March 24, 2026

Joint Statement on PANS/PANDAS Prevalence

The prevalence of PANS and PANDAS is not precisely known. Estimates in the literature and clinical community have suggested prevalence on the order of 1 in 100 or 1 in 200 (see: AAP Interview)*, indicating that these conditions are not rare, even as population-level data remains insufficient. The uncertainty reflects persistent systemic barriers, including underrecognition, underdiagnosis, the absence of a dedicated medical code, and limited clinical education.

Our organizations stand united in that we will not adopt language that characterizes these conditions as rare or minimizes their impact in the absence of reliable population-based data. More recent epidemiologic studies suggesting rarity are concerningly limited in scope and methodology and should not be used to define the field.

Available clinical evidence and community experience consistently demonstrate that PANS and PANDAS are underrecognized and associated with significant morbidity when not promptly identified and treated. Addressing the current gaps in clinical education, surveillance and research infrastructure is essential to determining true prevalence. Until such data exist, it is critical that public health and policy decisions reflect the reality of underdiagnosis rather than assumptions of rarity

Link to AAP Interview: https://aap2.silverchair-cdn.com/aap2/content_public/autogen-pdf/cms/12434/12434.pdf?Expires=2147483647&Key-Pair-Id=APKAIE5G5CRDK6RD3PGA&Signature=K~YbtMV4GhChaPYSrvEfe39mly47W-QG5TmyGJ7fqYRAgzK2as-L081~IRCbqo1U27aAufNqp-4nY3QE3xcIz75BFVrAQK6pwJhE0Gk~iY2sqjz~4Q7yN5~b2bQwIA8holP0qrStJzU2Nxo~L9~zgbnUHBeJ40ADTWyZPrHyfZRrh0XnH78GgDPFStqtuklUiorkdqlacPKMVTdxxnycyy6d0yXN~u2dL4vXq9zb49CtXYZOJvyAA3SnzVHt1p1Y6Yk4quRh1NFAP4nvKvyYUxSxv0AGGrGCkAbzivlT~W3mC0bYVoP89ektoUEYN~ASZN3bsHraul86py51uyy72w__

Alliance to Solve PANS & Immune-Related Encephalopathies (ASPIRE)

Bamboo Ranch

Look. Foundation

The Louisa Adelynn Johnson Fund for Complex Disease

The National Alliance for PANS/PANDAS Action (NAPPA)

National PANS Youth Alliance

Neuroimmune Foundation

Northwest PANDAS/PANS Network (NWPPN)

Associazione Genitori Pans Pandas Bge Odv

PANDAS Network