



Mission: Empower Oregon families experiencing disability in their pursuit of a whole life by expanding awareness, growing community, and equipping families.

February 6, 2023

Chair Senator Deb Patterson

Vice-Chair Cedric Hayden

Members of the Senate Committee on Health Care

RE: Support of SB 628 – Requires health benefit plan and health care service contract coverage of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome.

Chair Patterson, Vice-Chair Hayden, and members of the Committee,

FACT Oregon is a family-led nonprofit that works toward a future where communities are accessible to, inclusive of, and empower the self-determination of, people with disabilities. We support families, youth with disabilities, and partners to hold high expectations and set positive trajectory, navigate special education and disability systems and services, and advocate for the supports needed for youth to thrive at home, in school, and in community. Since 2012, we have served as the state and federally designated Parent Training and Information Center for special education.

FACT Oregon holds that disability is a natural part of the human condition and that people experiencing it have the right and ability to create whole, self-determined lives. We believe ableism must be dismantled and that there is no such thing as “too disabled” for self-determination. We appreciate the important role that parents/caregivers play in a child’s minor years to help them develop a vision of a whole life and set the child on a positive trajectory towards a life of self-determination. We believe that, with imagination and creativity, families can discover the right supports to increase their children’s independence and make a whole life possible.

We support Senate Bill 628, a bill to ensure insurance parity for Oregon children with pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome [PANDAS/PANS]. In May of 2022, Oregon passed coverage for Medicaid to pay for Intravenous Immunoglobulin (IVIg) Treatment, and the Insurance Commissioner of Oregon issued a notice to all Oregon insurers about this change. Unfortunately, insurers in Oregon still deny this medication treatment for PANDAS/PANS.

Please support SB 628 to ensure all of Oregon’s children with PANDAS/PANS can access the same treatments, regardless of their insurance. Thank you for considering this testimony.

Christy Reese, Executive Director

FACT Oregon