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On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB628

My daughter was a normal, easy, happy, baby and toddler. She was sweet, affectionate, silly, and very biddable. A few months before she turned 3, she came down with an illness and rash. The doctor told us that it was an opportunistic strep infection of the skin and prescribed a cream. Soon after that there was an abrupt change in her behavior. She began having nightmares and phobias. At one point, she became so frightened of having her clothing pulled over her head that we had to cut her clothing off. Then she started hitting, biting, and routinely fighting us on very simple requests. She started to complain about bright lights, loud noises, and the seams and tags in clothing. She suddenly would not eat the foods that were her staples before.

Gone was our happy child. In her place was an angry, rageful girl that we didn't recognize. Since onset, she has experienced a host of symptoms unless she's on steroids and antibiotics including OCD, Depression, Suicidal Ideation, Anxiety, Cognitive Changes, Seizure Activity, Loss of fine and gross motor skills, hallucinations and more.

Her symptoms continued to escalate, and we sought help from our pediatrician. Her lab work showed a high strep titer, and it was then that PANDAS was discussed. We were referred to a specialist and a neurologist who both agreed that she was suffering from PANDAS.

We did find some relief with steroids. But, as soon as the course was done, the symptoms would return in a slow, reliable progression. By the time she was 6, our PANDAS specialist made it clear that we needed to make the leap to IVIG. Her increasing trouble with school indicated that she was losing cognitive function. It was imperative that we stop the damage.

That's when we began the battle for IVIG coverage with Regence BCBS of Oregon began. Multiple requests and denials, appeal process exhausted, insurance commissioner complaints submitted to no avail. We had an army of doctors telling us that our daughter needed IVIG (pediatrician, psychiatrist, immunologist, rheumatologist, and our neurologist) and still the insurance company withheld coverage. We were eventually forced to find a way to pay for her treatment as we knew the delay was causing irreparable damage. We had to beg our family and friends for financial support in order to raise the \$12K per session for her IVIG.

What has happened to our family is horrifying. Our beautiful daughter has been left

helpless against an unrelenting autoimmune disorder that is damaging her brain. The refusal by Regence BCBS of Oregon to cover IVIG stalled her treatment for 2 years. During this time, she continued to spiral downward, sustaining neurological damage that may not be repairable. We may never know the child she should have been. I grieve for the child that I may never get to see.

My daughter has lost her childhood to this illness. She will never get that back. I'm so beyond sad for her. The emotional toll and loss that she has experienced is profound. I cannot believe that this is allowed to happen to a child.

The type of financial burden placed upon PANDAS parents when insurance companies deny treatment coverage is criminal. To withhold medically necessary treatment that has been recommended by multiple medical providers, has been approved by the State of Oregon and has been encouraged by our own Insurance Commissioner should never have been allowed. We cannot financially sustain paying for our daughter's treatments out of pocket, nor should we. This health disparity calls for your action so that others are not forced to watch their child succumb, with much pain, sorrow, and conflict, to an illness that alters their brain.

No family, especially no child, should have to endure what we have. We ask for your support on SB 628 in order to align coverage with that which the State of Oregon provides.

Thank you.