Sampling of Peer-Reviewed Publications Supporting Treatment for PANDAS and PANS

Compiled by Maryland PANDAS/PANS Support

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Key Finding	Publication Citation
Genetic variations associated with immune dysfunction and susceptibility to infection are associated with increased incidence of PANDAS.	Çelik, G. G., Taş, D. A., Tahiroglu, A. Y., Erken, E., Seydaoğlu, G., Ray, P. Ç., & Avci, A. (2018). Mannose-Binding Lectin 2 Gene Polymorphism in PANDAS Patients. <i>Noro psikiyatri arsivi</i> , <i>56</i> (2), 99–105. doi:10.29399/npa.22811
In PANDAS and PANS patients, testing showed strong association with autoantibody levels, supporting the idea of an immune-mediated process associated with patients' neuropsychiatric symptoms.	Smimasaki, C., Frye, R., Trifiletti, R., Cooperstock, MAppleman, J. (2020). Evaluation of the Cunningham PanelTM in pediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS): Changes in antineuronal antibody titers parallel changes in patient symptoms. <i>Journal of Neuroimmunology 339</i> (2020) 577138.
Impact of PANDAS and PANS is significant; over 75% of patients reported at least one "incapacitating" or "severe" episode, and fewer than 25% could function in school without accommodation.	Calaprice, D., Tona, J., Parker-Athill, E.C. & Murphy, T.K. (2017). A survey of Pediatric Acute Onset Neuropsychiatric Syndrome characteristics and course. <i>Journal of Child and Adolescent Psychopharmacology</i> 27(7): 607-618. doi: https://doi.org/10.1089/cap.2016.0105.
Families/caregivers of children with PANS report higher caregiver burden than caregivers of patients with Alzheimer's disease. Rapid intervention and treatment helps decrease caregiver burden.	Frankovich, J., Leibold, C. M., Farmer, C., Sainani, K., Kamalani, G., Farhadian, B., Thienemann, M. (2018). The burden of caring for a child or adolescent with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS): An observational longitudinal study. <i>The Journal Of Clinical Psychiatry</i> , 80(1). https://doi.org/10.4088/JCP.17m12091.
Research shows early treatment and preventative therapy can significantly improve outcomes for children with PANDAS/PANS.	Brown, K. D., Farmer,, & Frankovich, J. (2017). Effect of early and prophylactic nonsteroidal anti-inflammatory drugs on flare duration in pediatric acute-onset neuropsychiatric syndrome: An observational study of patients followed by an academic community-based pediatric acute-onset neuropsychiatric syndrome clinic' <i>Journal of Child and Adolescent Psychopharmacology</i> , 27(7), 619-628. doi: 10.1089/cap.2016.0193.

Outcomes are best when treatment is aggressive; 89% of patients reported at least some improvement with IVIG treatment.	Calaprice, D., Tona, J. & Murphy, T.K. (2017). Treatment of Pediatric Acute-Onset Neuropsychiatric Disorder in a large survey population. <i>Journal of Child and Adolescent Psychopharmacology</i> , August 2017, online ahead of print. doi: https://doi.org/10.1089/cap.2017.0101 .
Treatment of PANDAS/PANS, as recommended by a consortium of experts from various specialities across medicine, should involve a three-pronged approach: psychiatric treatment; antimicrobial therapy for identified illness; and immune-modulating and anti-inflammatory therapy.	Swedo, S. E., Frankovich, J., & Murphy, T. K. (2017). Overview of treatment of pediatric acute-onset neuropsychiatric syndrome. <i>Journal Of Child And Adolescent Psychopharmacology</i> , 27(7), 562-565.
Immunomodulatory therapies such as steroids, intravenous immunoglobulin, plasmapheresis and immunosuppressive drugs are recommended for severe disease by a consortium of specialists representing a variety of research institutions, hospitals and clinical practices.	Frankovich, J. & members of the PANS Consortium. (2017). Clinical management of pediatric acute-onset neuropsychiatric syndrome: Part II: Use of immunomodulatory therapies. <i>Journal of Child and Adolescent Psychopharmacology 17</i> (7), September 2017, 574-593. https://doi.org/10.1089/cap.2016.0148 .
Plasmapheresis produced significant symptom improvement in a cohort of severely ill patients with PANDAS/PANS, with 78% reporting long-term improvement.	Latimer, M.E., L'Etoile, N., Seidlitz, J., & Swedo, S. (2015). Therapeutic plasma apheresis as a treatment for 35 severely ill children and adolescents with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. <i>Journal of Child and Adolescent Psychopharmacology 25</i> (1). http://doi.org/10.1089/cap.2014.0080.
In a cohort of patients with PANDAS, most of whom had received at least one treatment with intravenous immunoglobulin, 88% reported few or no symptoms at long-term follow-up.	Leon, J., Hommer, R., Grant, P., Farmer, C., & Swedo, S. (2018). Longitudinal outcomes of children with pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANDAS). European Child & Adolescent Psychiatry 27(5), 637-643.
Use of plasma exchange and intravenous immunoglobulin produced significant symptom improvement in children with symptoms associated with PANDAS/PANS (pediatric OCD and tics), with most participants reporting near-complete resolution.	Perlmutter, S., Leitman, S., Garvey, M., Hamburger, S., et al. (1999). Therapeutic plasma exchange and intravenous immunoglobulin for obsessive-compulsive disorder and tic disorders in childhood. <i>Lancet 354</i> : 1153-1158.

Open-label use of intravenous immunoglobulin led to symptom improvements in a cohort of patients with PANDAS.

Williams, K. A., Swedo, S. E., ...& Leckman, J. F. (2016). New research: Randomized, controlled trial of Intravenous Immunoglobulin for Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections. *Journal of The American Academy of Child and Adolescent Psychiatry*, *55*, 860-867. doi:10.1016/j.jaac.2016.06.017.

Therapeutic apheresis (plasmapheresis) is recommended by the American Society for Apheresis as a second-line therapy for PANDAS, backed by "moderate evidence" and appropriate for most patients for whom first-line therapy has not been successful.

Schwartz, J., Padmanabhan, A., Aqui, N., Balogun, R. A., Connelly-Smith, L., Delaney, M., ... Shaz, B. H. (2016). Guidelines on the Use of Therapeutic Apheresis in Clinical Practice-Evidence-Based Approach from the Writing Committee of the American Society for Apheresis: The Seventh Special Issue. *Journal Of Clinical Apheresis*, *31*(3), 149–162. https://doi.org/10.1002/jca.21470