

PANS and PANDAS Scottish Government PANS PANDAS UK raised at Prime **PANS PANDAS UK** and Steering Group engage MPs **PANS PANDAS UK Minister's Questions** issues letter engages Children's write to Health and Early Day Motion regarding PANS regarding SEND and submitted Commissioner attendance agenda Minister **PANDAS** 2024 2024 <u>2020</u> 2022 2023 2024 2025 2025 2025 2024 2024

Ruth Cadbury MP convenes first PANS PANDAS All Party Parliamentary Group Back Bench
Parliamentary
debate on PANS
PANDAS in
Westminster Hall

PANS PANDAS UK
commences the
process to reconvene
PANS PANDAS APPG

PANS PANDAS UK
presents manifesto
to Department of
Health and Social
Care and meets with
Welsh Education
Department

reconvenes and engages with Education Secretary

PANS PANDAS APPG hears from clinicians

Following a meeting with a constituent, Ruth Cadbury MP set up an All Party Parliamentary Group (APPG) for PANS and PANDAS. The very first meeting took place in March 2020, just a few days prior to the first Covid-19 lockdown.

PANS PANDAS UK met with Juliette Cammaerts, Director of Policy, Planning and Delivery on behalf of the Children's Commissioner Dame Rachel De Souza. The meeting followed a letter to the Children's Commissioner from PANS PANDAS UK highlighting both the health and educational impacts on children and young people living with the conditions.

The meeting centred around the current impacts of the conditions on children and young people, the gaps in current provision, barriers to care and support and outlined suggested next steps.

A <u>backbench debate</u>, secured by Wendy Chamberlain MP, was held in Westminster Hall to discuss the conditions and to ask the Parliamentary Under-Secretary of State for Health and Social Care, Maria Caulfield MP, to respond to the issues raised by the other MPs in attendance.

There was cross-party consensus about the importance of improving care for PANS and PANDAS, and Maria Caulfield acknowledged that 'we have the evidence to sufficiently demonstrate that PANS and PANDAS are discrete disease entities' and committed to work in collaboration with the <u>PANS PANDAS All Party Parliamentary</u> <u>Group</u> and PANS PANDAS Working Group to move forwards in developing the evidence base through high quality research.

In August, PANS PANDAS UK wrote an <u>open letter</u> to the new Secretary of State for Health and Social Care, Mr. Wes Streeting, MP.

In this letter our Chair of Trustees, Vicky Burford, outlines the current challenges facing people living with PANS and PANDAS in the UK and calls upon the new Health Secretary for support.

In September, the <u>PANS PANDAS Steering Group wrote to Health Minister</u>, Wes Streeting, setting out their efforts to tackle the variation in care for the conditions. A full <u>response</u> was received from Baroness Merron (Minister for Mental Health)

Following on from a short period when the PANS PANDAS APPG temporarily lapsed due to the change in Government and the introduction of new rules for APPGs, PANS PANDAS UK began work to relaunch this critical group.

With support from Wendy Chamberlain MP and an incredible effort from our community to engage their MPs, we arranged a drop-in event in Parliament in November for MPs to come and speak to the charity team, family representatives and professionals about the issues facing our community.

For more information on the PANS PANDAS APPG, please click <u>here</u>.

On October 9th, PANS PANDAS Awareness day, the MP Wendy Chamberlain raised a crucial question in PM's question time as to whether it should be for a charity to fund the research, analysis and pathway needed in order to obtain adequate support for people living with PANS and PANDAS.

Adding to this, Wendy Chamberlain went on to ask the Prime Minister if he could facilitate a meeting with the Department of Health and Social Care. You can read more here.

Later that month Michelle Scrogham MP created an Early Day motion in Parliament, entitled 'Care for PANS and PANDAS' which draws attention to the challenges currently facing our community and the work being done to address this.

In November, PANS PANDAS UK met with the Parliamentary Under-Secretary of State for Health and clinical directors from NHS England to discuss the work underway to improve standards of care available and to seek the Department's support moving forward.

Representatives from the charity, Wendy Chamberlain MP and an expert clinician detailed the significant challenges facing families and professionals, and the current barriers to improving healthcare and patient experience. The Minister listened with interest, commending the work of both the charity and the PANS PANDAS Steering Group and agreed to enable further meetings looking at funding to support efforts to improve research and standards of care.

We shared our manifesto 'Count Us In' with the Minister, which details the ways in which the Labour Government's 10 Year Plan for the NHS could work to include people with PANS and PANDAS.

In correspondence received by Wendy Chamberlain MP from Neil Gray MSP, Cabinet Secretary for Health and Social Care at the Scottish Government, the Scottish Government clarified support for families affected by PANS and PANDAS.

Find out more and view the letter <u>here</u>.

In January, the Inaugural General Meeting of the newly reconvened PANS PANDAS APPG was held.

Comprising four officers, and 25 members, such strong membership demonstrates both the community's need for improved standards of care and the commitment of the MPs to drive forward change for all those affected by these debilitating conditions.

Recognising that the effects of PANS and PANDAS go far beyond health impacts, the PANS PANDAS APPG wrote to the Rt Hon Bridget Phillipson, Education Secretary emphasising the urgent need for teacher training on PANS and PANDAS. You can read more about their priorities and access the letter <u>here</u>.

To address some of the significant impacts of PANS or PANDAS on the education experiences and outcomes for children and young people living with the conditions, PANS, PANDAS UK has recently undertaken several workstreams.

These include a creating a <u>response to the Children's Wellbeing and Schools Bill</u>, producing an <u>Education Briefing</u> document, attending a meeting facilitated by Claire Young (Liberal Democrat MP for Thornbury and Yate) regarding the SEND and attendance agenda and facilitating via the <u>APPG</u> further and <u>ongoing dialogue</u> with the Department for Education.

The second APPG meeting of 2025 saw consultant paediatric neurologist, Professor Rajat Gupta, and consultant paediatrician, Dr Tim Ubhi, present to parliamentarians about the conditions and the work which needs to be done to secure prompt and accurate assessment, diagnosis and treatment on the NHS for everyone affected by PANS and PANDAS.