

To Whom it may Concern:

As I sit here and write this brief paragraph (how do I compile the last few years into a short paragraph?) my 11 year old PANS son who is currently in a several months long flare, is continuously talking about how he is going to live in the bathroom, so that he doesn't have to worry about contamination from other family members, nor be a burden upon me or my husband for the trials he thinks he puts us through (which we strongly and lovingly remind him he doesn't). He has already washed his hands to the point of bleeding, will not eat food without rinsing his mouth with mouth wash first, and has to disinfect anywhere anybody coughs for whatever reason. He won't breathe through his nose because he once heard that you have a higher chance of getting sick if you breath through your mouth. If he forgets, he runs to the bathroom to mouthwash again (we have replaced regular mouthwash with a mint extract and water placebo). These are just a few of his current and ever changing symptoms. He is positive he is going to die early, and thinks we would all be better off if he did. His carried guilt of this debilitating illness that he did nothing to get, is enough to make me fall to my knees in desperation and prayer. And I do, every night. This once vibrant, healthy, smart, and amazingly social and funny boy, has now been reduced to this. He used to have a smile so big his eyebrows were up at his hair line, yet now it has been replaced with a permanent scowl, constant fear, and sometimes, moments of uncontrollable sobbing because of the emotional and physical pain it causes. This is not how or whom God made him to be. When his OCD and tics first started, he was misdiagnosed with having traditional OCD, though P/P had been brought up by me a time or two prior. Without realizing he had PANS, he was put on an SSRI, which P/P kids are known to react to poorly. This started months of absolute terror and episodes of psychosis that brought us to an early consideration of schizophrenia. If it weren't for his counselor contacting a different pediatric psychiatrist who suggested we look further into PANDAS/PANS I don't know where we would be. We took him off the SSRI, and have tried courses of antibiotics, several rounds of Prednisone, and CBT all with no significant help. We can't just treat the symptoms, we have to treat the CAUSE. IVIG is next, but at \$10,000 per round, it just isn't feasible. IVIG is known to work...it gives life back to these kids, and hope back to their families and friends. There isn't a person it doesn't affect. My husband and I pay for the highest premium/lowest deductible insurance with Premera through his work, with the assumption that treatment like this would be covered. The fact that it would be denied is unfathomable to me. I recognize I am a Washington resident, but I just had to take the time to write to you in support of this bill. Oregon kids are just like my kids, and I know that if Oregon takes this step to offer real help to these families, Washington will follow suit. The work of Harvard, Stanford, Mayo, and all the doctors and researchers give me hope that one day, there will be a cure. My heart grieves for the parents out there who aren't given the answer to their child's drastic change, and for those who are denied the treatment to help it when they do. I am that mom, and even with a community as large as ours (1 in 200 kids), it is still a dreadfully lonely place to be. Don't ignore or deny us. Be the legislator that votes in favor of this bill, and votes in favor of letting us all feel the sun on our faces and in our souls once again. Be the legislator who turns our tears of grief into tears of gratefulness. Thank you....