

**UNLESS SOMEONE** LIKE **YOU** **cares** a WHOLE aWFUL Lot,  
*NOTHING* is going to get better, it's not. -Dr. Suess

Dear Educator,

I've written this letter specifically for teachers and asked friends and family to help me pass it along. I am on a mission to raise awareness of an under-appreciated childhood disorder, and I felt it was essential to start with the wonderful teachers that love, observe and spend so much time with our children every day! In April 2016, my son was attacked by PANDAS... no, not the bears—but an equally threatening disorder caused by a misdirected immune response in the body that results in inflammation of the brain, and causes extremely scary, overnight symptoms to present themselves in an otherwise healthy, happy child! What you observe in the child over the first days and weeks is terrifying, confusing and gut-wrenching (see example timeline below—every child's case is different); because of *your* interactions with children and influence on them and their families, I wanted to urge you as a teacher to take just 30 minutes of your day to read about:

**PANDAS.** Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep.

If you have a child in your care that is dealing with this, be as caring and patient as you can and understand the parents are in a great deal of distress trying to find and receive the proper treatment for this disorder. And if you witness a child changing drastically before your eyes, gently approach the parents about it and if they concur that the child's behavior and personality are suddenly different, make sure they are aware of PANDAS and encourage them to do their research and seek medical help by a PANDAS-knowledgeable doctor! 1 in 200 children are affected by PANDAS! It is treatable!

Thank you for teaching our children, loving on them all day and being another set of eyes and ears to help us catch health issues like these!

When my son was thrust into this unexpected maze of illness, leaving us powerless and searching for answers, I found myself wondering daily "what would I do if he were in public school?!" We homeschooled and most days his debilitating OCD and new fear of germs made just getting dressed an impossible feat. His decreasing handwriting skills made his penmanship illegible to even me, and he couldn't focus long enough to listen to a story, let alone memorize multiplication facts! If he was enrolled in traditional school, he very likely would have been held back and possibly even disciplined for behavior changes out of his control. He received the proper treatment (after we ignored doctors who believed he was going crazy and needed to be in a mental ward!) and is doing 100% better, because not only is he healed, he is grateful and wanting to help others so their PANDAS timeline can also be a short one with a happy ending!

Imagine a healthy, loving, playful, clever, sociable, talented child in your care presenting the following symptoms with no warning:

KNOWLEDGE ~ EMPATHY ~ RESPONSIBILITY ~ COMPASSION

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

**Day One:** your child wakes up and has OCD. Just like that...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 he has a severe phobia of germs.

**Week 4:** Your child is a sobbing, depressed mess. There is no explanation for their 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 perfectly healthy mentally 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 doing so is bad for your 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 it. You aren't crazy. And more importantly, your child is ***not*** crazy.

This is just a glimpse at how PANDAS introduces itself into a family's life. For most, it's a year+ of determining it's PANDAS they're faced with and then finding doctors who can help them down this less-beaten path. We "fired" the doctors who thought my son was crazy and found knowledgeable, empathetic, responsible and compassionate doctors who believed in and treated my son for PANDAS. Every single symptom is gone; he is entirely himself again.

**Be informed. Know the signs. Help the families.**

## ***Helpful info:***

[www.pandasnetwork.org](http://www.pandasnetwork.org)

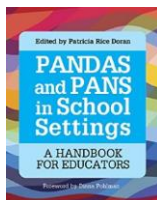
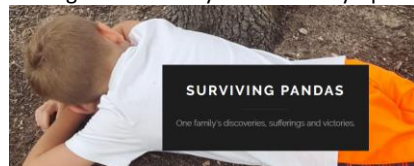
-An informative site where you can also learn about PANS, a very similar misdirected immune response that causes inflammation in the brain, but instead of being caused by strep, can be caused by other infections (Lyme's Disease, Mycoplasma, and more)

<https://iocdf.org/pandas>

-Provides a quick, easy to understand explanation of what PANDAS/PANS is in first paragraph!

<https://survivingpandas.wordpress.com/>

-A blog of *our* weekly timeline of symptoms, doctor visits and medicines tried, tests completed, surgeries, IVIG, etc.



And every school should have these:

Encourage your school to make the small \$40 investment to own a copy of PANDAS and PANS in School Settings and the children's book In a Pickle Over PANDAS