

7th August 2024

Dear Mr. Streeting,

I am writing, on behalf of the charity PANS PANDAS UK, to congratulate you on your new role as Secretary of State for Health and Social Care and to bring our cause to your attention.

I understand that this letter will be one of many you receive in the coming weeks, however I must urge you to take a moment to consider the unnecessary suffering currently being experienced by children, young people and adults with PANS and PANDAS across the UK due to a lack of adequate healthcare.

What are PANS and PANDAS?

PANS (Paediatric Acute onset Neuropsychiatric Syndrome)

PANDAS (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Strep)

PANS and PANDAS are **post-infectious neuropsychiatric disorders** in which severe symptoms of obsessive-compulsive behaviours, tics or eating restrictions develop suddenly. These primary symptoms are accompanied by a constellation of secondary symptoms, such as sleep and urinary disturbances, decreased cognitive ability and changes in behaviours, personality, and mood.

Occurring in the wake of common infections (such as Group A Streptococcus, chicken pox, influenza, and Covid-19), the underlying cause of PANS and PANDAS is suspected to be an abnormal immune and/or inflammatory response to infection.

Put simply, a child or young person can have a common infection and go on to develop multiple, severe physical and mental symptoms which drastically alter the course of their life. **It is hard to convey in writing just how profoundly debilitating these conditions are.**

Treatments are simple, safe and inexpensive if the conditions are identified and treated promptly. Early identification, treatment and support are known to lead to better outcomes.

The current situation

Low levels of awareness in the UK means that those affected are very often left undiagnosed and without access to appropriate treatment on the NHS. A recent survey we carried out suggested that as many as **95% of GPs did not know about the conditions. 43% of children waited over a year for a diagnosis and a further 18% waited over 5 years.** Many young people end up on the CAMHS referral pathway where there are long waiting lists and low levels of awareness that an infection can precipitate the development of multiple neuropsychiatric symptoms.

Misdiagnosis is common as are unfounded safeguarding referrals due to a lack of understanding of the symptoms of these conditions, further adding to the burden experienced by families. The impacts of these conditions are devastating and wide-ranging both for the person affected, and for those caring for them.

PANS and PANDAS are conditions with a very high risk of long-term disability, exclusion from society and failed education. To give you some indication of the realities faced by this community, you should

know that **77% of children with PANS and PANDAS struggle to attend school after onset**. Many of these children develop sudden, unexpected Special Educational Needs. **46% of families have had to leave employment to look after their child**. For both families and the public purse, the financial implications alone are staggering. The physical and emotional suffering caused by the conditions themselves, and the current lack of healthcare, is far harder to quantify.

Change is needed in the UK to ensure that those affected receive accurate and prompt diagnosis, treatment and support.

What is being done about this?

In September 2023, a [Parliamentary Backbench debate](#) was held to debate PANS and PANDAS. Cross-party consensus was reached on the importance of improving levels of awareness of the conditions amongst professionals and of providing prompt, patient-centred care.

Nearly a year has elapsed since the debate, but little has changed in practice for people living with these devastating conditions. Families continue to face barriers to accessing healthcare, with a great number having no option but to seek help from private doctors which they can ill-afford.

The [PANS PANDAS Steering Group](#) (PPSG) was formed in 2022, with the support of NHS England and representation from the relevant medical Royal Colleges. This group was convened to address the variation in care available to children and young people presenting with symptoms of PANS and PANDAS. The PPSG oversees four sub-working groups which individually focus on research, guideline development, service specification and education.

Support needed from the Government

The PANS Guideline Development Group commenced work on the first UK clinical treatment guidelines in April this year. This critical step towards ensuring parity of care is, however, in significant danger of failing due to the lack of funding to carry out the necessary literature review and Delphi study to reach consensus. Additionally, the surveillance study required to understand the true number of those affected by the conditions comes at a cost.

To date, no source of funding has been identified for these simple, but fundamental processes which will help put an end to the unnecessary suffering experienced by so many people with PANS and PANDAS. We desperately need support from yourself and the Government to implement meaningful measures to bring about change for this community of people.

I would greatly welcome the opportunity to discuss with you the challenges currently facing people with PANS and PANDAS, and the simple, cost-effective measures which can be implemented to improve beyond measure the quality of life for those affected.

Yours sincerely,

Vicky Burford

Chair of Trustees, PANS PANDAS UK