

Mom - Jennifer Rowan
Son - Drew Clark (age 5)
Stayton, OR 97383
Dx PANS. Current Psych Dx Anxiety disorder with OCD

Drew was an active healthy "daredevil" of a 4 year old. Big for his age at 4 1/2, he lied to a ride operator at a local fair and told the man he was 7, in order to scam his way onto a 2-story zipline. He loved it! That kind of daredevil. Fearless. Though he frayed my nerves I miss that side of him so much.

A few weeks after the zip line incident, he became ill with the same bug as all the kids at daycare, fever & persistent cough. Soon after he recovered from his illness he became increasingly anxious. He had extreme difficulty separating from me, to the point of vomiting. At first we thought this was a normal developmental phase but as his anxiety worsened, we began calling doctors. As we waited for an appointment his symptoms worsened. On Monday November 6, 2017 he woke up with OCD. By the end of that day he exhibited every OCD symptom you can imagine. Excessive hand washing, mopping floors, lining up toys, anorexia, suicidal ideation. Yes in a 4 year old. He became obsessed with the size of his tummy & refused to eat until lost 7 lbs in less than a week. Then he became paranoid about water and became dehydrated. He talked about dying & wanting to "cut the nervous germs out of my tummy". I came into the kitchen to find him trying to stab himself in the stomach with a steak knife, his shirt torn open & skin bleeding. At the same time he was losing fine motor skills (no more legos or silverware) social skills (afraid of everyone except me) language (down to one-word utterances & grunting) and all areas of executive functioning. The first ER doctor we saw wrote a diagnosis of "autism with psychosis" & referred us to Doernbechers. Doernbechers doctors categorically do not believe PANS/PANDAS is real & though spinal tap, MRI etc etc revealed nothing, refused to try a simple round of antibiotics. They chalked his symptoms up to judging me as "an anxious mom" and that "four year olds go through funny phases". The next day I drove him to Randall's ER. They also had not heard of the condition but that doctor's more reasonable approach was "In the absence of another diagnosis to offer you I'm willing to prescribe antibiotics." Hallelujah. Two days after his first dose of azithromycin my son started to come back to me.

Fast forward.... we are in a good space now. My son took months to heal. Extreme anxiety, OCD, & hyperactivity have been the main residual symptoms. We go to Children's Naturopathic Centre for treatment, where the doctor is both an MD & ND. She prescribes traditional treatment as well as naturopathic supplements & dietary regimen. Her costs are not covered by insurance. Neither are the supplements. We have Moda. I realize we are lucky to not need IVIG or other advanced treatments (yet) but I'm also aware that my son could have a setback at any time. We dread the upcoming cold & flu season. That said, we spend about \$420 per month on doctor visits & supplements. I am a special education teacher, my husband is a janitor. We have good insurance but these costs are a huge burden. Not to mention the costs of our 3 hospital visits that were mostly but not all covered. My husband decided to retire early so we could keep my son home to prevent infection & eliminate daycare expenses. I took a second job to compensate. It has not been easy.

To have insurance pay for treatment will save quality of lives, and perhaps bring awareness & recognition of this debilitating condition. I am sure also from the insurance & state services standpoint, there are cost savings in treating underlying medical costs as opposed to providing years of mental health treatment & ongoing support services. It makes sense from all angles. Thank you for your efforts and advocacy for our kids. You are much appreciated !!

Warm regards,
Jennifer Rowan