

PANDAS Physicians Network Responds to the British Paediatric Neurology Association Statement Regarding PANDAS/PANS

MOORESVILLE, N.C., June 3, 2021 – The British Paediatric Neurology Association (BPNA) has published a statement regarding the treatment of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS), a disorder primarily associated with Obsessive Compulsive Disorder (OCD) presentation. Unfortunately, they based their recommendation on literature associated with tic disorders, not OCD. They cite Martino et al, 2021, and longitudinal studies of children with long term tic disorders despite Dr. James Leckman (the lead author on one of the studies) stating in 2012 that “he and his coauthors had been studying the wrong children...True PANDAS/PANS cases weren’t represented in his study in any meaningful way.” [\[1\]\[2\]](#)

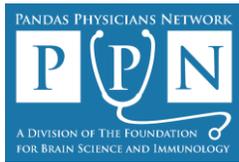
BPNA also refers to two inconclusive studies on biomarkers, despite one of the papers (Dale 2017) studying children with Tourettes (not PANS/PANDAS) and the other paper needing to publish corrections due to failure to collect samples properly. [\[3a\]](#) [\[3b\]](#) BPNA did not cite articles from the Frontiers of Psychology and Journal of Neuroimmunology that properly separated cases based on CAM-Kinase II activation [\[4a\]](#) [\[4b\]](#) nor did they find papers on the long term outcome for children with PANS/PANDAS who have been treated. [\[5\]](#)

Further, BPNA stated that their intent was to provide “best evidenced care when reviewing a child with acute neuropsychiatric presentations, including suspected PANS/PANDAS” and yet failed to use evidence from the 1998 Perlmutter study [\[6\]](#) (class 1 evidence) and the results from the 2014 NIMH study. [\[7\]](#) While they correctly point out that there were responders on antibiotics in the control group, they miss that the OCD scores dropped by >60% for all who received IVIG in the open label section of the trial.

This challenge of confusing symptoms of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) with traditional tic disorders was one of the main reasons why the criteria was tightened and the association with comorbidities is required. [\[8\]](#) Children with PANS/PANDAS do not present the same as children with tic-only or traditional OCD. It is the comorbidities in addition to the nature of onset and the crippling OCD that differentiate the children and their treatment. [\[9\]](#) Based that the study by BPNA focused only on long term tic disorders and not on OCD symptoms and comorbidities, the statement does not provide strong evidence for their recommendation to solely treat the symptoms and not address a possible medical cause.

About the PANDAS Physicians Network (PPN)

PANDAS Physicians Network is a non-profit organization dedicated to maintaining the industry standard PPN Guidelines for Diagnostics and Therapeutics, foster continuous education and communication within the multi-disciplinary medical community, and to sponsor research for developing diagnostic tests, treatment protocols and a cure for PANDAS/PANS within this generation. Learn more at www.pandasppn.org.



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