Dear Chair Representative Prusak and Members of the Healthcare Committee,

I am emailing you to request your support for HB 2390. My husband and I are residents of Silverton, OR and we have an 8 year old daughter, Laney, diagnosed with PANS. This autoimmune disorder (Pedactric Autoimmune Neuropsychiatric Disorder) is something that has impacted our entire family, my daughter's schooling, and our finances. Our story is actually more common than people realize, as it is estimated that 1 in 200 kids are impacted by PANS/PANDAS.

I hope to share our story so that you can see how desperately needed your support is! When Laney was 5 years old, she got Scarlet Fever. Within a few days, she started having tics that she couldn't control. She became extremely agitated and was unable to sleep at night for hours at a time. Soon she was a different child. We treated the strep, but she continued to struggle with tics and mood swings. We had several other medical issues that triggered immune responses in that same year that resulted in bizarre behaviors including severe separation anxiety, OCD, and constant tics. After almost 2 years of seeing these scary changes happen for months at a time, we finally found a Dr. who was able to diagnose her. Basically, if my daughter gets strep, several other common viruses, or if her seasonal allergies are particularly bad (hello Oregon!), her immune system responds by creating inflammation in her brain that causes many scary and intense behaviors, not limited to OCD, anxiety, tics, insomnia, rapid deterioration in school abilities, joint pain, etc. The list is long and the symptoms, that typically appear overnight, are hard to see my daughter endure. Laney's treatment plan got her back to a healthy baseline and we got our happy, healthy girl back after several months of aggressive treatment. We have flares that still happen as this is a condition that Laney will deal with for many more years due to the inevitable exposure to things that will cause her immune system to trigger the PANS. The treatments can include antibiotics, steroids, multiple supplements, medications, and if needed, IVIG, which costs a TON of money but is effective. Appropriate treatments can cost in the $10,000 range and is usually not covered by insurance. HB 2390 requires insurance companies to cover certain treatments for PANS and PANDAS kids in our state. Several states have passed similar bills, and I am asking for your support in passing HB 2390. Currently we spend around $7,000 a year out of pocket for doctor visits, specialists, and supplements to keep her immune system healthy. My husband and I are lucky to have health insurance, but unfortunately, most of the treatments and Dr. visits are not covered by our insurance.

We have been blessed with the support of many people in our lives, including family, our local school district, school counselors, nurses, teachers, and our doctors. These people have made managing Laney's illness easier, though it is literally a daily effort to keep her healthy. I am asking for your help for my daughter as well, through your support of HB 2390.

Please reach out to me if you have questions!

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