

Senate Testimony

Good afternoon Chair Patterson and members of the Health Care Committee, for the record my name is Sarah Signe Lemley and I am the Executive Director and Co-Founder of the Northwest PANDAS/PANS Network.

More importantly, I am the mother of a child who had PANDAS.

PANDAS and PANS are post-infectious neuroinflammatory disorders due to a misdirected immune system response in which the body's immune system mistakenly attacks healthy brain cells, leading to autoimmune processes that affect central nervous system function. An affected child generally has an abrupt onset of obsessive-compulsive disorder (OCD), restricted eating, tics or other abnormal movements, anxiety, personality changes, decline in math and handwriting abilities, sensory sensitivities, rage, suicidal ideation and more.

SB 628 is a simple bill in that it **aligns health insurance coverage** with that with which **the State of Oregon provides to Medicaid recipients**. *To note, current bill language will be amended to reflect Oregon Health Authority, Health Evidence Review Commission (HERC) approved coverage guidance language that was issued on May 19th, 2022 specific to IVIG.*

As stated in the OHA HERC report, "coverage guidances are developed to inform coverage recommendations for public **and private health plans** in Oregon'

The **State of Oregon has APPROVED and now provides IVIG treatment coverage for PANDAS/PANS**.

Formal notice of this decision was provided to all Oregon insurers by our insurance commissioner, Andrew Stolfi, on June 22, 2022.

Despite this, certain insurers in our state continue to deny medically necessary treatment to sick children.

Most of these families cannot afford to pay privately for these lifesaving treatments.

Instead, they are **forced to watch** their child **be crippled by psychiatric distress**, losing parts of their childhood they will **never get back**.

No parent should face such a tragedy that is preventable when access to treatment is available.

Senate Bill 628 is endorsed and supported by NIH Emeritas, Dr. Sue Swedo, Dr. Jenny Frankovich co-director of the Stanford PANS Clinic, Dr. Dritan Agalliu of Columbia, The PACE Foundation, The Alex Manfull Foundation, International OCD Foundation, Oregon Nurses Association, Oregon Society of Physician Assistants, Disability Rights Oregon, FACT Oregon, Our Children Oregon, Oregon NAMI and OCD Oregon.

Those who require IVIG are the sickest, most debilitated children.

They are being withheld medically necessary treatment.

Their health is being put at risk the longer they go without medical care and this increases the risk of serious neurological and psychological harm, long-term disability or even loss of life.

Their suffering is being allowed to continue unnecessarily.

Insurers are getting away with this.

In order to enforce coverage that aligns with that which the state provides, passage of this bill is necessary.

While strides have been made, to only have this lifesaving treatment available to those on Medicaid or those affluent enough to pay privately is further highlighting this health inequity. Many will still be without the necessary medical care to end their suffering.

We cannot allow this health disparity to continue.

All children deserve equitable access to this care.

Thank you.