

Dear Representative Rachel Prusak and Co-Chairs Representative Andrea Salinas and Representative Cedric Hayden:

Thank you for the opportunity to provide testimony in support of HB 2390. I understand that requiring insurance companies to cover certain treatments is difficult to support in the current economic climate. As an insured individual myself, I share the concern that costs remain low for all consumers. With this in mind, ***also consider the costs of misdiagnosis and lack of access to treatment.*** Our family's expensive journey to diagnosis and treatment is as follows:

- Nov. 3, 2017: OCD onset. I called pediatrician, who could not give me an appointment until 10 days later.
- Symptoms worsened. My previously normal 4 ½ year old son had attempted suicide twice, had lost fine motor skills and much language. He would not eat, had lost 7 pounds and was deteriorating before my eyes. I called again and described symptoms. Still unable to get an earlier appointment.
- I reached out to colleagues/school psychologists. Two psychologists identified my son's symptoms as consistent with PANS/PANDAS, and recommended I get him antibiotics as soon as possible.
- I immediately brought him to Santiam Hospital ER. They refused to consider a diagnosis of PANS, or prescribe antibiotics. Instead they referred us to Doernbecher's. Diagnosis "Autism with Psychosis."
- Doernbecher's would not consider a PANS diagnosis. They performed a spinal tap, an MRI, multiple blood draws and other tests, revealing nothing. No conclusive diagnosis, and still no antibiotics.
- The following day I admitted my son to Randall's Children's Hospital ER. The doctor was unfamiliar with PANS but stated "In the absence of another diagnosis to offer you, I am willing to treat this as PANS." She prescribed antibiotics.
- Within 24 hours of first dose, my son began to recover. Within 10 days he was recognizable as the little boy I knew a month before. It took nearly a year to heal fully, but only required relatively inexpensive, over-the-counter treatments.

Our insurance company paid \$7,100.44 for three hospital admissions plus follow up with our pediatrician, when all my son needed was \$60 worth of antibiotics to start his journey to healing.

This scenario is repeated over and over again in our state, some families going to many doctors for years before getting an accurate diagnosis and treatment. Had I not been persistent in obtaining antibiotics, our insurance company would likely be paying for long term psychiatric care for years to come. My son does in fact have permanent brain damage, which is fortunately limited to hyperactivity and anxiety disorder. We continue to pay out of pocket for appropriate treatment to prevent a recurrence of PANS symptoms. In addition, as a Special Education Program Associate, I also see the costs of disability and mental health disorders in our educational and adult care systems, including students with PANS/PANDAS who have not received adequate treatment. A healthy child is also a less expensive child.

None of us wants our children to have IVIG or plasmapheresis. These are treatments of last resort, horrific for the patient and their families. Access is, however, imperative for those few children who have reached that point of suffering and desperation. My goal, along with that of NWWPN, is that someday every pediatrician will recognize the symptoms and get the child an appointment immediately. That child will leave the office with a prescription for antibiotics, and begin recovery before permanent brain damage can occur. Should they require higher levels of treatment, it would be readily accessible. They will go on to live normal, healthy lives. That would be a win for insurance companies, consumers, taxpayers and most especially, for the 1:200 children affected by PANS/PANDAS.

Thank you for the work you do for citizens of Oregon, and for your support of HB 2390.

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