



**Don't just think
'That's really sad,
those poor children'.
Think 'What action
can I take to help?'**

- Alice, 14

**PANS, PANDAS
and Parliament**

Roundtable review

On Wednesday 15th April, twelve members of the PANS PANDAS UK Youth Board delivered a presentation to Members of Parliament and hosted a drop-in session where they bravely answered questions about their experiences of the neuropsychiatric conditions PANS and PANDAS.

This document captures some of what was discussed, including the young people's hopeful messages for future change. Please read their powerful words ahead of the upcoming backbench debate.

Hearing [the young people's] experiences first hand was incredibly powerful. Each of them spoke with such clarity and courage about deeply personal challenges, and their willingness to do so was truly admirable.

Wendy Chamberlain, MP

The testimonies were really difficult to hear, but very powerful. Shameful that all of the children and young people we heard said they needed to seek treatment and support privately. Freddie van Mierlo, MP

The youth board are incredible. I promise to carry their voice forward and push for change! Lee Pitcher MP

The young people were remarkable - so articulate. Bambo Charalambous MP

How inspiring they are - amazing young people passionate about raising awareness. Connor Rand MP

Thank you

Produced with many thanks to the PANS PANDAS UK Youth Board, clinical and health professionals, and attending MPs for their valuable insights and feedback.

Understanding PANS and PANDAS

PANS and PANDAS are post-infectious neuropsychiatric conditions that impact both physical and mental health. They can be triggered by common infections such as strep throat, Covid 19, chickenpox, or influenza.

These conditions primarily affect children and young people with onset typically occurring between the ages of 3 and 13. They are usually relapsing and remitting, with sudden severe symptoms including tics, obsessive-compulsive behaviours, eating restrictions, urinary and sleep disturbances.

PANS: [Paediatric Acute-onset Neuropsychiatric Syndrome](#)

PANDAS: [Paediatric Autoimmune Neuropsychiatric Disorders](#)

[Associated with Streptococcal Infections](#)



Who do PANS and PANDAS affect?

From these quotes alone, you will see that PANS and PANDAS can affect children and young people of varied ages. Although both conditions have the word 'paediatric' in their name, it is now recognised that the conditions can persist into adulthood.

“ I’m Olivia, I am twelve years old and have had PANDAS for two years.

“ I’m Poppy, I am thirteen and have lived with PANS since I was four.

“ I’m Alice, I am fourteen and I have PANS.

“ I’m Evie, I am seventeen years old and my symptoms started when I was four.

“ I am Tilda, I have PANS since I was five, I’m nine now.

“ I’m Emily, I’m sixteen and I help my younger brother James who has had PANDAS for four years

“ My name is Teagan, I’m sixteen. My sister Avilee is eighteen. Her symptoms started when she was nine, and I was seven.

Awareness

Our young people are passionate about raising awareness of PANS and PANDAS. These quotes demonstrate why this is such an important topic for them.

I saw lots of different doctors; a neurologist, an immunologist, lots of paediatricians, an allergy doctor, an ear, nose and throat doctor, and a psychiatrist.

There was a lot of travelling, and lots of questions about things I didn't really want to talk about with strangers.

Nobody told me what was wrong with me.

- Tilda, 9

As a child I remember feeling like no one believed me. I was anxious all the time, confused, angry and disorientated - no child should ever feel like that.

It took **over four years for us to find someone who could help**, and all the time I felt ignored. Invisible. LOST.
- Evie, 17



The PANS PANDAS UK Youth Board with mascot Glitch

Symptoms

Symptoms of PANS and PANDAS are severe and often relapsing- remitting*. Each occurrence, or flare, of symptoms can bring challenges that may influence learning, wellbeing, and confidence.

“Every time I got ill, my symptoms got worse. My tics spread to my neck, arms, back and fingers, and **my thoughts became even more frightening**. Some days it was really hard to leave my mum and go into school. I wanted to see my friends, but **I felt like something terrible might happen...**”

Things like handwriting, or sitting still, became difficult. Sometimes I **felt I had to repeat things over and over again** to my teachers, and I felt very self-conscious.
- Tilda, 9

“My illness caused me to **miss the last two years of primary school** entirely. I remember that my teachers really didn't know how to help ... just like most of my doctors, **my teachers had never heard of PANS or PANDAS** either.
- Evie, 17

“I am **bullied a lot** for my differences and tics and I am constantly made fun of. My teacher thought that by telling me off, my symptoms would stop, so she would personally **take me out of class to shout at me**.
- Poppy, 13

“Every time I was ill, I would **suddenly start to be incontinent**; I would spend a lot of time on the toilet wiping myself excessively and washing my hands for hours.
- Evie, 17

*Flares are occasions when an individual experiences a worsening of symptoms

Treatment

As the only charity supporting families affected by PANS and PANDAS, we hear many stories evidencing the dearth of healthcare knowledge and understanding of the conditions. This significantly delays diagnosis, treatment and recovery.

I was given a treatment known as intravenous immunoglobulins. It worked really well and my consultants both agreed that I need more, but after only two rounds NHS England **denied me further funding.**

- Evie, 17

Getting help has been the most challenging part. Doctors are very quick to **dismiss the problems** and send you to CAMHS*. When medical professionals, who are supposed to help you and get you better, aren't helping you, you have **no hope.**

- Alice, 14

By the time I was diagnosed, my symptoms were severe and I had already lost **almost 20 percent of my body weight** because I had stopped eating. Because of the lengthy delays in receiving my diagnosis and the lack of appropriate treatment, **I am still suffering 14 years later.** I can't do most of the things my peers enjoy and I need 1:1 support in college. **It's not fair...** especially when you consider timely diagnosis and appropriate treatment could have changed everything!

- Evie, 17

I was offered someone to talk to, but at that age [seven], **I needed something different** - play therapy, art therapy - something to help me process what words couldn't. - Teagan, 16

Family impact

Caring for someone affected by PANS or PANDAS can impact the whole family, from parents who may have to leave work, to siblings who face daily trauma at home.

When you live with a sibling who has PANS, you learn to **walk on eggshells** every single day. Her OCD kept her awake screaming until two in the morning and I couldn't sleep through it. It **stopped us leaving the house**, so I was late to school. I couldn't invite friends over for years because **I never knew what might happen.**

Some of what I experienced was traumatic. **I developed flashbacks, panic; symptoms of PTSD.**

Loud or excitable people became triggers. Revising for exams felt impossible when **I couldn't feel safe in my own home.**

Through all of this, **I stayed quiet** because I didn't want to add to my parents' stress.

- Teagan, 16

My mum has had to **give up her career** to become a full-time carer as my brother is no longer able to attend school.

- Evie, 17

For a family who used to love socialising, hosting friends and family regularly, **our world feels very small**; sometimes it feels as if we are in lockdown again.

- Emily, 16

When my sister first became seriously unwell, I was young. **I didn't have the tools to understand what was happening**, let alone how to help. But I felt responsible anyway; especially when I saw her distressed at school.

- Teagan, 16

It can sometimes feel very isolating as I **can no longer have friends over** to our home due to my brother's contamination OCD. It is also **difficult for me to spend quality time with my parents** as they are continuously helping James to do even the most basic tasks in life.

- Emily, 16

What you can do

As Members of Parliament, you have the power to change the experience of these young people, and of future families affected by PANS and PANDAS. This is what our young people want you to think about before the upcoming backbench debate.

If treatment could be available on the NHS, as it is with many other health conditions for children, **this would help so many families like mine** to navigate this devastating condition.

- Emily, 16

There are **thousands of young people all over the country who are struggling** with PANS and PANDAS, many who will not know it due to misdiagnosis, not being listened to or told they are naughty.

- Olivia, 12

[I hope] **more doctors are informed on PANS and PANDAS**, and can issue antibiotics early on, soon after onset.

- Evie, 17

I've missed out on my entire childhood. It's time for change. **I don't want any other child to suffer with this illness like I have.**

- Evie, 17

I think about my little sister Nina, who is three. If this happened to her, I would want her to be treated quickly. **I would want people to understand what was happening to her**, so she could get better.

- Tilda, 9

Siblings of PANS sufferers are carrying more than most people realise. **Please don't overlook us.**

- Teagan, 16

Don't just think 'That's really sad, those poor children'. Think **'What action can I take to help?'**

- Alice, 14

The roundtable in numbers

14 MPs attended the PANS PANDAS UK roundtable

8 MPs pledged to speak at the forthcoming backbench debate on PANS and PANDAS



(L-R) Teagan, Julie Minns MP, Jack, Tilda and Albie



(L-R) Evie, Teagan, Wendy Chamberlain MP and Lee Pitcher MP.

8 MPs said they would raise PANS and PANDAS with the NHS, the Department for Education and the Department of Health and Social Care.

5 MPs said they would request a briefing from PANS PANDAS UK to learn more about the conditions.

3 MPs said they would join the PANS PANDAS All-Party Parliamentary Group



(L-R) Caroline Nokes MP, and Vicky Burford CEO, PANS PANDAS UK

Roundtable reflection

It was a privilege to hear the youth board speak today. **They spoke with such honesty and courage about their experiences.** Their unity, collaboration and determination to make MPs listen, raise awareness and **drive change for other young people** and families really shone through.

- Vicky Queralt, Clinical Psychologist and PANS PANDAS UK Trustee

We anticipate that hearing such impactful stories from our incredible Youth Board will have provided **the motivation for MPs to stand up and speak up for PANS and PANDAS** at the upcoming backbench debate.

- Vicky Burford, CEO, PANS PANDAS UK.

They made such an impact. **No adult could have conveyed what they did**

It was a huge achievement for her to speak so openly and clearly to the MPs. **She said she felt 'seen'.**

[It was] very cathartic to **finally have her voice heard** after all these years of being dismissed and disbelieved!

- Proud parents of some members of the Youth Board

To witness the **power of youth advocacy** in action was an experience I will never forget, and to watch the room fall silent as the youth board shared their stories was something very special indeed. They should all be incredibly proud of what they have achieved.

- Katy Hindson, Health and Policy Lead, PANS PANDAS UK

Case study

Jack developed PANDAS aged just three years old. His abrupt onset of severe symptoms included aggression, tics, obsessive-compulsive behaviours and severe attachment problems. Jack was misdiagnosed with Tourette's, allergies, and told he was autistic.

Experiences like Jack's illustrate the lack of awareness amongst medical professionals about PANS or PANDAS.

“ Jack developed tonsillitis and he became **suddenly very aggressive**. At the time we put it down to his age, but after this he developed tonsillitis a further 10 times and his behaviour worsened each time. Not only was he aggressive but he also developed a tic which made it difficult for him to play with his friends.

He then developed anxiety, attachment issues and had trouble wanting to communicate and eat. It got to the point where Jack didn't want to leave the house and some days, he wouldn't speak a word. He would bite his own arm as he was so anxious and we would struggle to get him dressed each day as he said the clothes hurt him.

Some days, we would look at him and **it was like there was no-one there**. We took Jack to many different doctors and we **could not find the answers** to these changes in behaviour. Not only was Jack suffering mentally, he was also physically very poorly, he lost finger nails and toe nails and had little energy

We had listened to so many different opinions and had been made to feel like we were being paranoid. We felt so alone, and **we were so worried for Jack's future**.

Then we saw an article on 'This Morning'. A mother was talking about her son, the symptoms were very similar to Jack's. The doctor who was interviewed on the show described PANS and PANDAS and described it as a "treatable condition". We contacted our own doctor and from this moment on, our family's lives changed for the better. Jack was diagnosed with having PANDAS. He was prescribed a course of antibiotics and **within two weeks we had our son back**. The worried look in his eyes was no longer there. His tic had completely gone and his behaviour drastically improved. He started eating normally again and was able to leave the house without any anxiety. He is improving every day.

Unfortunately, **there are many families who are not as lucky as we have been and are left totally unaware**. As few as 10% of NHS doctors have heard of the conditions, meaning that many children are misdiagnosed with mental health conditions, or simply labelled as 'naughty children', where really, they could receive treatment and see a significant improvement.

Written by Jack's parents, Neil and Lucy. Jack's full story, and more case studies, are available at www.panspandasuk.org





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➡ www.panspandasuk.org