\*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 join 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.**

**The APPG is chaired by Robin Millar (MP for Aberconwy) and PANS PANDAS UK are the Secretariat. Please email** [**robin.millar.mp@parliament.uk**](mailto:robin.millar.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 1,000 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](http://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml) [Compulsive Disorder](http://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml) (OCD) and/or tics and/or eating restrictions.
* [PANS and PANDAS can include a variety of other comorbid symptoms](https://moleculeralabs.com/thirddev/symptoms-of-pans-pandas/) 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**

A recent survey of UK PANS families by PANS PANDAS UK highlights the extent to which the lack of knowledge about the condition is impacting on the quality of life, health and education of sufferers and their families. I attach some shocking statistics from the PANS PANDAS UK parent survey in 2021 for your reference.

As a result of the poor standard of awareness amongst medical professionals, 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. 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.

\*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 and hope that you will be able join the APPG and show your support.**

Kind regards

\*Insert your name\*

[Link 1: PANS PANDAS UK Survey results – Key findings](https://www.panspandasuk.org/_files/ugd/5769d0_e553e22f948b4d9381343beb3466529c.pdf)

[Link 2: Further information on PANS PANDAS](https://www.panspandasuk.org/)

[Link 3: Case study of Jack Gilson who received treatment](https://www.panspandasuk.org/_files/ugd/5769d0_494a25de6d1043608b72d0a2f37eba4e.pdf)

\*OPTIONAL\* Attachment: Our story