

February 6, 2023

Chair Patterson and Members of the Health Care Committee,

My happy healthy daughter's onset of PANDAS was June 25th, 2015 at the age of 6. PANDAS is nothing short of living hell but my girl was lucky because we could pay the \$48,000 for the 6 High Dose IVIG's our insurance company denied. She's now a healthy 14-year-old in remission for over 3 years because of the IVIG treatment we had the means to access.

I started working for Northwest PANDAS/PANS Network in Dec 2018 because of the inequity in accessing medically necessary care for this population. I am the Oregon Outreach Coordinator and Head of Family Support. I have spoken with and tried to help hundreds of families. Thankfully, the most vulnerable Oregonian can access IVIG through Medicaid as if Jan1, 2023 but this leaves families in the middle without care. I have personally heard the devastation when a family has been told the only thing that will help their kid is IVIG, insurance has denied the care and they have no way to pay for it. This is a damaging and costly disorder in so many ways. It can destroy families, traumatize parents and sibling, if left undertreated for too long result in lifelong mental illness or suicide but it's not insolated to just families. **We all pay a high price for undertreated PANDAS/PANS. Some examples below:**

Special education service where it previously wasn't needed, many times extensive.

Disruption in classrooms as children exhibit unpredictable and volatile behaviors.

Inability to attend school.

Reliance on 911 response.

Lost tax revenue from parents having to leave the work force.

Getting caught up in the juvenile justice system sometimes resulting in prolonged detention.

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Insurance companies also pay a price because of the treatment they deny, unfortunately with no benefit to the child.

Multiple ER visits. One family had over 10 in 1 year.

Outpatient psychiatric care.

Inpatient psychiatric care.

Psychiatric medications.

Psychiatric care for parents and siblings.

We have a mental healthcare crisis in Oregon. Doesn't it make sense to treat the patients that have underlying medical causation appropriately, taking them out of the equation? You could do this by supporting SB 628. Help ensure all Oregon PANDAS/PANS children can access the care they need.

Warmly,
Kym McCornack