

## European advocacy organizations respond to PANS/PANDAS article

### To the Editor:

As representatives of the pediatric acute-onset neuropsychiatric syndrome (PANS)/pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) organizations in Europe, we have concerns about the commentary by Gilbert et al,<sup>1</sup> given its potential to negatively influence the treatment of children suffering from these devastating conditions.

Gilbert et al state that “It is not uncommon in our practice that the diagnosis of PANDAS or PANS distracts families from pursuing clinically important psychiatric and behavioral interventions and sometimes leads to inappropriate, expensive, and risky treatments.”<sup>1</sup>

In our experience, parents are often willing to try psychiatric and behavioral interventions in an attempt to alleviate their child’s suffering. Unfortunately, these strategies do not resolve severe symptoms and the interventions can have negative consequences when underlying conditions are not properly managed. In addition, in our opinion, it is not uncommon for children to be misdiagnosed with psychiatric conditions and improperly medicated, prior to an underlying medical condition even being considered.

Gilbert et al argue that the assumption that inflammation plays a prominent role in PANS/PANDAS, often “leads to overuse of antibiotics and unwarranted exposure of children to powerful immunomodulatory agents.”<sup>1</sup> They provide a single, retrospective, 10-year-old study<sup>2</sup> with a small number of patients, to support this claim. In our experience, it is uncommon for parents to continue ineffective treatments and few families have access or the resources to pursue expensive treatments.

The PANS Research Consortium has based its diagnosis and treatment guidelines on the experience of managing more than 1000 patients. Because the treatment recommendations of Gilbert et al are not supported by any better evidence, we conclude that children must be treated based on the best knowledge available.<sup>1,3-6</sup>

We agree with the authors that PANS/PANDAS poses many challenges and that ongoing research is vital to improve our understanding of the mechanisms involved, symptoms, and best treatment practices. Meanwhile, parents of children with PANS/PANDAS deserve the medical community’s respect and compassion. We urge the authors to work collaboratively with patients, parents, researchers, and clinicians, in cross-disciplinary collaboration, to find solutions.

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