



February 7, 2021

Dear Chairman Kevin A. Cahill and members of the Insurance Committee,

On behalf of the Alliance to Solve PANS and Immune Related Encephalopathies (ASPIRE), we members of the ASPIRE Professional Advisory Board, write to express our strong support for Bill #A00877: Requires health insurance policies to cover costs for pediatric acute-onset neuropsychiatric syndrome rehabilitation treatment. As clinicians and scientists, we know that passage of the bill will significantly improve the health and well-being of patients with PANS and ease the financial and emotional burdens of their families.

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) is characterized by the abrupt and dramatic onset of obsessive-compulsive symptoms, restricted intake of food or fluids (sometimes to the point of starvation or dehydration), anxiety, depression and suicidality, emotional lability, personality changes, sensory hypersensitivity, cognitive deficits and physical symptoms, such as arthralgias, urinary dysfunction, and severe insomnia. As its name implies, PANS affects children, primarily those aged 4 - 9 years. A viral or bacterial infection triggers most cases; when Group A streptococcal infections (such as strep throat or impetigo) triggers symptoms, the disorder is known as Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS). In recent months, a number of studies have proven that PANS/PANDAS is a form of autoimmune encephalopathy—or inflammation of the brain. Treatment of PANS/PANDAS involves a three-pronged approach that utilizes psychiatric medications to provide symptomatic relief, antibiotics to eliminate the source of neuroinflammation and immune-modulating therapies to treat disturbances of the immune system. When these therapies are instituted promptly, many children recover completely and return to full functioning. Delays in obtaining treatment not only prolong the child's suffering needlessly but also increase the risk that the PANS/PANDAS symptoms will become entrenched, leading to long-term psychiatric, neurologic, and cognitive dysfunction.

Unfortunately, there are currently several barriers that delay or prevent treatment of PANS/PANDAS. At the outset, families are confronted with a paucity of physicians available to treat PANS/PANDAS. Bill #A00877 would address this concern through efforts to educate providers and raise awareness about PANS/PANDAS. Without such measures, many families must travel long distances to access treatment at great emotional and monetary expense. For others, the inability to travel due to financial circumstances or the severity of a child's illness postpones or precludes therapeutic interventions entirely.

Lack of insurance coverage for PANS/PANDAS further delays or, in some cases, completely prevents access to treatment. Particular difficulties are experienced with obtaining reimbursement for intravenous immunoglobulin (IVIG) and other immunotherapies. Insurers routinely deny insurance coverage, and a lengthy cycle of repeated denials and appeals frustrates both healthcare providers and families. More importantly, the denials/appeals process prolongs the patients' suffering and family trauma and increases the risk of serious neurological and psychological harm, long-term disability or even loss of life. Faced with continual denial of care, many families attempt to self-pay for the treatments, forcing them to take on heavy credit card debt, deplete retirement/college funds or sell their homes to raise funds to pay for a treatment that should be covered by insurance.

While we acknowledge that the cost of immunotherapies (particularly IVIG) is substantial, it is small in comparison with the cost of emergency interventions, in-patient psychiatric treatment, and/or pediatric hospitalizations for the complications of severe PANS/PANDAS, such as starvation/dehydration, aggressive behaviors, and self-injury or suicidality. Delayed or denied care also carries a risk of long-term care for serious neurological, emotional, and behavioral disabilities. In addition to the increased expenditures for medical care, untreated PANS/PANDAS also increases education-related costs, as children often require specialized, individualized instruction and significant accommodations for cognitive, neuropsychological, and psychological dysfunction.

In closing, we ask that you alleviate the burdens placed on families, physicians, and other community members who strive to serve the critical needs of children with PANS/PANDAS. Please enable their doctors to make appropriate medical decisions free from administrative and time constraints posed by insurance coverage denials. We urge you to join your fellow legislators in Arkansas, Delaware, Indiana, Illinois, Minnesota, and New Hampshire and require insurance coverage for PANS/PANDAS treatment. Your leadership on this important issue will help ensure children with PANS/PANDAS receive appropriate treatment, enabling them to experience all of the joys of childhood and reach their full potential.

Thank you for your time and consideration. Please don't hesitate to contact us if we can provide additional information and answer any questions that may arise.

ASPIRE Professional Advisory Board Members (PAB)

Susan Swedo, MD

Scientist Emerita, National Institute of Mental Health

Mark Pasternack, MD

Unit Chief, Pediatric Infectious Disease, Mass General for Children

Contact Information:

Gabriella True, PAB Secretary and Board President

Email: gabriella@aspire.care

Mobile: 562-480-7560

Website: www.aspire.care