if you have a child, or you know a child, who has OCD or tic disorder and doesn't seem to be responding to traditional medications and therapy, it would be an excellent job to just look into this a little bit further. You are more than welcome, obviously, to make an appointment at our clinic, at TRF Pediatric Health, that's collaborating with Excel for Life. It is something that, again, is usually not seen in the primary care, but really needs more awareness.

Dr. Nancy: For the people that are listening on our podcast, can you actually give us your website, if anybody wants to make an appointment with you?

Tara Fox: Yes, it's www.trfpediatrichealth.com.

Dr. Nancy: Okay. And that's F, as in Frank, right?

Tara Fox: F in Frank. Yep.

Dr. Nancy: Okay. Awesome. Great. Well, thank you so much, Tara. It's great information. I think you're going to open up eyes to a lot of parents with kids that are experiencing this, that really don't realize what's going on. So, thank you for sharing this information with us today.

Tara Fox: Of course. Thank you for having me, Dr. Nancy.

Dr. Nancy: Okay. Have a awesome day.

Tara Fox: You too.

Dr. Nancy: Thanks.

Tara Fox: Bye. Take care.

Dr. Nancy: Bye.