July 27, 2026

Members of the New York State Assembly and Senate Insurance Committees

Re: New York State Assembly Bill A9659 and Senate Bill S2655A regarding insurance coverage for Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS)

Dear Honorable Legislators in New York:

I am the co-founder and Executive Director of The Alex Manfull Fund (TAMF), a 501(c)(3) corporation created after my daughter Alex died due to PANDAS. My husband and I, devastated by the loss of our only child, established this organization to increase awareness, education, and research on PANDAS and PANS. We do not want another life to be cut short -- or derailed-- by these disorders.

I am writing on behalf of TAMF to express our unequivocal support for Bills A9659 and S2655A and to urge you to vote in favor of this significant legislation to ease the burden on individuals and families dealing with these debilitating conditions.

TAMF is painfully aware of the financial hardships suffered by families with children with these disorders. These families are already navigating a complex medical disorder that drastically alters the lives of their children and every other member of their household. Those suffering from PANDAS or PANS experience varying degrees of neuropsychiatric symptoms that can range from needing special education plans to requiring therapeutic day school placements and even in-patient hospital stays. Families sometimes "split up" so that one parent will be the caretaker of the child with PANDAS or PANS and the other parent or family member will take care of the other child or children. And, in the worst-case scenario, as was the case with my daughter Alex Manfull, those with PANDAS and PANS succumb to the condition.

All too often, the families are met with insurance denials for treatments prescribed by providers. Without successful treatment, these other costs will continue to mount, and the lives of the children, adolescents, and young adults suffering from PANDAS or PANS remain on hold while their conditions worsen. Plainly, the costs to the state only increase when treatment is denied.

Despite solid research from multiple institutions such as Stanford, Harvard, Yale, Dartmouth, Georgetown, Columbia, Albert Einstein College of Medicine, and the Universities of Arizona and San Francisco, insurance companies continue to attempt to substitute their judgment for that of providers who have familiarized themselves with the rapidly changing research regarding treating PANS and PANDAS. Furthermore, an efficient and effective process for procuring insurance coverage is critical since PANS/PANDAS recovery is more complete and durable when treatment is administered early.

The landscape for mandatory treatment of PANS and PANDAS has changed dramatically in the last few years. Please help New York join 15 other states—including Connecticut, Massachusetts, California, Virginia and Illinois—that have already enacted similar insurance coverage requirements for PANS/PANDAS. Aetna, one of the country's largest insurers, recently set a precedent by updating its policy to recognize these disorders and cover treatment.

These changes in the coverage landscape are not abstract for our families and clinicians. Behind each denial letter are real faces and names—children facing acute neuropsychiatric symptoms, families trying to shoulder financial and emotional strain, and practitioners constrained in their ability to provide medically necessary treatment. We see this landscape changing, and we are hopeful that New York will be the next state to update its policy to meet current treatment protocol.

TAMF urges you to support NYS Assembly Bill A9659 and Senate Bill S2655A and help those with PANDAS/PANS obtain the treatment they need to resume their healthy and productive lives.

Very truly yours,

Susan Manfull

Susan Newman Manfull, PhD
Executive Director and Co-Founder