

Submitter: C scott
On Behalf Of: NWPPN
Committee: Senate Committee On Health Care
Measure: SB628

To Whom it may Concern:

I am writing in support of SB628. My son was diagnosed with PANDAS/PANS/AE around 2019. While he is right now in remission, I know that any viral, bacterial, or environmental trigger can impact him immensely and put us back on the road of trying to find the treatment that sticks. I have a difficult time recounting just how sick he was at one point, but one example of his condition included continuously talking about how he was going to live in the bathroom or run away, so that he didn't have to worry about contamination from other family members, or "burden us" with his symptoms (which we strongly and lovingly remind him he didn't). He'd wash his hands to the point of bleeding, used to hold his own spit for fear of contamination, amongst a whole host of other issues, and still to this day will not eat food without rinsing his mouth with mouth wash first. He'd often disinfect anywhere anybody coughed, and refused to walk in our backyard if a neighbor simply stopped by to borrow a garden tool. He has several facial and verbal ticks that impacts breathing and talking, and even though he is almost to baseline, several lingering symptoms affect his confidence immensely. He would often think he was going to die early, and thought we would all be better off if he did. His own 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. When healthy, he is a vibrant, healthy, smart, and amazingly social and funny boy, but when he is sick and in a flare, he is unrecognizable. He has a smile so big his eyebrows seem to rise up to his hair line, but when in a flare, it gets replaced with a permanent scowl or moments of uncontrollable sobbing and despair. 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 poorly to if prescribed too high, and without addressing the underlying cause. And even when it works, it is just a bandaid. The first ssri 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. So many families have tried a myriad of treatments, and often IVIG is the only one that treats the underlying cause. 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 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 those who have to be 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 and adults), 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,
Christine Scott