

Peer-Reviewed Support for Merit of Prompt Treatment for PANDAS/PANS (Narrative format)

Compiled by Maryland PANDAS/PANS Support

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Extensive literature supports prompt diagnosis and appropriate treatment for children with PANDAS and PANS. A few of the most significant studies are summarized below.

The 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, Tona, Parker-Athill & Murphy, 2017). Families and caregivers of children with PANS report higher caregiver burden than caregivers of patients with Alzheimer’s disease. Rapid intervention and treatment helps to decrease caregiver burden (Frankovich et al, 2018). In fact, research shows early treatment and preventative therapy can significantly improve outcomes for children with PANDAS/PANS (Brown et al., 2017). 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, Frankovich & Murphy, 2017). Rapidly progressing research has identified raised autoantibody levels in patients diagnosed with PANDAS and PANS (Shimasaki et al., 2020), further supporting the hypothesis that immunotherapy can be helpful for this group of patients. In fact, immunomodulatory therapies such as steroids, intravenous immunoglobulin (IVIG), 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 & members of the PANS Consortium, 2017). In fact, the American Society for Apheresis has recommended plasmapheresis as a second-line therapy, supported by evidence (Schwartz et al., 2016). Outcomes are best when treatment is prompt and aggressive when indicated; 89% of patients in a large survey group reported at least some improvement with IVIG treatment (Calaprice, Tona & Murphy, 2018). Use of plasma exchange (plasmapheresis) and IVIG produced significant symptom improvement in children with symptoms associated with PANDAS/PANS (pediatric OCD and tics), with most participants reporting near-complete resolution (Perlmutter et al, 1999). Plasmapheresis alone produced significant symptom improvement in a cohort of severely ill patients with PANDAS/PANS, with 78% reporting long-term improvement (Latimer, L’Etoile, Seidlitz & Swedo, 2018). Open-label use of IVIG led to significant symptom improvements in a cohort of patients with PANDAS (Williams et al, 2016). After long-term treatment, including (for most) at least one treatment with IVIG, 88% of patients reported few or no symptoms at long-term follow-up (Leon et al., 2018).

References

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