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# Letter to the Editor of Acta Paediatrica

# On diagnosing and treating PANS/PANDAS: questions from a patient support group (Title)

# K Pettersson on behalf of SANE and G R Karlinger, C Sutton on behalf of Sane Norge

# Letter to the Editor of Acta Paediatrica

# Thank you to Pfeiffer et al. (2021) for their article, *Clinical guidance for diagnosis and management of suspected Pediatric Acute‐onset Neuropsychiatric Syndrome in the Nordic countries.* This is an important step, and we anticipate revised versions as new knowledge on the relationship between infection and neuropsychiatric symptoms emerges, e.g. in light of research on long-haul COVID19.

We know all too well that if left untreated PANS/PANDAS symptoms can lead to permanent brain damage, treatment resistance, and in some cases death. As primary caregivers, parents witness first-hand illness progression, symptom expression and observe treatment effectivity. In the Nordic countries patients have a legal right to influence treatment services and these services are obliged to involve users and their representative bodies. We look forward to a fruitful dialogue between our respective patient groups, the working group and service providers on how these guidelines will be implemented, addressing questions such as:

* The guidelines do not differentiate treatment levels according to symptom severity. The more severe the symptoms, the more important it is to initiate immunosuppressive treatment quickly and aggressively. How can these guidelines ensure that patients receive appropriate levels of treatment?
* The authors point to the need for a multi-disciplinary team including psychiatrists, psychologists and neurologists. What role might an immunologist and rheumatologist play given that this diagnosis is determined not only based on excluding psychiatric conditions but also the exclusion of somatic conditions?
* How can patients be ensured a swift diagnosis and treatment to avoid undue suffering and the development of unnecessary serious chronic complications? In Norway, for example, there is a 3-month waiting period between referral and a first appointment for psychiatric evaluation, with an additional 3 months for evaluation.
* While the authors set the bar high for immunosuppressive and other non-psychogenic treatments, they proscribe “psycho-education”, psychotherapy and psychotropic medications according to established guidelines for psychiatric disorders, without referencing evidence of successful treatment for PANS/PANDAS patients. How can patients be assured that this line of treatment will not do more harm than good, or is more effective than other approaches?
* We recognize the authors’ desire to develop a homogenous approach to diagnosing and treating this patient group. Given that no two patients are the same, symptoms vary in severity and can be triggered by a variety of infections and other factors, how can individual patients be assured that their illness progression and response to treatment will be taken seriously if it does not conform wholly to the authors’ description?
* How can parents and patients be assured that their own experiences of living with these symptoms and illness is considered, and how can our organisations input on planning and decision-making in relation to the development of services and treatment?

Finally, the authors note several times that this is a controversial diagnosis. Internationally renowned researchers and practitioners are engaged with PANS/PANDAS, and PANS is expected in ICD 11. We hope that having now devised this first set of guidelines, the authors agree that it is no longer constructive to frame this as a controversial illness. Let us focus instead on together identifying the best modes of treatment that lead to the least harm done for these patients as quickly as possible.

# On behalf of SANE, Katrin Pettersson, Chair

# On behalf of Sane Norge, Geir Rune Karlinger, Chair of the Board and Caroline Sutton, Member of the Board

References

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