

February 23, 2021

Representative Rachel Prusak, Chair Representative Cedric Hayden, Vice-Chair Representative Andrea Salinas, Vice-Chair House Committee on Health Care 900 Court Street NE Salem, OR 97301

Delivered electronically.

Re: House Bill 2390, Coverage Mandate for PANS/PANDAS

Chair Prusak, Vice-Chairs Hayden and Salinas, and Members of the Committee:

Thank you for the opportunity to provide comments on HB 2390. HB 2390 requires commercial insurance to cover two specific conditions: pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome (PANS/PANDAS). Unlike other insurance mandates, however, the bill calls out two invasive and expensive treatments for coverage: intravenous immunoglobulin (IVIG) and plasmapheresis. IVIG essentially infuses a patient with blood serum to replace antibodies, and plasmapheresis separates a patient's blood plasma for treatment.

I've met with the parents trying to get coverage myself, and the stories are undoubtedly difficult. But PANS/PANDAS is also a difficult disease to categorize and describe, given the wide variety of symptoms and their severity each child can face. Consequently, the medical evidence for how to treat patients has been building over time. Just this month, the Health Evidence Review Commission within the Oregon Health Authority opened up a comment period to begin the process of developing coverage guidance. HERC is in the first phase of a multi-step process, so a pause is warranted. The coverage guidelines that do exist only call for IVIG and plasmapheresis to treat extreme and life-threatening cases. It's telling that the bill allows for billing of another condition rather than PANS/PANDAS; it is a tacit acknowledgement that we may be racing ahead of the medical evidence.

We would urge that you consider waiting for HERC to develop coverage guidance. This bill is well-intentioned, but the medical evidence is not fully developed to mandate such invasive treatments. Thank you for your consideration.

Sincerely,

Richard Blackwell Director, Oregon Government Relations