

February 8, 2023

Hello. My name is Pamela Glerup. I am an Oregon registered voter and the grandmother of a child with PANS/PANDAS. I am reaching out in support of **Senate Bill 628**, a bill to ensure that all children in Oregon with PANS/PANDAS have access to **the same care that the State of Oregon provides.**

Medicaid coverage for IVIG was approved for these kids in May of 2022 and, despite the Insurance Commissioner of Oregon issuing notice to ALL Oregon insurers about this advancement in coverage, Oregon insurance companies are still denying this medical treatment and delaying medical care for the sickest children in our state, with PANS/PANDAS. Mind you, this treatment costs thousand of dollars out of pocket without insurance coverage, making it out of reach for the average Oregon family.

I URGE YOU to understand that without proper treatment (IVIG), these kids will continue to decline both physically and mentally, which then leads to a multitude of disastrous consequences for these children, their families, and ultimately Oregon communities. My grandson's symptoms acutely appeared at age 14 in the form of sudden severe anxiety, OCD, and a slew of other mental/emotional symptoms. He became an entirely different person, practically overnight, compared to his former self of 14 years. Since then, he has spent nearly 3 excruciating years suffering mentally and emotionally from the insidious symptoms of PANS/PANDAS without proper diagnosis and/or treatment. Now, as a teenager and after dozens of failed mental health treatments (because they were not treating the true source of his problems), my grandson has turned to drugs and alcohol in a desperate attempt to feel better. **I, along with his parents, am CERTAIN that had he been properly diagnosed AND TREATED for P/P, he would not have gone down this path.** He does not have a single traditional risk factor for mental illness, nor drug use and abuse. **His substance abuse is a DIRECT result of the untreated, ongoing mental and physical torture that comes with PANS/PANDAS. This type of infection-caused mental illness CANNOT be treated solely with mental health therapy.**

Ten other US states have already passed legislation ensuring that children in their state have access to this vital care. Please stand in support of Oregon's children who also deserve this same access to care. Don't let insurers decide to withhold medically necessary treatment that our own state provides! **PLEASE. Help these children, their families, and communities heal by getting the treatment they need without the interference of politics and red tape.**

PANS/PANDAS is a crisis of monumental proportions that is being completely overlooked and dismissed by thousands of doctors in both the United States and worldwide. As if this weren't enough of a hurdle for families to overcome, they don't need insurance companies denying the coverage of vital treatments that they work tirelessly to finally receive.

PAMELA GLERUP