

What if? - A Mother's Perspective on PANDAS

Imagine you have an 11 year old son who does well in school, has lots of friends, likes his teachers and enjoys sports. Life is busy, but "normal" busy. Then he gets strep throat, and your world changes. Your healthy, happy child develops a sudden, almost overnight, onset of anxiety, tics, OCD and rage. The child you once knew is gone. School, sports and friends are no longer a part of your normal routine. You go from a life of predictability and consistency to chaos and confusion. You are racking your mind wondering what has happened to your child. Knowing your child better than anyone else, you know that something is terribly wrong. Then you start researching to find answers. You confide in a few good friends. One of them says she has heard of a friend's son with similar symptoms. You connect and hear about PANDAS. You vaguely remember hearing about a connection between strep and anxiety so you google PANDAS. Interestingly, your child meets the diagnostic criteria to a tee! You contact your pediatrician who says she doesn't believe in PANDAS. So you find a new pediatrician. This is when you realize it is solely on you to be the advocate for your child. You mourn as you watch your child deteriorate in front of your eyes. Simple tasks that you once took for granted are almost impossible. Instead of waking your child up, eating and heading off to school, your mornings are defined by your child screaming and fighting not to go to school, and even trying to jump out of the car. You experience feelings of confusion, anxiety, guilt and hopelessness. You feel alone.

Then you research more and you network. You know you have to get your child back. You find strength that you did not know you had. Your family is affected socially, economically, physically, spiritually and psychologically. You realize that parents are the driving force in getting their PANDAS kids better. You also realize that there is no way anyone can possibly understand the nightmare of PANDAS unless they have lived it. You have to remind yourself that the hurtful words your child says, he doesn't really mean. Although hugs and kisses are replaced by anxiety and rage, you know it's not your child. So you fight even harder to get him back. Because PANDAS is often misunderstood, people may question your parenting or think that your child is just misbehaving. Adding to that, your child may look healthy from the outside, but may be battling OCD, intrusive thoughts, attachment issues, and many more disabling symptoms. You are beyond frustrated but you love your child and you have to keep fighting like hell to get him better. Then one day you see a light at the end of a tunnel. Your child is coming back. You rejoice, but not a day goes by that you don't worry about losing your child again... When you are out of "survival mode" from a flare you continue to advocate. You try to explain that PANDAS is a "medical condition" causing neuropsychiatric symptoms. You hear PANDAS coined an "orphan condition" because there isn't a specific medical specialist that treats it. Do you see a pediatrician, immunologist, neurologist, ENT, infectious disease, or a psychiatrist? We saw someone from almost everyone of these specialties. Then you read that most people see an average of 9 doctors before they get the help they

need, and you feel for them. You get it. You've been there. You enjoy the summer. Your son is doing well and you are even able to go on a few trips. Then school starts. A few weeks later, your child is sick again. This time the symptoms are significantly worse than before. You have read that subsequent infections can cause more dramatic flares. Your child is gone again. In addition to OCD, ADHD, tics and rage, your child starts seeing things and is banging his head against the wall. Thankfully he doesn't remember these events, but we do. It is etched in our memory. School is no longer an option. You resign from one of your jobs and home school. Thankfully your child's school is supportive of your situation and they offer home bound services. Teaching a child with a limited attention span, hyperactivity and a short fuse is challenging, but you do it anyway. Your daughter spends most weekends with friends to get away from the stress induced by this illness. You miss her but know she needs a break. So PANDAS becomes your new "norm". You learn to recognize certain behaviors that signal a flare. You continue to research and network. You pursue all available treatment options. You keep fighting the fight and know that one day, you will get your child back. PANDAS is a terribly debilitating illness - not just for the child who has it, but for the entire family. Your marriage suffers. Intimacy is gone, you rarely laugh anymore, and you fight over the best way to deal with the flares. Siblings suffer. Your attention is so focused on your PANDAS child that you have very little energy left over for them. Some strategies that have helped our family - a good cognitive behavioral therapist can help with discipline and structuring your day, especially during a flare. Learning not to yell during a flare also helps, no matter how frustrated you are! It only escalates the situation. Also listen and try to have minimal conversation when your child is irrational - there is no reasoning with them. Learn to work together with your spouse as a team. Let your spouse take over when you feel like you are losing control. Praise your child for good behavior. Take a day off and relax. That will help you cope better on the bad days. Spend alone time with your other child/ children. And certainly find a good support group and the support of caring friends and family. We are all in this fight together to get our kids back!