



Department
of Health &
Social Care

*From Baroness Merron
Parliamentary Under-Secretary of State for
Patient Safety, Women's Health and Mental Health*

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Ms Vicky Burford
Chair of Trustees
Paediatric Acute onset Neuropsychiatric Syndrome (PANS) Paediatric Autoimmune
Neuropsychiatric Disorder Associated with Strep (PANDAS)
By email to: vicky.burford@panspandasuk.org

2 December 2024

Dear Ms Burford,

Thank you for your further correspondence of 8 September to the Secretary of State about PANS/PANDAS. I am sorry that you have not received a more timely reply; I wanted to ensure that I could be as helpful as possible, and I am grateful for your patience. I am responding as Minister responsible for Mental Health.

I was sorry to read that you are dissatisfied with the Department's previous reply (our ref: DE-1518697). I hope you find the following information useful in resolving your concerns.

We want a society where every person, including those with a long-term condition such as PANS/PANDAS, receives high-quality, compassionate continuity of care. We will change the NHS so that it becomes not just a sickness service, but able to prevent ill health in the first place. This will help us be better prepared for the change in the nature of disease and allow our services to focus more on the early identification and management of long-term conditions like PANS/PANDAS.

I would like to reassure you that the Department is keeping abreast of the work being undertaken by the PANS PANDAS Steering Group (PPSG) to develop standards of care and to define pathways and service models to assist all primary and secondary clinicians to manage patients with symptomatic presentations of either/both PANS or/and PANDAS in the UK.

We have taken note of the statement issued by the PPSG on 24 February 2023 and recognise that this statement supersedes the 2021 British Paediatric Neurology Association (BPNA) Consensus statement. We have also taken note of the fact that the 2023 PPSG statement makes recommendations for all NHS Trusts to develop multidisciplinary team services to review and treat children with acute-onset neuropsychiatric symptoms. We are also aware that the statement emphasises that the absence of such a service should not lead to referrals of these patients being rejected, nor that clinicians should be prevented from exercising their own proficiency and judgement.

We recognise that there are currently two international peer-reviewed treatment guidelines for PANS/PANDAS, which the PPSG signposts clinicians to whilst work proceeds on the development of a UK clinical guideline. We are aware that the PPSG oversees four

working groups, including The PANS Guideline Development Group, which in conjunction with the Royal College of Paediatrics and Child Health, is working to develop a UK clinical guideline for PANS/PANDAS.

As you correctly point out, the BPNA is not in isolation, working with NHS England to consider relevant pathways for PANS/PANDAS. Rather, the BPNA is working collaboratively as a member of the PPSG to improve services available for this cohort.

With regard to funding for the necessary literature review, Delphi study and surveillance study, the Department commissions research through the National Institute for Health and Care Research (NIHR). The NIHR welcomes funding applications for research into any aspect of human health, including research into post-infectious neuropsychiatric disorders. Details of the various funding programmes are available at www.nihr.ac.uk/research-funding/funding-programmes. The NIHR Research Support Service also provides free and confidential support for researchers to apply for funding and develop and deliver clinical and applied health and care research.

We recognise how serious and debilitating the symptoms of PANS/PANDAS can be. We also recognise that there is still a long way to go in raising the levels of awareness and understanding of PANS/PANDAS amongst healthcare professionals and improving the services and support available for these patients.

Thank you for providing some further information on the key workstreams currently being undertaken by the PPSG.

I hope this reply is helpful.

All good wishes,

A handwritten signature in black ink, appearing to read "Gillian", enclosed in a thin black rectangular border. The signature is written in a cursive style with a long horizontal stroke at the end.

BARONESS MERRON