MHANYS
Mental Health Association
in New York State

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Memorandum in Support of Concept

S10208 (Harckham)/A9659 (Cashman)

AN ACT to amend the insurance law, in relation to requiring certain health insurance policies to cover costs for pediatric acute-onset neuropsychiatric syndrome

MHANYS **strongly supports** the passage and enactment of S10208/A9629, which would amend New York State Insurance Law to require health insurance policies to cover medically necessary rehabilitative treatment of pediatric acute-onset neuropsychiatric syndrome (PANS). Since its founding over 65 years ago, MHANYS has been a leader in seeking to strengthen coverage for mental health and substance use disorders.

The National Institute of Mental Health (NIMH) defined Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) as "conditions that are characterized by a sudden and severe onset of obsessive-compulsive disorder (OCD) or restrictive eating disorder in children before puberty. PANS and PANDAS are also often associated with noticeable changes in mood, behavior, and sensory and motor function in children." NIMH reports PANS can be triggered by infections, immune system issues, or environmental factors with PANDAS categorized as a subtype of PANS associated with infection from streptococcal (strep) bacteria. In both cases, the systems come on quickly and unexpectedly and can include compulsions, obsessions and motor and vocal tics.[1] NIMH reports that scientists and researchers do not know the exact cause with exact prevalence unknown but considered rare. Experts report that early identification and treatment are critical for ensuring better outcomes in the short and long-term. Treatment addresses the underlying triggers, stabilization of the immune system, as well as psychiatric support. Additional research is underway to further enhance diagnosis and treatment.

According to the Alliance to Solve PANS and Immune-Related Encephalopathies (ASPIRE), an organization that focuses on improving the lives of children and adults affected by PANS/PANDAS, lack of mandated coverage means patients face frequent insurance denials for medically necessary care that does not address the underlying disease because they are considered experimental or off-label. The lack of coverage for care, including immume-based therapies, can result in high out-of-pocket costs as well as emergency department visits, prolonged education disruption, long-term disability, workforce loss when parents or adult patients are unable to work. ASPIRE reports 20 states have enacted coverage mandates including Arizona, Arkansas, California, Colorado, Delaware, Georgia, Idaho, Illinois, Indiana, Kansas, Louisiana, Maryland, Massachusetts, Minnesota, New Hampshire, Oregon, Rhode Island, Tennessee, Virginia, and Washington. ASPIRE also reports that states have enacted such a coverage mandate have

[1] https://www.nimh.nih.gov/health/publications/pandas

seen “a negligible impact on insurance premiums.” Aetna, a major insurer nationally and in New York State, recently announced a change in policy recognizing PANS/PANDAS and reiterating its commitment to covering care and treatment.[2]

The American Academy of Pediatrics (AAP) issued a report in 2025 recognizing PANS/PANDAS as a “likely diagnosis” but also noting “…the diagnostic process is challenged by a lack of well-accepted evidence to guide the clinician.” The AAP noted the need for additional research to “develop a dependable and clear evidence base that supports evaluation, diagnosis, and treatment to address a specific child’s symptoms.” The AAP publication recommends “… that the best care for children with potential or diagnosed PANS is provided in a medical home, is family centered, and is delivered by a multidisciplinary team.” PANS/PANDAS is not a standalone diagnosis in the Diagnostic and Treatment and Statistic Manual and is absent from ICD-10/11 coding as a standalone diagnosis. Currently, PANS/PANDAS are usually diagnosed in DSM terms with the symptoms they exhibit, such as Obsessive-Compulsive Disorder, or Tourette Syndrome, or Anxiety Disorders, or Tic Disorders. Others may document “acute-onset OCD” or “rule out PANS/PANDAS” or “OCD associated with autoimmune process.”

MHANYS supports the concept of the legislation to enable those with PANS/PANDAS receive care and treatment to ensure the best possible outcomes in the short-term and long-term for patients. As drafted, MHANYS recognizes the need for potential clarification around the practitioner who would attest to medical necessity, which is currently placed on the attending physician but may need to be broadened to include the pediatrician or other specialists who may be involved recognizing the guidance of AAP that a multidisciplinary team is likely to be involved. The legislation also does not amend provisions of the Public Health Law and Social Services Law, which covers public health insurance programs including Medicaid to ensure those populations receive this benefit as well.

For these reasons, MHANYS **strongly supports** the passage and enactment of the above referenced legislation, while recognizing that additional amendments may be necessary to ensure that PANS/PANDAS are fully and effectively covered.

[2] https://aspire.care/blog/aetnas-pans-and-pandas-coverage-policy-and-the-case-for-state-mandates/