



Dear Chair Weprin and Assembly Insurance Committee Members,

I am writing you today as the parent of a child who lost her life needlessly at age 14 as a result of Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS). PANS and PANDAS are neuroimmune disorders that produce devastating, life-altering symptoms which may include severe OCD, anxiety, tics, joint pain, gastrointestinal distress, extreme sleep disturbance, disordered eating, aggression, irritability, cognitive decline and more as a result of immune system dysfunction following common infections such as strep and the flu.

While symptoms appear psychiatric in nature, PANS and PANDAS are multisystem disorders which may require treatment with antibiotics or antivirals, immunomodulatory therapy such as steroids or intravenous immunoglobulin (IVIG), and behavioral therapy. PANS and PANDAS inflict profound burdens on health care systems, schools, and employers as caregivers often are no longer able to work. These illnesses affect every facet of life and place major stressors on families medically, financially and socially.

I strongly urge you to support Assembly Bill A9659, which would require health insurance plans to cover treatment for PANS and PANDAS. The passage of this bill would alleviate economic burdens on families who frequently pay out of pocket medical expenses despite having insurance or are otherwise forced to forgo treatment, thereby resulting in further decline of a loved one. In doing so, New York would join policymakers in 16 states to date who have passed similar legislation.

I along with the many families impacted by PANS and PANDAS would be very grateful for your support. Thank you for your time and consideration.

Sincerely,

Alissa Johnson
Co-Founder and Advisor
The Louisa Adelynn Johnson Fund for Complex Disease
<https://tlajfundforcomplexdisease.com/>