

\*Your Address\*  
\*Your Telephone Number\*  
\*Your Email Address\*

\*Insert date\*

Dear \*Insert name\*

I am writing to you as a constituent, who has been personally impacted by a devastating condition called PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) **\*and/or\*** PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections).

As my representative in Parliament, I ask for your support in resolving the current, extensive barriers to appropriate treatment in the NHS. These barriers affect access to education and are causing unacceptable additional suffering for my own family and many other families living with PANS or PANDAS.

**How can you help?**

**Please help to reinstate the PANS PANDAS All Party Parliamentary Group (APPG) to ensure that a treatment pathway is developed and that ALL children have equitable, effective and excellent treatment for these conditions.**

Due to changes in the rules for APPGs, and the changes which have ensued as a result of the July 2024 General Election, the PANS PANDAS APPG has temporarily lapsed. Work is underway to reinstate the group.

PANS PANDAS UK act as the Secretariat for this group. Please email <mailto:wendy.chamberlain.mp@parliament.uk> to register your interest in joining the APPG.

**About PANS and PANDAS**

PANS and PANDAS are infection-induced immune-mediated conditions, which commonly present with both physical and psychiatric symptoms.

They are little-known conditions which are poorly managed in the UK, despite being formally recognised by the World Health Organisation. There is currently no formal data about incidence of PANS or PANDAS in the UK, but a conservative estimate is that approximately 8,500 children in the UK have these conditions at present. The charity PANS PANDAS UK currently supports more than 6,500 families and that number is growing by the day.

- PANS and PANDAS are caused by a misdirected immune response to common infections (for example Strep, Covid 19 or Chickenpox).
- A patient's normal neurologic functioning is disrupted, resulting in a sudden onset of Obsessive Compulsive Disorder (OCD) and/or tics and/or eating restrictions.
- PANS and PANDAS can include a variety of other comorbid symptoms such as anxiety, loss of previously gained skills, psychosis, intrusive thoughts, irritability, hyperactivity, sleep disturbances, mood swings and urinary problems amongst others.
- Despite having the word 'paediatric' in its name, adults can develop PANS and children who are not treated can take the illness into adulthood.
- All too often, children and adults with PANS and PANDAS are misdiagnosed as having a purely psychiatric illness, or a developmental condition such as Tourette's syndrome or ASD.
- Many sufferers are treated solely with psychotropic drugs to manage their symptoms. It is

known amongst PANS-aware clinicians that these patients often respond badly to standard doses of these medications. Furthermore, these drugs fail to address the root cause of the symptoms and can result in long-term damage to the sufferer.

- There is a growing scientific literature base which demonstrates that, when given appropriate anti-microbial, anti-inflammatory and/or immunological treatment (as recommended in published international peer-reviewed treatment guidelines), PANS and PANDAS patients can experience complete symptom resolution, or dramatic reduction in symptom severity.

### **Current situation**

Levels of awareness of PANS and PANDAS amongst medical professionals are low and access to appropriate healthcare is currently extremely challenging. As a result, many families are forced to seek expensive private treatment and/or left to suffer for extended periods, with sometimes tragic consequences.

PANS PANDAS UK have established a working group with key Royal Medical Colleges and a number of other health organisations in order to develop a pathway for treating these children. A [Clinical Guideline Development Group](#) has been formed to put an end to the current variation in care available to those affected. There is, however, still a great deal of work to be done to ensure that all children presenting with these acute-onset neuropsychiatric symptoms have access to speedy diagnosis and effective treatment on the NHS.

The PANS PANDAS APPG has been instrumental in all the progress made to date. Please can you help the APPG see its vital work through to fruition?

**\*OPTIONAL\*** I attach our personal story.

**\*OPTIONAL\*** I would also like to meet with you to discuss this further ahead of the APPG if possible.

**I look forward to hearing from you on this urgent issue.**

Kind regards

**\*Insert your name\***

[Link 1: Further information on PANS PANDAS](#)

[Link 2: Case study of Jack Gilson who received treatment](#)

**\*OPTIONAL\* Attachment: Our story**