



April 15, 2026

Re: NYS Assembly Bill A9659 and NYS Senate Bill S2655A,

Requirement of health insurance policies to cover costs for Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) rehabilitation treatment.

Dear Senator Bailey, Assemblyman Weprin and Distinguished Members of the New York State Assembly Insurance Committee and Assemblyman Weprin and Members of the New York State Senate Insurance Committee,

PLEASE pave the way for others and recognize important cutting-edge PANS research led by research clinics at Columbia, Yale, Stanford, Harvard, Oklahoma & Arizona Universities!

I have been the Executive Director of PANDAS Network since 2013, a national 501c3 organization based in California. We represent 30,000+ children and families in the U.S. and worldwide. These children have been hurt by this pediatric autoimmune disease that damages the blood brain barrier and injures the brain. Early diagnosis and treatment prevent permanent lifelong injury.

New 2020 research by Stanford, Yale and Columbia Universities prove that brain inflammation is occurring with strep and other infections in a subset of children. We also believe there is a genetic component making these children more susceptible; but this is not incurable illness!

Youth can heal with treatments that are available but costly without insurance coverage.

Insurance coverage is critical because the expense of treatment together with debilitating, daily symptoms make lack of coverage inhumane and devastating financially. Early recognition of illness onset of PANS has the best chance of assuring children a rapid and substantial recovery. The average age of onset is between ages 4-10. Untreated, the child will often struggle with lifelong neurological and psychological problems. Families and social services will incur financial costs potentially well into the hundreds of thousands of dollars and strain many underfunded systems in society.



Treatment guidelines have been written by experts and the prognosis for healing is excellent if these guidelines are followed. On a personal note: Both my daughter and son developed PAS in 2007 at the age of 7 and the other in 2016 at age 12. With early identification and the use of IVIG and anti-inflammatory medication both children (now ages 25 and 21 years old) have had full and, thus far, lasting remissions.

Finally, please consider that in our lives as adults we are presented with so many recalcitrant illnesses and issues but AB9659 and S2665A can reverse tragic illness and potentially STOP social and economic problems for your entire community.

Sincerely,

Diana Pohlman

Executive Director,
PANDASNetwork.org, 501c3 calif corp