

**Deborah Miller Testimony in favor of HB 2390
Oregon House Health Care Committee,**

Good afternoon Chair Prusak, 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 12 on March 31st.

I am here today to testify in support of House Bill 2390, which would ensure that children impacted by PANDAS/PANS are able to access the treatment they need to reach their full potential.

PANDAS and PANS **is not RARE, just RARELY diagnosed or MISDIAGNOSED**. My son was a victim of this as he went 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. Our normally bright and advanced child began to regress in school to the point where he could no longer be in a regular classroom. Because of this he has lost connection with friends and feels disconnected from his peers.

We lost our child. Kamden has blackout episodes where he hallucinates and is extremely violent. He will punch, he will kick he will bite, he will pinch, he will do anything to cause harm. These behaviors aren't memorable to him as he has no recall of these events once he becomes lucid again. He becomes apologetic and voices his desire to not live like this and that he'd rather be dead because these actions are so out of his control.

We lost stability in our other 2 children as this disorder affects siblings as well. His older brother Broden has severe depression and thoughts of suicide because he is no longer able to handle the volatile situation with Kamden. Our family has also lost our financial stability as so **many of the costs associated with diagnosing and treating him were not covered by our insurance**. Providers who weren't covered, but were essential to making the correct diagnosis, travel out of state to see a PANS specialist that aren't covered, labs that weren't covered but needed to confirm his diagnosis. We have exhausted our savings when we had health insurance that we pay \$1,500 to insure us.

These expenses were vital to **finally obtaining an accurate diagnosis and getting Kamden on the path to treatment**. We were able to confirm that Kamden had multiple triggering factors causing his bodies misdirected response, including; MRSA in his sinuses, Bartonella, H-pylori, and an overgrowth of yeast.

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 'standard of care' for severe cases which Kamden is. These treatments are upwards of \$5,500 a round and Kamden needs this every 3-4 weeks until his symptoms subside.

Our insurance has denied IVIG for Kamden. We have pursued appealing their decision and even filed a complaint with the state about their denial. We were **FORCED to fundraise on social media BECAUSE OUR INSURANCE WILL NOT COVER THIS TREATMENT AND OUR CHILD'S ONLY HOPE TO RESTORE A NORMAL CHILDHOOD IS IVIG**.

Because of the insurance denials and appeals, we have lost precious time. 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 possessed our son.

Kamden, along with the **other children in Oregon** suffering from PANDAS/PANS deserve a normal life and access to treatment. 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 Oregon children are suffering, my child is suffering. I BEG you to support HB 2390 so Kamden, and his brothers, have a chance regain and experience a normal childhood. **NO child deserves to suffer when treatment is available and has been proven effective**. No child in Oregon should be forgotten. Please vote in support of this bill.

