



February 6, 2023

Dear Honorable Legislators in Oregon,

I am the Executive Director and co-founder of The Alex Manfull Fund, a non-profit organization dedicated to increasing awareness, education and research on PANDAS and PANS. My husband and I founded this organization because we lost our only child due to her PANDAS condition, and we do not want another life to be cut short – or interrupted – by these disorders.

I am imploring you to support Senate Bill 628. As I understand it, the State of Oregon has already established coverage for IVIG treatment, and that coverage is being denied by Oregon insurers despite the fact that the Insurance Commissioner has notified insurers of this advancement in coverage.

The State of Oregon must hold these insurers accountable for this coverage instead of allowing them to withhold medical care that is essential for some children diagnosed with PANDAS/PANS.

New Hampshire is one of 10 other states that have passed legislation already. Every state should ensure access to such care for their constituents. The devastating effects of PANDAS/PANS extend way beyond the patient, wreaking havoc in the family, the school, and the community which, in many cases, is faced with providing additional services to the patient.

While we were dealing with an insurance company in another state, our daughter died before receiving treatment. Alex's death did not need to occur.

Please ensure that the children with PANDAS/PANS, just like children with other medical disorders, are afforded access to the medicine they need – which may include IVIG -- in Oregon.

Thank you very much.

Very Sincerely,

Susan Newman Manfull, PhD

Executive Director and Co-Founder
The Alex Manfull Fund