

To whom it may concern,

Our daughter had her initial onset of PANDAS/PANS over three years ago, when she was only 3.5 years old. She had recently had an ear infection and strep throat and had been treated with a course of antibiotics several weeks earlier. Our daughter went from being a typical three year old, to a child experiencing severe OCD, rage, emotional lability, wetting herself, night terrors, minor facial tics, refusing to eat, and extreme anxiety and separation anxiety. It was so horrible that for several weeks we barely left the house because she would fling herself out of our arms to hoard every stick or flower she could find. We couldn't be out of her line of sight or she'd see terror stricken, and her rage and behavioral outbursts were completely out of control. It was a living nightmare. We took our daughter to our pediatrician, who was not helpful at all. As my child was screaming and growling under the check-out table, all the physician could offer was a stack of mental health places to call about a psychiatric evaluations including places that offer residential treatment, and a comment that maybe my child had an explosive personality disorder. My three year old! After about a month of barely keeping our heads above water, a friend mentioned she had heard of something called PANDAS, and since my child had had strep throat I should look into it as a possibility of the behaviors we were seeing. After researching a comprehensive list of pandas symptoms I immediately knew my daughter had it. I then went back to the pediatrician, who reluctantly put in a referral for a comprehensive psychiatric evaluation at OHSU and her saying it was highly unlikely that it was PANDAS, because it was "so rare". After waiting six weeks to be seen at OHSU, a team of three psychiatrists confirmed that indeed, my child had PANDAS. Unfortunately, they had no advice on where to go for treatment and sent us on our way. I was then lucky enough to stumble upon a ND who was able to see my child another month or two later, and she confirmed PANDAS as well. We then began the process of extensive lab work and trying to find an antibiotic that would work for my child. All of this was paid 100% out of pocket, because we have Tricare as our insurance provider. We had to forgo IVIG treatment because it would've cost our family over \$20,000 out of pocket, and living on a military income, that was not a possibility for us. I started this journey with my child 3.5 years ago, and didn't know a single family going through this struggle. I now have connected with nearly 90 families in Oregon who are all in a similar situations. PANDAS/PANS is NOT RARE, it is just RARELY diagnosed, and the children and families suffer because of this. Experts estimate that 1 in 200 child suffer from PANDAS at various degrees of severity. What we desperately need is for our physicians to be knowledgeable about PANDAS/PANS, and for our insurance companies to provide coverage for treatment!

Thank you for your time,
Candie Hotchkiss
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