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February 1, 2023

Senator Kate Lieber
Oregon State Legislature
900 Court St. NE, S-417
Salem, OR 97301

Dear Senator Lieber:

I write to you as the Executive Director of the International OCD Foundation (IOCDF), the nation's largest organization solely dedicated to advocating for everyone affected by obsessive-compulsive disorder (OCD) and related disorders, including pediatric autoimmune neuropsychiatric disorders (PANDAS/PANS). The IOCDF wishes to convey our endorsement of SB 628, which would extend insurance coverage to include the full range of evidence-based PANDAS/PANS treatments.

While we have known for many years that children can develop OCD, PANDAS/PANS have only recently been distinguished as illnesses that are unique from more typical cases of childhood-onset OCD. Researchers believe PANDAS/PANS is caused by a malfunctioning immune system that mistakenly attacks the brain instead of an infection. Unlike in typical OCD, where symptoms set in gradually over months or even years, symptoms in PANDAS/PANS appear rapidly following an infection (e.g., strep throat).

The symptoms of PANDAS/PANS resemble severe OCD and tic disorders. Affected children may become extremely anxious, act out in disruptive ways, or be unable to eat. The speed with which children develop these symptoms — seemingly overnight — is truly frightening to parents, and the intense needs of a child with PANDAS/PANS can leave families reeling. When left untreated, PANDAS/PANS can be permanently disabling or even deadly.

Treatments that work for children with OCD may not necessarily work for children with PANDAS/PANS. Thankfully, there are several therapies that scientific research has shown to be effective: cognitive behavioral therapy, antibiotics, plasmapheresis (TPE), and intravenous immunoglobulin therapy (IVIG) are among the best treatments currently available for PANDAS/PANS.

In mild and moderate cases of PANDAS/PANS, cognitive behavioral therapy and antibiotics are the recommended treatments. IVIG is recommended in moderate and severe cases, per treatment guidelines published in 2017.¹ The use of IVIG to treat PANDAS/PANS is supported by the results of multiple double-blind, placebo-controlled studies and numerous case reports.^{2,3} In one study, the children who received IVIG treatment experienced a 45% reduction in symptoms, and the vast majority continued to be improved when researchers followed up with them one year after treatment. TPE is also supported by research and was shown to reduce symptoms by 58%. However, it is a riskier

and more costly treatment and is recommended only in extreme or life-threatening cases.

Out of pocket costs for IVIG or TPE are significant: IVIG can cost up to \$15,000 and TPE is even more expensive. The average family will struggle to afford the right treatment for a child with moderate to severe PANDAS/PANS if their insurer does not provide coverage. By mandating coverage for the full spectrum of available evidence-based treatments, SB 628 will ensure that every Oregon child with PANDAS/PANS has a chance at recovery.

On behalf of our members and all Oregon families who are caring for a child with PANDAS/PANS, we respectfully ask the Oregon Legislative Assembly to pass this bill. Should you or any other Assembly members have questions about PANDAS/PANS or its treatments, please do not hesitate to contact us.

Sincerely,



Jeff Szymanski, PhD
Executive Director
International OCD Foundation

¹ Frankovich, J., Swedo, S., Murphy, T., Dale, R. C., Agalliu, D., Williams, K., ... & Muscal, E. (2017). Clinical management of pediatric acute-onset neuropsychiatric syndrome: part II—use of immunomodulatory therapies. *Journal of child and adolescent psychopharmacology*, 27(7), 574-593.

² Perlmutter, S. J., Leitman, S. F., Garvey, M. A., Hamburger, S., Feldman, E., Leonard, H. L., & Swedo, S. E. (1999). Therapeutic plasma exchange and intravenous immunoglobulin for obsessive-compulsive disorder and tic disorders in childhood. *The Lancet*, 354(9185), 1153-1158.

³ Williams, K. A., Swedo, S. E., Farmer, C. A., Grantz, H., Grant, P. J., D'Souza, P., ... & Leckman, J. F. (2016). Randomized, controlled trial of intravenous immunoglobulin for pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections. *Journal of the American Academy of Child & Adolescent Psychiatry*, 55(10), 860-867.