

Dear \*INSERT\*

I am writing to you as a concerned 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).

I would like to ask for your support as my representative in Parliament, in resolving some of the current, extensive barriers to appropriate treatment in the NHS and to accessing education, that are causing unacceptable, additional suffering for many PANS PANDAS families.

PANS and PANDAS 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 around incidence of PANS or PANDAS in the UK, but in the US, it is estimated that 1 in 200 children are affected to some degree. The Charity PANS PANDAS UK currently supports more than 3,300 families and this number is growing by the day.

**PANS and PANDAS are infection-induced immune mediated conditions, which commonly present as a mental health disorder.**

- PANS and PANDAS are caused by a misdirected immune response to common infections, targeting the brain.
- 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. PANS PANDAS UK currently support over 160 adults with the conditions.
- All too often, children and adults with PANS and PANDAS are mis-diagnosed as having a 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 which in many cases they respond very badly to.
- Psychotropic drugs do not address the root cause of the symptoms and can result in long-term damage to the sufferer.
- **Growing research and empirical treatments show that when given appropriate anti-microbial, anti-inflammatory and/or immunological treatment, PANS and PANDAS patients can experience complete symptom resolution, or their symptoms are dramatically reduced.**

A 2020 survey of UK PANS families by the PANS PANDAS UK charity, highlighted the extent the lack of knowledge about the condition is impacting on the quality of life, health and education of sufferers and their families.

**Some shocking statistics from the PANS PANDAS UK parent survey in 2020 (cohort of 350)**

#### **MEDICAL PROFESSIONALS**

- **95%** of respondents say **GP did not suggest PANS or PANDAS**
- **42%** of respondents say **Paediatrician had not heard of PANS or PANDAS**
- **31%** of respondents have been **reported for concerns regarding their parenting** and or/referred to parenting classes

\*PANDAS is listed under the ICD-10 code D89.89 and the ICD-11 code 8E4A.0

### **SCHOOL absence due to PANS PANDAS symptoms**

- 88% of respondents say their child has missed some time at school.
- 35% of respondents say their child has missed more than 6 months of school.
- 6% of respondents say their child has missed more than 1 year of school.

### **WORK absence due to PANS PANDAS symptoms**

- 65% of respondents have had to reduce their working hours.
- 50% of respondents have had one adult in the family leave employment.
- An estimated total of 9,642 working days have been lost collectively by our respondents.

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.

Thanks to the tireless work by the Charity PANS PANDAS UK and a group of NHS and Private health professionals in the UK called the PANS Physicians Network (PPN UK), progress is being made. They are working to increase awareness, to deliver training, support families and have created provisional UK treatment guidelines, that could promise improved outcomes and more timely diagnosis.

**However, there is still so much to be done, with time of the essence for those struggling without access to NHS treatment and support.**

**ACTION:** To ensure that the guidelines are accepted by the NHS AND that the pace of change necessary for families like mine, to ensure the health and future of our children is to continue; I politely request you join the **PANS PANDAS All Party Parliamentary Group (APPG)** which has been established for one year now.

The meetings are co-chaired by Ruth Cadbury (MP for Brentford and Isleworth) and Robin Millar (MP for Aberconwy). Please contact Ruth Cadbury's office to register your interest in attending the next meeting.

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

**\*OPTIONAL\*** I attach our personal story and further information leaflets from PANS PANDAS UK.

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

Kind regards

**\*INSERT NAME\***

Link 1: UK PANS PANDAS 2020 Survey

<https://www.panspandasuk.org/for-families>

Link 2: Further information on PANS PANDAS

<https://www.panspandasuk.org/what-are-pans-and-pandas>

Link 3: Case Study of Jack Gilson who received treatment

<https://www.panspandasuk.org/real-life-stories>

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