Dear \*INSERT\*

I am writing to you as a concerned constituent, who has been personally impacted by a devastating condition called Paediatric Acute-onset Neuropsychiatric Syndrome or ‘PANS’.

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 families.

PANS is little known and poorly treated in the UK, despite being formally recognised by the World Health Organisation (ICD-11 code 8E4A.0) and accepted research identifying that as many as 1 in 200 children are likely to be impacted to a varying extent.

**PANS and a subset** Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections or **PANDAS, are infection-induced autoimmune conditions, that can manifest as being mental health disorders.**

* They are caused by a misdirected immune response to common infections, targeting the brain.
* This disrupts a patient’s normal neurologic functioning, resulting in a sudden onset of [Obsessive Compulsive Disorder](http://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml) (OCD) and/or motor tics.
* [PANS and PANDAS can include a variety of other symptoms](https://moleculeralabs.com/thirddev/symptoms-of-pans-pandas/) such as severe food restriction, anxiety, loss of previously gained skills, psychosis, intrusive thoughts, irritability, hyperactivity, sleep disturbances, mood swings and urinary problems.
* All too often, children and adults with PANS and PANDAS are misdiagnosed as having a psychiatric illness, or developmental condition such as Tourette’s syndrome or Autism in the UK.
* Because of this they may be treated solely with psychotropic drugs to manage their symptoms.
* Unfortunately, for PANS and PANDAS patients this does not address the root cause of the symptoms and can actually result in greater harm and long term damage.
* **However repeatedly, research has shown that when given appropriate anti-microbial and/or immunological treatment, PANS and PANDAS patients experience complete symptom resolution, or their symptoms are dramatically reduced.**

Despite this, a 2020 survey of UK PANS families by the PANS PANDAS UK charity, highlighted the extent the condition is impacting the quality of life, education and health of suffers, as well as a lack of knowledge and resistance amongst physicians to help. (Please see attachment 1 to understand more about the outcomes of this reserach).

The most staggering conclusion was that:

**95% of UK General Practitioners were unfamiliar with the condition, leading to delays in treatment and misdiagnosis.**

As a result, many families were forced to seek expensive private treatment and/or left to suffer for extended periods, with sometimes tragic consequence.

Thanks to the tireless work by PANS PANDAS UK and a group of NHS and Private health professionals in the UK PANS PANDAS Physicians network, 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 take part in a forthcoming All Party Parliamentary Group (APPG) focusing on PANS and PANDAS,** driven by the work of the charity. The inaugural meeting took place on 3rd March 2020 and we would be grateful if you could lend your support to the next meeting.

**The meetings will be chaired by Ruth Cadbury (MP for Brentford and Isleworth) and I would aks you to contact her 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.

I attach our personal story, further information leaflets from PANS PANDAS UK and the draft guidelines for treatment.

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

Kind regards

\*INSERT\*

Attachment 1: UK PANS PANDAS 2020 Parent Survey

Attachment 2: Further information on PANS PANDAS (Information leaflet/research)

Attachment 3: Treatment Guidelines

\*OPTIONAL\* Attachment 4: Our story - Example