



New York State School Social Workers' Association
149 Center Street
East Aurora, NY 14052

To whom it may concern,

I am writing on behalf of the New York State Association of School Social Workers in support of bills A9659 and S10208, which would mandate that insurance companies cover treatment of PANS/PANDAS in this state.

NYSSSWA represents approximately 4000 social workers who provide mental health services in public schools in every district in New York. We are licensed and trained practitioners who are involved in direct clinical therapy to help students navigate trauma, and emotional struggles. We also perform risk assessments and play an integral role in creating IEP and other plans that help students succeed in the academic environment. Additionally, we serve as liaisons between parents and school districts.

Our role in a student's daily academic and social life gives us a unique understanding of the many different issues students can face, and as research identifying and supporting the PANS/PANDAS diagnosis has become available, many of us have begun to recognize it in the schools where we work. Not only do we see these children in crisis, we may have known them before onset and truly understand the magnitude of the change and the significant impact across all domains of functioning. This illness affects everything from executive function, activities of daily living such as eating, toileting, and sleeping and social relationships. The abrupt onset of OCD, acute anxiety and brain fog can make school attendance impossible.

NYSSSWA members play a vital role in supporting the parents, teachers and other stakeholders to help affected students in the school environment. While creating IEPs or 504 plans, and in-school counseling can make it possible for some affected students to continue to manage in the classroom, medical treatment to address the immune dysfunction that has directly caused these neuropsychiatric symptoms and behaviors is essential. With deep sadness and frustration, we have watched families struggle first to find this diagnosis and then to manage the heavy costs of the treatment some of these children require.

When students have this illness there may be a financial cost to schools as well. Sometimes recovery takes a long time and in-school supports are needed for months or even years. This can increase the burden on school budgets and staff. In some cases, children are homebound for long periods, requiring schools to pay for in-home tutoring. Increasing the accessibility of medically necessary treatments through the passage of these bills would reduce the burden on schools to provide these services, thus allowing resources to go to other children in need.

Additionally, expanding access to treatment would also increase awareness of this disease, hasten diagnosis and treatment and enable students to rejoin their friends in school sooner and complete their education on time. Studies have shown that the quicker the diagnosis is made the better the outcome for the child. Without treatment, some children may never return to school or reach their full adult potential. Instead, they may need lifelong supports. Insurance companies already cover treatment for many mental illnesses, some of them costly. PANS/PANDAS should not be different.

Thank you for your consideration,

Wendy Castiglia

NYSSSWA Board President

