

Submitter: Robert Millis

On Behalf Of:

Committee: House Committee On Behavioral Health and Health Care

Measure: SB628

I urge you to vote in favor of SB 628 to provide crucial medical treatment and protect children from permanent harm. This bill will also prevent financial devastation for Oregon families who have no other choice.

Our daughter suffered severe brain inflammation following infection when she was 12 years old. She became a different person overnight, experiencing paranoia, suicidal ideation, debilitating OCD, and struggling with simple tasks like writing.

She was diagnosed with PANS by a specialist who prescribed immediate IVIG treatments based on clear symptoms and well-established protocols. However, insurance coverage was denied without any review of her case, and the hospital would not proceed without insurance preauthorization.

While her doctor spent days trying to appeal the denial, our daughter's symptoms rapidly grew worse. Suicidal ideation became suicidal intent; hallucinations and paranoia became severe. We could no longer protect her from herself and had to admit her to a psychiatric hospital. It was the hardest thing I have ever done as a parent.

If you consider nothing else from my testimony, focus on this:

To save my young child's life, I had to leave her suffering and terrified of her own mind behind locked doors in the care of strangers because low-level insurance employees denied IVIG as a matter of policy —dismissing medical professionals, ignoring established treatment protocols that other insurers recognized, and doing so without reviewing the facts of her case.

The psychiatric center sent our daughter home on new medication with serious side effects, but that still did not resolve the brain inflammation or underlying infection.

When symptoms became extreme again, we brought her to the emergency room. The ER doctors recognized what was happening and ordered IVIG treatment to be administered immediately.

That IVIG treatment gave us back our daughter. It saved her life. No other treatment would have had that effect.

The bill for her emergency treatment was over \$40,000. Our insurance company

agreed to pay for most of it only after reviewing the successful results. Ironically, it would have cost them a fraction of that if IVIG had been administered when prescribed.

Consider what happens to a typical family faced with an unexpected \$40,000 medical expense. That is a full year's wages for many. Predatory lending for medical costs is often the only option to pay over time, and it can take more than a decade to pay off.

Insurance denials and delays for post-infectious neuropsychiatric disorders like PANS and PANDAS lead directly to permanent harm to children's mental and physical health.

Again, I urge you to vote in favor of SB 628 to provide life-saving medical treatment to children.