

March 26, 2025

American Academy of Pediatrics
345 Park Boulevard
Itasca, IL 60143

Dear American Academy of Pediatrics Leadership,

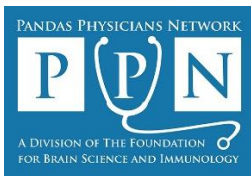
PANDAS Physicians Network (PPN) is urging the American Academy of Pediatrics (AAP) to provide pediatricians with up-to-date evidence-based guidelines and actionable steps for evaluating, diagnosing, and treating children experiencing abrupt and dramatic neuropsychiatric symptoms.

The AAP's incomplete literature review negatively influenced recommendations for patients with acute onset neuropsychiatric symptoms.

The AAP's acknowledgement of PANS (Pediatric Acute Onset Neuropsychiatric Syndrome) as a clinical syndrome characterized by abrupt onset of dramatic behavioral and neuropsychiatric symptoms in children is a step forward for helping those suffering from this condition, including the strep-triggered subset known as PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections). However, the literature review conducted by the AAP for the PANS Clinical Report was incomplete, as it excluded many relevant papers published prior to the initial literature review in 2020 and the subsequent review in 2023. These omissions negatively influenced the Report's conclusions and recommendations. Further, the literature has continued to evolve, as there are now more than 50 relevant publications published between 2018-2025 that the AAP did not take into account. PPN has provided a list of these publications at www.pandasppn.org/research-updates. Consideration of the entire body of PANS and PANDAS research would lead the AAP to more accurate and clinically useful recommendations. Without a comprehensive and up-to-date literature review, the AAP's guidelines cannot provide the highest standard of care to children and families.

Actions needed from the AAP.

1. **Perform Strep Test when Presented with Acute Onset of Neuropsychiatric Symptoms:** Update recommendations to advise pediatricians to perform strep tests on children presenting with abrupt-onset obsessive-compulsive behaviors, restrictive eating, or other abrupt neuropsychiatric symptoms, just as they would with pharyngitis and other typical signs of strep throat. As noted in the 2024 AAP *Red Book*® (page 795), asymptomatic Group A Strep infections can produce and trigger recurrence of dangerous sequelae including acute rheumatic fever and Sydenham chorea. Research shows over 70% of patients with Sydenham's chorea develop obsessive-compulsive symptoms (Swedo, 1989¹ and Asbahr, 1998²). Even though a negative strep test does not rule out the clinical diagnosis of PANS or PANDAS, completing strep testing and treating an infection can reduce long-term psychiatric suffering in impacted children and prevent strep-related complications.
2. **Incorporate Latest Research:** Update the PANS Clinical Paper to reflect the full body of research including the 50+ research studies from 2018-2025 not taken into consideration or cited in the paper.
3. **Provide Evidence-Based Care:** Commit to regular guideline updates and/or direct pediatricians to PPN's guidelines and literature reviews to ensure they have access to the most reliable and current information.



PANDAS PHYSICIANS NETWORK

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PPN's offer to collaborate.

As a leading authority on PANS and PANDAS, PANDAS Physicians Network is ready to partner with the American Academy of Pediatrics to ensure we all remain focused on the well-being of children and families impacted by these conditions. Pediatricians and families need assurance that guidelines and recommendations are evidence-based and in the best interest of the child. PPN's recommendations are based on comprehensive literature reviews and the clinical expertise of pediatricians, child psychiatrists, and pediatric subspecialists with first-hand knowledge of the clinical presentation, pathophysiology and disease course of PANS and PANDAS.

For over a decade, we have compiled and analyzed this information, summarizing the "best practices" and providing trusted, reliable information to pediatricians so that they can make the best decisions about the diagnostic evaluation, treatment, and case management of children in their care. Our resources undergo regular reviews to continuously enhance and update the information we provide. With research on these conditions being published at an increasing pace, it's crucial that providers have access to the most up-to-date empirically-based recommendations to support these vulnerable patients.

PPN has reached out to the AAP on multiple occasions to discuss this important topic, with no response. It is essential that AAP collaborates with PPN immediately to establish a collaborative effort of providing pediatricians with trusted, up-to-date evidence-based resources.

Sincerely,

Susan Boaz
Executive Director
PANDAS Physicians Network

¹Swedo, S. E., Rapoport, J. L., Cheslow, D. L., Leonard, H. L., Ayoub, E. M., Hosier, D. M., & Wald, E. R. (1989). High prevalence of obsessive-compulsive symptoms in patients with Sydenham's chorea. *The American journal of psychiatry*, 146(2), 246–249. <https://doi.org/10.1176/ajp.146.2.246>

²Asbahr, F. R., Negrão, A. B., Gentil, V., Zanetta, D. M. T., da Paz, J. A., Marques-Dias, M. J., & Kiss, M. H. (1998). Obsessive-Compulsive and Related Symptoms in Children and Adolescents With Rheumatic Fever With and Without Chorea: A Prospective 6-Month Study. *American Journal of Psychiatry*, 155(8), 1122–1124. <https://doi.org/10.1176/ajp.155.8.1122>