



March 24, 2022

Dear Members of the Senate Health and Human Services Committee,

I urge you to support Georgia House Bill 1484 - Social services; three-year pilot program to provide coverage for the diagnosis and treatment of PANDAS and PANS under Medicaid. Early and thorough treatment is crucial to an optimal outcome. Children who are treated early and appropriately within the first year of initial onset often recover. Conversely, children who do not receive timely and complete medical treatment may require more invasive protocols to heal. Patients who are not appropriately treated may remain affected both neurologically and psychologically throughout their entire childhood and 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 this disease's financial, emotional, and physical impact by providing provider education and insurance coverage for PANS/PANDAS.

Current research in the PANS shows there are multiple etiologies. Still, the research field elucidates 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 children, their families, and 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 children. This disease negatively impacts home life due to managing symptoms of OCD, separation anxiety, rage, restricted eating, sleep issues, and more. Multiple siblings may have PANS. Caregivers often leave work to provide the required in-home support of a medically sick child. It affects the family unit, but the repercussions of leaving children 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 versus a short period.

This legislation is critical. Diagnosing and treating 100 children each for three years means that 300 families will have significant relief from the physical, emotional, and financial devastation. This will allow doctors to treat these children 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 children 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.

Additionally, it is essential to note that this bill will also provide critical outreach to pediatric providers to help them quickly recognize, diagnose, and appropriately treat pans/pandas. This outreach will impact children and families outside of the 300 children for decades to come. Providers must have a solid educational base in PANS PANDAS. Too many children are being misdiagnosed with other disorders, thus not receiving appropriate treatment, which may consign them to a lifetime of mental illness. Pediatric providers from multiple specialties must be provided with education, or they simply cannot treat appropriately. Primary care providers play an important, ongoing role in diagnosing, treating, and recovering children with PANS/PANDAS. An experienced multi-disciplinary team of specialists or a PANS/PANDAS specialist may be needed to treat children with a moderate or severe/life-threatening onset of a complex presentation. Delayed diagnosis and inaccurate treatment or lack of treatment cause considerable suffering for children and families, including interrupting education and immense financial burdens.

Critically ill children in Georgia need your help to receive appropriate medical intervention. We must help these families now. We must minimize this disease's financial, emotional, and physical impact by providing insurance coverage for PANS. Therefore, it is paramount that you and your fellow legislators support and pass HB 148. Allow your constituents to access insurance appropriate care when confronted with PANS and the medical challenges it creates; give providers the tools they need to care for their patients. Please join your fellow legislators who support the amendment to HB 1484. This is a bi-partisan issue.

Please reach out to me for additional information via email or phone. Thank you for your

Best regards,

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