August 15, 2025

Dear Senator Kevin Hertel and Senate Health Policy Committee Members,

I am writing to urge you to support **SB447 Insurance: insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders**. The passage of this bill will positively impact patients and their families suffering from Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS).

Early and thorough treatment is crucial to an optimal outcome. Patients who are treated early and appropriately within the first year of initial onset often recover. Conversely, patients who do not receive timely and complete medical treatment may require more invasive protocols to heal. Due to a lack of insurance coverage for PANS, the process of denials and appeals delays or prevents crucial immune therapy, which can lead to a worsening of symptoms and long-term disability due to untreated brain inflammation. Patients who are not appropriately treated may remain affected both neurologically and psychologically throughout their entire childhood and into their adulthood. It is fiscally more responsible to identify and treat this illness than to create a situation of life-long care. Failure to treat the patient places a significant burden on the patient and their social, educational, and family systems. We must help these families now. We must minimize the financial, emotional, and physical impact of this disease by providing insurance coverage for PANS/PANDAS.

Current research in the PANS shows there are multiple etiologies. Still, the research field is elucidating that it is a type of autoimmune encephalopathy (inflammation and swelling of the brain) typically triggered by a common infection such as strep, mycoplasma pneumonia, and others. Currently, physicians are prescribing medically necessary and effective treatments for PANS/PANDAS, which include but are not limited to: long term antibiotics, steroids, intravenous immunoglobulin (IVIG), and in rare, severe cases, plasmapheresis. Doctors consider the use of IVIG in a small subset of patients who have severe symptoms; IVIG is deemed to be disease-modifying and can halt the autoimmune process. Ideally, patients will recover with the least invasive treatment if diagnosed and treated appropriately by treating the source of inflammation and infection and halting the autoimmune process so these patients can live healthy lives.

Alliance to Solve PANS & Immune-Related Encephalopathies (ASPIRE) speaks with doctors, therapists, families, and educators every day. PANS/PANDAS may only affect a small population, as physicians and researchers still consider it rare. Still, the impact on these patients, their families, as well as their community is substantial. ASPIRE sees the burden this disorder puts on families. In addition to the difficulty of caring for a child with this disorder, many families must shoulder the additional financial stress of selling their homes, incurring credit card debt, and using life savings to treat their loved ones. This disease negatively

impacts home life due to having to manage symptoms of OCD, separation anxiety, rage, restricted eating, sleep issues, and more. Multiple siblings may have PANS. Caregivers often have to leave work to provide the required in-home support of a medically sick child. Not only does it affect the family unit, but also the repercussions of leaving patients medically untreated impacts the school system. Children commonly miss a significant amount of school and require multiple supports while in school. They often require special education services (IEPs and 504 plans) as symptoms can include significant regressions in handwriting, fine motor, math skills, school refusal, and behavioral regression. When PANS is not treated, children can require special education throughout their time in school as versus a short time period.

A vote for this legislation will provide doctors with the ability to treat these patients in the manner that their professional experiences dictate without burdening families with the additional task of fighting with insurance companies. The prolonged denial and appeal process of insurance coverage delays treatment for these patients and puts them at risk of further decline and potential long-term disability. Please help our doctors make the best medical choices without worrying about the implications of insurance company denials.

Critically ill patients with PANS PANDAS in Michigan need your help to receive appropriate medical intervention. We must help these families now. We must minimize the financial, emotional, and physical impact of this disease by providing insurance coverage for PANS. We are hopeful that one day all insurers will cover PANS, but families in simply cannot wait for this happen; it is paramount you and your fellow legislators support and pass **SB447 Insurance: insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders**. Your constituents must be given the opportunity to access insurance coverage when confronted with PANS and the medical challenges it creates. Please join your fellow legislators who support **SB447**. This is a bi-partisan issue.

Please reach out to me for additional information via email or phone. Thank you for your time and consideration. Thank you for your continued efforts to assist these families in our community, so our loved ones grow up and reach their full potential.

Best regards,

Gabriella True
ASPIRE, President
Email: Gabriella@aspire.care
Mobile: 562-480-7560
www.ASPIRE.care