

To whom it may concern,

I'm writing today to plead for the insurance coverage that children with PANDAS so desperately need and deserve. Please vote to support SB 628.

My daughter Avery had her initial onset when she was just three years old, following a bout of strep throat. Although she completed a round of antibiotics, a short time after the illness she suffered a debilitating initial onset of PANDAS. Those first days and weeks were nothing short of terrifying and traumatizing for her, as well as for us as parents. Our loving and exceptionally bright three year old became someone we could no longer recognize overnight. She experienced auditory and visual hallucinations, night terrors, severe separation anxiety, severe hoarding OCD, enuresis, rage, and emotional lability. Things were so bad that there was a stretch of several weeks where we couldn't even leave our home. When reaching out to our pediatrician we were told PANDAS was highly unlikely, it was suggested our child may have an explosive personality disorder, and we were advised to contact a residential mental health treatment facility. FOR OUR THREE YEAR OLD! Through countless hours of researching online, we stumbled upon the possible diagnosis of PANDAS. Our child met every single criteria, as well as nearly every single typical symptom. And yet, we had no formal diagnosis, no viable treatment options, and very little hope to end the nightmare of PANDAS for our family. After waiting several months for an appointment, we were finally given a diagnosis of PANDAS by a team of three psychiatrists at OHSU. Receiving the initial diagnosis was a giant relief; finally there was confirmation that my child was, in fact, very ill and not just struggling with extreme behaviors. Unfortunately, the team at OHSU sent us on our way without any treatment plan or supports for our family. After waiting another four months, we were able to find a brilliant Naturopathic Doctor who was able to begin the long path of finding the right antibiotics to treat my child. My daughter is now nine years old, and still struggling with PANDAS. We have had to pull her from public school, and homeschool her for several years because she is not able to learn in a public school setting when she is experiencing a flare. I'm thankful to have the background of being an Elementary Special Education Teacher, but putting my career on hold in order to educate my child should not be something a parent is forced to do. Because our insurance won't cover the physician we see, and will not cover IVIG, we have been forced into using long-term antibiotics to treat my daughter's illness. We have paid for every appointment related to PANDAS treatment completely out of pocket. We do not have the means to pay for IVIG ourselves, and so we use antibiotics that have significant potential long-term side effects, as our only means to treating this illness. My husband works full time as a Major for the Oregon National Guard. He has risked his life deployed to an active war zone in Iraq. And yet, our military insurance will not cover the one treatment that could end this nightmare of PANDAS for our family. Please, I beg of you, pass this bill to provide insurance coverage of IVIG for all of our children!

With much respect,
Candice Hotchkiss
Tualatin, Oregon