

Oregon Senate Health Care Committee,

Good afternoon Chair Patterson and members of the Health Care Committee, for the record my name is Deborah Miller.

I am the parent of a son diagnosed with PANS who will be 14 on March 31st.

I am here today to testify in support of Senate Bill 628.

My son was misdiagnosed for 6 long years. His diagnosis came at the age of 8.5 when his onset of symptoms had initially occurred **6 years prior** at the age of 2.5. Over these 6 years he received a variety of other diagnoses, including; Tourette's syndrome, ADHD, sensory processing disorder, oppositional defiant disorder, OCD and extreme anxiety.

Over these 6 years our family suffered greatly and endured many losses. The loss of connection as others around us could not understand Kamden's behavior. The loss of our normally bright and advanced child who began to regress in school to the point where he could no longer be in a regular classroom. The loss of stability in our other 2 children as this disorder gravely affects siblings as well.

We lost our financial stability as **many of the costs associated with diagnosing and treating him were not**

covered by our insurance. We have exhausted our savings when we have health insurance that we pay \$18,000 a year to insure us.

But the biggest loss is that--

We lost our child. Kamden has blackout episodes where he hallucinates and is extremely violent. Because he has no recall of these events, once he becomes lucid again he becomes apologetic and voices his desire to not live like this. My SON voices that **he'd rather be dead** than be in this state.

Because of the length of time Kamden went **without being accurately diagnosed and the severity of his case**, the **prescribed treatment for him by his medical provider is IVIG.** IVIG is the 'gold standard' for severe cases which Kamden is. These life saving treatments are upwards of \$5,500 a round.

Despite IVIG being approved through the Oregon HERC process and the insurance commissioner of Oregon issuing a notice to all insurers about this development, Our insurance, BCBS of Oregon, has continued to deny IVIG **MULTIPLE TIMES.** We have appealed their decision and even filed a complaint with the state about these denials.

OUR FAMILY IS UNABLE TO PAY PRIVATELY FOR THESE TREATMENTS.

Because of the insurance denials and appeals, we have lost precious time. Precious time that our son won't get back. Time when Kamden could have already been on the track to healing. The longer Kamden goes without proper treatment the **higher probability that Kamden will have irreversible brain damage and lifelong psychiatric issues.** Every day is a day closer to not being able to get our **Kamden back.** PANS has robbed us of our son and BCBS of Oregon has robbed him of the chance to access life saving treatment.

Kamden, along with the **other children in Oregon** deserve access to treatment that has been proven effective and that has been approved by the State of Oregon via the HERC process. We need to ensure all Oregon insurers are held to the coverage level that our state provides.

This bill is more than necessary to heal my son and give our family our lives back, it is required. Kamden deserves better. The children of Oregon deserve better.

I BEG you to support SB 628 so Kamden, and his brothers, have a chance to regain and experience a normal childhood.

