

Re: NYS Assembly Bill A9659 and NYS Senate Bill S2655A

Dear New York State Assembly Insurance Committee and Assemblyman Weprin; New York State Senate Insurance Committee and Senator Bailey,

My name is Sarah Signe Lemley and I am the Executive Director and Co-Founder of the Northwest PANDAS/PANS Network, a 501c3 nonprofit serving Oregon, Washington and Idaho.

More importantly, I am the mother of a child who had PANDAS. PANDAS and PANS are post-infectious neuroinflammatory disorders affecting as many as 1 in 200 children. 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.

NYS Assembly Bill A9659 and NYS Senate Bill S2655A will ensure access to medical care that is required for children with PANDAS/PANS.

The State of Oregon has APPROVED and now provides IVIG treatment coverage for PANDAS/PANS. This decision was made after a 14-month review process for the inclusion of coverage for Medicaid recipients. Shortly thereafter, Senate Bill 628 was passed which mandates private and commercial insurers provide the same coverage. This bill received unanimous and bi-partisan support in both the House and Senate floor votes.

Most PANDAS/PANS families cannot afford to pay privately for the care and treatments that are so often denied by insurers. 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.**

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 and suicide. Their suffering is being allowed to continue unnecessarily.

In order to ensure every child in New York has access to the medical care they require, passage of this bill is necessary.

Sincerely,

Sarah Lemley, MPA; HA

Executive Director

Northwest PANDAS/PANS Network (NWPPN)

nwestppn@gmail.com