

Unless SOMEONE LIKE YOU CARES a whole awful lot, *nothing is going to get better, it's not.* – Dr. Seuss

Until recently, all (I thought) I needed in a pediatrician was knowledge. Then, in April of this year (2016), we visited our child's pediatrician for some wise counsel and I realized I needed more: empathy. **Sympathy** is feeling sorry for me. **Empathy** is putting yourself in my position.

Don't send me off with a sympathetic smile and another prescription. Instead, with empathy, **imagine what we're going through** and how you'd react if it happened to your own helpless child. Wouldn't you dig deeper? Learn more? Keep pushing for answers?

When my son was thrust into an unexpected maze of illness, leaving us powerless, dependent, and searching for answers, I found myself in doctor's office after doctor's office seeking clarity and guidance, only to be met with indifference, confusion and even disbelief.

PANDAS. Pediatric Autoimmune Neuropsychiatric Disorders Associated with Strep. If you're a pediatrician and you're reading this, you've either heard of PANDAS or you haven't, and you either believe in it or you don't. Regardless of where you fall on the spectrum, I beg you to read this. Be empathetic. *What if it were your child?*

Because of our persistence in finding knowledgeable, *empathetic* doctors and our refusal to follow the original doctor's advice of looking at local mental wards, our agonizing journey lasted under 5 months... but that is NOT the case for most families. As a parent my heart was ripped out time and again watching my son go through what he did, and then stomped on by doctor after doctor who "didn't believe in"/"thought it was controversial"/"saw too many red flags"/"couldn't get on board" or others who had never even heard of this disorder. If it is true that you went into pediatrics because you truly care for children and their well-being, I feel it safe to assume you'd want to be well-equipped to help the next child who comes to you with the extremely frightening symptoms of this very real disorder. (Real. Not Rare. 1 in 200 children are affected.)

I asked for knowledge and empathy; now I'm pleading for responsibility and compassion. Learning more about this is the responsible, compassionate thing for someone in your position to do. And if it ever plagued your own child, you wouldn't doubt this disorder's legitimacy.

Imagine the following timeline playing out in your own home. **Envision** your healthy, loving, playful, clever, sociable, talented child presenting the following symptoms with no warning. **Conceive** the confusion, terror, stress and agony it would flood your home with... **Consider** how quickly your child's ability to learn and socialize at school would diminish. **Picture** the toll it would take on your heart, your sanity, your faith, your finances, your relationships and *all* of your children if this occurred in your home. **EMPATHIZE**. *Would you take your kid to a mental ward?* Because that is what our (then) pediatrician said to do. Instead, we got our son PANDAS-knowledgeable doctors, discovered the hidden infection (staph in his tonsils- strep came back negative), and administered IVIG. He is 100% better and wanting to help others so theirs', too, can be a shorter timeline with a happy ending.

Sample PANDAS timeline (every child is different in order, presentation and severity of symptoms).

Day One: your child wakes up and has OCD. Full-blown, debilitating OCD.

Week 1: Your child's OCD has worsened, their personality is fading and they have massive anxiety.

Week 2: Your child can't get dressed for school or make it through the day; his handwriting is changing (which is frightening to see), his mood is alarming, he restricts his own eating and is wetting the bed

Week 3: You barely recognize your child; he has physical tics and is hyper and defiant. He still isn't eating, he doesn't sleep well and now has a severe phobia of germs.

Week 4: Your child is a sobbing, depressed mess. There is no explanation for his sudden change in demeanor, behavior and mood. *You* are a sobbing mess because you can't comfort your child (who no longer engages with you or your other children like he did before). Doctors are suggesting mental help but you know that your child was mentally healthy just weeks ago. Everything was acute onset.

The research you do yourself only gives you more questions than answers.

Week 5: It's been a month but it feels like a year; you lie awake at night trying to recall what life was like JUST 30 DAYS AGO! What happened? What am I missing? What doctor will know about this? How do I find this doctor and how quickly can I get in? What if another doctor sends us home without answers?

Week 6: Some doctors you've seen have prescribed antibiotics, but for differing reasons and differing amounts of time. Some suggest keeping him on antibiotics for the long-term, but everything you read tells you this is so bad for his gut health. You wonder if they'll work, for how long, if your child will suffer long-term effects of being on all these, and if they're really necessary, or if there is something else out there. Still other doctors think your child's problem is strictly mental and antibiotics aren't the path, but rather psychiatric help. You're physically sick to your stomach and haven't slept in weeks; it's too difficult to wrap your mind around, let alone explain it to family and friends nearest you who wonder what is going on with your family. As sick as you are, your child is sicker. And it's a real sickness. This isn't your child and you know it. You aren't in denial about mental illness, you just know it's something else and the doctors are missing something. You aren't crazy. And more importantly, your child is *not* crazy.

This is only a glimpse at how PANDAS can barge into your life. For most, it's a years of determining it's PANDAS they're faced with and then finding doctors who can and will help their child beat this disorder. We "fired" the doctors who thought my child needed psychiatric intervention and found knowledgeable, empathetic, responsible and compassionate doctors who eradicated the infection and then calmed and retrained his immune system. Every single symptom went away entirely and he was himself again.

It is my moral obligation to do what I can to ensure that every child has a chance at the treatment my son did. Don't miss this diagnosis. Don't send these families away. What would you do for YOUR OWN CHILD?!

www.pandasnetwork.org

www.neuroimmune.org

www.nimh.nih.gov/

Knowledge ~ Empathy ~ Responsibility ~ Compassion