Submitter:	Carly Absher
On Behalf Of:	my daughter living on campus
Committee:	Senate Committee On Health Care
Measure:	SB628

I am writing as the mother of two daughters diagnosed with post-infectious encephalopathies (NMDAR and PANS/PANDAS). One lives in Tacoma, WA and the other lives in Portland.
Because of a complete lack of awareness, or perhaps willful and criminal ignorance of the latest research concerning PANS/PANDAS by NW Higher Education institutions, a total lack of providers who treat these horrifying disorders, and because suffering families already experience extreme duress & medical discrimination while trying to access healing and relief for their children…we MUST have access to care by requiring all private insurers to cover medically necessary treatments AND educate local providers. As long as families like mine are discriminated against in the medical community, we will be forced to continue traveling outside the Pacific NW to access treatment for their children. And worst of all, families like mine will have to pay exhorbitant fees to heal their children.

All providers who are genuinely knowledgable of PANS/PANDAS go through a tiered treatment process of NSAIDS, steroids, antibiotics and anti-virals, and many other immune suppressing medications before ever considering IVIG for their patients. Once all else has failed, only then does a knowledgable PANS/PANDAS physicians AND naturopaths prescribe the use of IVIG. Only about 10-20% of PANDAS patients require this treatment. 1 in 200 kids have PANDAS/PANS. There are roughly over 4,000 PANS/PANDAS patients (mostly undiagnosed) in Oregon…that means this committee could change the lives of approximately 400 Oregon children and their families.

My NDMAR daughter was misdiagnosed for 4 years. Because doctors did not understand the signs and symptoms of her disease. Same is true for my PANS/PANDAS daughter who suffered misdiagnosis for 6 years: she was prescribed unnecessary and ineffective psychiatric medications, endured 4 inpatient psychiatric stays, 1 long term residential treatment stay out of state, unsuccessful wrap-around services...and a host of other horrifying problems that I cannot begin to describe in an email, before we traveled to Chicago to visit a PANDAS specialist who saw her dire need for proper medical intervention. He immediately ordered steroids and high dose IVIG for my daughter. After losing over 6 years of her childhood, she finally began healing with relief of symptoms. Today, she does not take a single psychiatric medication.

We paid for her IVIG completely out of pocket and as a result, my PANDAS daughter is able to attend Portland State University. This was unthinkable before receiving appropriate diagnosis and medical intervention. She can become a viable, contributing member of society. Other children are not so lucky and if left untreated end up in psychiatric wards, juvenile justice system and far worse.

My daughters illness remission saves my insurance company huge sums of money every year.

What PANDAS/PANS families endure is unimaginable to clinicians and to the rest of the world. Please do the right thing: help our children who suffer the most with no relief, who have no hope of a future. How much is a life worth?

Thank you for thoughtfully considering the plight of families like mine with such limited resources and help in the Pacific NW,

Carly Absher