

Debate Pack

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Debate on Paediatric Acute-onset Neuropsychiatric Syndrome and Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections

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1

What are PANS and PANDAS?

Some children have been observed to develop a range of behavioural, emotional and physical symptoms following an infection. These can include the symptoms of obsessive compulsive disorder, restricted eating and tics.¹

Paediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) are diagnoses that were first proposed by paediatrician Susan Swedo and colleagues to explain the sudden development of these symptoms.²

A neuropsychiatric disorder is a mental disorder that is thought to be caused by a brain malfunction. Neuropsychiatry aims to understand and treat both the physiological and psychological aspects of an illness.³

There is currently no medical consensus about the definition, causes or appropriate treatment of PANS and PANDAS.⁴

PANDAS is thought to follow infection with Group A Streptococci bacteria (also known as Strep A or GAS).⁵ [Strep A is a common bacterial infection that can cause a range of illnesses](#), including sore throats and scarlet fever.⁶

PANS is a broader term, reflecting uncertainty about the causes of these conditions, and the observation that similar symptoms may develop after several different infections, including the flu and chickenpox.⁷

PANS and PANDAS are thought to be caused by an autoimmune response following an infection. In these conditions, the body's immune system may be [attacking part of the brain, leading to inflammation that affects thought, behaviour and movement](#).⁸

¹ PANS PANDAS UK, [What are PANS and PANDAS?](#) No date, accessed 16 August 2023; PANDAS Physicians Network, [PANDAS/PANS Diagnostic and Treatment Guidelines](#), no date, accessed 16 August 2023

² Susan E Swedo and others, [Paediatric autoimmune neuropsychiatric disorders associated with streptococcal infections: clinical description of the first 50 cases](#), American Journal of Psychiatry, Vol 155, No 2, February 1998; Susan E Swedo and others, [From Research Subgroup to Clinical Syndrome: Modifying the PANDAS Criteria to Describe PANS \(Paediatric Acute-onset Neuropsychiatric Syndrome\)](#), Pediatrics & Therapeutics, Vol 2, No 2, 2012 (PDF)

³ Royal College of Psychiatrists, [Neuropsychiatrist](#), no date

⁴ Colin Tidy, [PANDAS](#), Patient.info, 24 September 2021

⁵ Jonathan Beebee, [Raising awareness of PANS PANDAS and the RCN's co-signing of the recent position statement](#), 18 May 2023

⁶ [Strep A](#), NHS, 16 December 2022

⁷ Colin Tidy, [PANDAS](#), Patient.info, 24 September 2021; Jonathan Beebee, [Raising awareness of PANS PANDAS and the RCN's co-signing of the recent position statement](#), 18 May 2023

⁸ [PANDAS – Questions and Answers](#), National Institute of Mental Health (US), 2019, accessed 16 August 2023

2

Symptoms of PANS and PANDAS

PANS and PANDAS are characterised by the sudden development of a range of behavioural, emotional and physical symptoms.

These include the abrupt onset of the symptoms of [obsessive compulsive disorder \(OCD\)](#)⁹, restricted eating, or [tics](#) (fast, repetitive body movements or sounds).¹⁰

Other symptoms can occur alongside these, including anxiety and depression, emotional or behavioural problems, developmental regression, insomnia and enuresis (loss of bladder control).¹¹

2.1

Diagnostic criteria for PANS

A set of diagnostic criteria for PANS have been proposed by the [PANS/PANDAS Research Consortium](#), a group of researchers and clinicians based in the United States.¹² These criteria were developed at the 2013 PANS Consensus Conference, held at Stanford University.¹³

The primary symptom is the abrupt development of [obsessive compulsive disorder \(OCD\)](#)¹⁴ and/or severely restricted food intake.¹⁵

For a diagnosis to be made under these criteria, these symptoms should appear alongside two or more of the following symptoms:

- Anxiety
- Emotional lability and/or depression
- Irritability, aggression, and/or severely oppositional behaviours
- Behavioural (developmental) regression
- Deterioration in school performance (related to attention-deficit/hyperactivity disorder [ADHD]-like symptoms, memory deficits, cognitive changes)

⁹ [Overview – Obsessive compulsive disorder \(OCD\)](#), NHS, 4 April 2023

¹⁰ [Overview – Tics](#), NHS, 5 April 2023

¹¹ PANS PANDAS UK, [What are PANS and PANDAS?](#) No date, accessed 16 August 2023

¹² Stanford Medicine, [PANS Research Consortium](#), No date, accessed 1 September 2023

¹³ Kiki Chang and others, [Clinical Evaluation of Youth with Pediatric Acute-Onset Neuropsychiatric Syndrome \(PANS\): Recommendations from the 2013 PANS Consensus Conference](#), Journal of Child and Adolescent Psychopharmacology, Vol 25, No 1, 19 February 2015, p3-13.

¹⁴ [Overview – Obsessive compulsive disorder \(OCD\)](#), NHS, 4 April 2023

¹⁵ PANS PANDAS UK, [What are PANS and PANDAS?](#) No date, accessed 16 August 2023

- Sensory or motor abnormalities
- Somatic signs or symptoms, including sleep disturbances, enuresis, or urinary frequency¹⁶

These symptoms should not be explainable by another known neurological or medical condition.

2.2

Diagnostic criteria for PANDAS

Diagnostic criteria for PANDAS have been proposed as follows:

- Presence of OCD and/or tic disorder according to DSM-5 [Diagnostic and Statistical Manual of Mental Disorders 5] criteria.¹⁷
- Onset occurring between 3 years of age and puberty.
- Episodic course.¹⁸
- Temporal association of exacerbation of symptoms with GABHS [Group A beta-haemolytic streptococcal] infections.
- Presence of abnormal results on neurological examination in absence of chorea [a movement disorder].¹⁹

This diagnosis involves identifying a recent infection with Group A Strep (here referred to as GABHS) and the exclusion of a diagnosis of chorea.

Chorea is a movement disorder that can occur in several illnesses.²⁰ In particular, Sydenham chorea (or Sydenham's chorea) is a movement disorder that can occur after infection with Group A Strep.²¹

¹⁶ Kiki Chang and others, [Clinical Evaluation of Youth with Pediatric Acute-Onset Neuropsychiatric Syndrome \(PANS\): Recommendations from the 2013 PANS Consensus Conference](#), Journal of Child and Adolescent Psychopharmacology, Vol 25, No 1, 19 February 2023, p3-13.

¹⁷ The [Diagnostic and Statistical Manual of Mental Disorders](#) (DSM) is published by the American Psychiatric Association. It classifies and defines mental disorders and is the main guide to their diagnosis in the United States. DSM-5 is the most recent edition of the manual, published in 2013 and updated in 2022.

¹⁸ In an illness with an episodic course, symptoms are present during an episode and then improve or resolve, but may recur later.

¹⁹ Colin Tidy, [PANDAS](#), Patient.info, 24 September 2021

²⁰ [Chorea](#), National Institute of Neurological Disorders and Stroke (US), no date, accessed 16 August 2023

²¹ [Sydenham chorea](#), Medline Plus, 2 May 2022

3

Recognition of PANS/PANDAS

PANS and PANDAS have been described as "controversial" diagnoses.²² They are relatively newly defined conditions, and current diagnostic criteria and treatment options are primarily based on clinical expertise and judgement (see section 1.3 below).

The published research evidence about these conditions is limited. There is ongoing uncertainty about the causes of the conditions, and the most effective treatments.²³

3.1

British Paediatric Neurology Association Consensus Statement (2021)

The [British Paediatric Neurology Association \(BPNA\)](#) describes itself as “the professional organisation for doctors who specialise in the care of children with neurological disorders”.

In April 2021, the BPNA published a [Consensus statement on childhood neuropsychiatric presentations, with a focus on PANDAS/PANS](#).²⁴ The stated aim of this document was to “provide a UK focussed document to support British Paediatric Neurology Association (BPNA) members to provide best evidenced care when reviewing a child with acute neuropsychiatric presentations, including suspected PANS/PANDAS.”

The development of the consensus statement was prompted by “increased referrals for review of possible underlying neurological disorders among children with acute neuropsychiatric presentations”.²⁵

BPNA stated that it had not issued any specific guidance because of the lack of high quality research evidence on which to base any recommendations. Specifically, they cited a lack of “class 1 evidence” in the form of “robust data from randomised controlled trials”.²⁶ The consensus statement highlights the lack of research evidence on PANS and PANDAS and argues that new research

²² Colin Wilbur and others, [PANDAS/PANS in childhood: Controversies and evidence](#), Paediatrics and Child Health, Vol 24, No 2, May 2019, p85-91; Donatella Marazziti and others, [Obsessive-Compulsive Disorder, PANDAS and Tourette Syndrome: Immuno-inflammatory Disorders](#), Advances in Experimental Medicine and Biology, Vol 1411, 23 March 2023, pp275-300 (subscription required)

²³ Colin Tidy, [PANDAS](#), Patient.info, 24 September 2021

²⁴ BPNA, [Consensus statement on childhood neuropsychiatric presentations, with a focus on PANDAS/PANS](#), April 2021

²⁵ As above

²⁶ As above

is needed to inform diagnostic criteria and treatment options for affected children.

[PANS PANDAS UK](#) is a charity that works to increase awareness and improve the diagnosis and treatment of these conditions in the UK. It criticised the BPNA consensus statement. In August 2022, it asserted that the document contained errors and did not take into account all published evidence or existing international guidelines.²⁷ It noted that:

Since April 2021, the charity has become increasingly aware of the detrimental impact the BPNA statement has had on UK families managing PANS/PANDAS. The statement has resulted in many patients being refused initial, or continued, appropriate treatment and an increase in the number of Fabricated or Induced Illness (FII) accusations being made against families.²⁸

[Fabricated or induced illness \(FII\) is a rare form of child abuse](#), that involves a parent or carer exaggerating or deliberately causing the symptoms of an illness in a child.²⁹

PANS PANDAS UK has published a [position statement](#) and [a guide for professionals](#) in relation to allegations of FII.³⁰

3.2

International Classification of Diseases (ICD-11)

The World Health Organization (WHO) produces and maintains the [International Statistical Classification of Diseases and Related Health Problems \(ICD\)](#). This international standard is used in health systems around the world as a means of ensuring the consistent recording and analysis of health data.

ICD-11 is the eleventh revision of the ICD. It was endorsed by WHO members in May 2019 and officially took effect in January 2022, although it is still being rolled out in many health systems.

ICD-11 is the first edition of the ICD to include mention of PANDAS, under two separate entries:

- Paediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) appears under Paraneoplastic or

²⁷ PANS PANDAS UK, [PANS PANDAS UK's response to the BPNA Consensus Statement on PANS and PANDAS](#), 5 August 2022

²⁸ As above

²⁹ NHS, [Overview – Fabricated or induced illness](#), 15 March 2023

³⁰ PANS PANDAS UK, [Fabricated or Induced Illness Position Statement](#), November 2022 (updated May 2023); PANS PANDAS UK, [PANS, PANDAS & Fabricated or Induced Illness: A Guide for Social Work, Healthcare and Education Professionals](#), May 2023

autoimmune disorders of the central nervous system, brain or spinal cord (8E4A.0)

Tics due to paediatric autoimmune neuropsychiatric disorders associated with streptococcal throat infections appears under Infectious or postinfectious tics (8A05.10)

4

Guidance on PANS/PANDAS

The [National Institute of Health and Care Excellence \(NICE\)](#), the body that produces recommendations for the diagnosis and treatment of health conditions in the NHS in England, has not produced any guidance for the treatment of PANS or PANDAS.

4.1

International guidance

PANS PANDAS UK provides the details of proposed treatment guidance produced elsewhere:

- Thienemann and others have proposed [psychiatric and behavioural treatments](#) to address symptoms, including cognitive behavioural therapy (CBT) and medicines that are used to treat anxiety and OCD.³¹
- Frankovich and others have proposed [immunomodulatory treatments](#) (medicines that affect the body's immune response) for persistent or severe symptoms, including the use of non-steroidal anti-inflammatory drugs, corticosteroids and intravenous immunoglobulin treatment.³²
- Cooperstock and others have proposed treatment guidelines for [the management and prevention of infections in PANS/PANDAS patients](#), including prompt use of antibiotics for suspected infections, and antibiotic prophylaxis for those with severe or recurrent symptoms.³³

All three of these proposed guidelines were developed based on the available evidence and the agreement of the clinicians and researchers involved.

In addition, [proposed guidance on the diagnosis and management of suspected PANS in the Nordic countries](#) was published in 2020.³⁴ These proposals were developed by a working group of clinicians based in Denmark, Norway, Sweden and the UK.

³¹ Margo Thienemann and others, [Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I – Psychiatric and Behavioral Interventions](#), Journal of Child and Adolescent Psychopharmacology, Vol 27, No 7, 1 September 2017

³² Jennifer Frankovich and others, [Clinical Management of Pediatric Acute-onset Neuropsychiatric Syndrome: Part II – Use of Immunomodulatory Therapies](#), Journal of Child and Adolescent Psychopharmacology, Vol 27, No 7, 1 September 2017

³³ Michael S Cooperstock and others, [Clinical Management of Pediatric Acute-onset Neuropsychiatric Syndrome: Part III – Treatment and Prevention of Infections](#), Journal of Child and Adolescent Psychopharmacology, Vol 27, No 7, 1 September 2017

³⁴ Helle Cecile Viekilde Pfeiffer and others, [Clinical guidance for diagnosis and management of suspected Pediatric Acute-onset Neuropsychiatric Syndrome in the Nordic countries](#), Acta Paediatrica, Vol 110, No 12, 13 April 2021

This guidance includes recommendations to treat bacterial infection with antibiotics (but does not recommend prophylactic antibiotic treatment), the use of non-steroidal anti-inflammatory drugs or steroids to reduce inflammation, and the use of intravenous immunoglobulin for severe cases.³⁵

Intravenous immunoglobulin (IVIg) is a treatment that is used to treat some autoimmune neurological conditions. It is thought to work by changing the way the immune system works, reducing the body's autoimmune response.³⁶

³⁵ As above

³⁶ St George's University Hospitals NHS Trust, [Intravenous Immunoglobulin \(IVIg\) for Neurological Conditions](#), September 2022 (PDF)

5 UK initiatives on PANS/PANDAS

The UK Government has not specifically commented on PANS/PANDAS.

5.1 PANS PANDAS Working Group (2022)

In November 2022, [the PANS PANDAS Working Group \(PPWG\) was established](#). This group includes representatives of BPNA, PANS PANDAS UK, the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health, the Royal College of Nursing, the Royal College of Occupational Therapy, the British Paediatric Allergy, Infection and Immunology Group, the Royal College of General Practitioners, and the British Association of Social Workers.³⁷ The working group is supported by NHS England.³⁸

In February 2023, the PPWG issued [a statement describing the group and its aims](#):

The PPWG are embarking on collaborative work to develop standards of care and to define pathways and service models to assist all primary and secondary clinicians to manage patients with symptomatic presentations of both PANS or PANDAS in the UK.³⁹

This statement included some initial recommendations that aim to reduce variation in how children who present with acute-onset neuropsychiatric symptoms are managed in the NHS. These include the development of multi-disciplinary team (MDT) provision, and comprehensive medical evaluation for children who present with these symptoms.⁴⁰

In July 2023, PANS PANDAS UK posted [an update on the work of the PPWG](#), announcing a “nationwide surveillance study” to establish the number of children and young people presenting to healthcare professionals with symptoms matching the diagnostic criteria for PANS or PANDAS. It also announced the establishment of a “dedicated taskforce” who will develop a consensus on how PANS and PANDAS should be managed in the UK.⁴¹

³⁷ PANS PANDAS UK, [PANS PANDAS Working Group](#), July 2023, accessed 16 August 2023

³⁸ As above

³⁹ [PANS PANDAS Working Group Statement](#), 24 February 2023

⁴⁰ As above

⁴¹ [PANS PANDAS Working Group Update](#), July 2023, accessed 16 August 2023

6 Parliamentary Early Day Motions

[PANS PANDAS UK Working Group Statement, 24 February 2023](#)

EDM (Early Day Motion)948: tabled on 08 March 2023

[Diagnosis and support for PANS and PANDAS](#)

EDM (Early Day Motion)708: tabled on 14 December 2022

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Useful links

British Paediatric Neurology Association

[PANS/PANDAS](#)

PANS/PANDAS UK - charity

<https://www.panspandasuk.org/>

Royal College of Occupational Therapists

[PANS / PANDAS Standards of Care](#)

Royal College of Nursing

[PANS PANDAS: A mysterious and debilitating paediatric disorder](#)

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