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Please see our website to download these journal articles in full. <https://www.panspandasuk.org/resources>

## Who we are

### About us

It is our mission to raise national awareness of these life changing conditions, create support networks for families who are affected and develop an ongoing relationship with a network of doctors in order to encourage education in these conditions.

### Contact us

-  [www.panspandasuk.org](http://www.panspandasuk.org)
-  [panspandasuk@gmail.com](mailto:panspandasuk@gmail.com)
-  PANS PANDAS UK Support Group
-  @PandasPans



**PANS PANDAS UK**  
awareness support education

**Medical Professional's Leaflet** (April 2019)  
c/o Baldwins, Pegasus House, Pegasus Court, Tachbrook Park,  
Leamington Spa, Warwickshire CV34 6LW

# Medical Professional's Leaflet

## PANS PANDAS UK

### PANS

*Paediatric Acute-Onset Neuropsychiatric Syndrome*

### PANDAS ICD-11: 8E4A.0

*Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections*



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awareness support education

## Diagnostic Criteria

A sudden onset of OCD, tics or severely restricted food intake where the symptoms are not better explained by a known neurologic or medical disorder; with 2 or more similarly severe accompanying symptoms such as:

- Anxiety (heightened anxiety, separation anxiety, irrational fears, panic episodes)
- Emotional lability and/or depression
- Irritability, aggression and/or severe oppositional behaviours
- Hyperactivity
- Behavioural and/or developmental regression
- Sudden deterioration in school performance
- Motor and/or sensory abnormalities
- Insomnia and/or sleep disturbances
- Enuresis and/or urinary frequency
- Hallucinations and/or psychosis

“ By the time parents get to me, they have usually diagnosed their children already and they are usually right! ”

### DR ANDREW CURRAN

*Consultant Paediatric Neurologist*  
Alder Hey Children's Hospital

New and evolving research has begun to substantiate that this syndrome involves a misdirected autoimmune process that affects or weakens the blood/brain barrier. The region of the brain primarily affected is the basal ganglia which is responsible for the following functions: movement, cognitive perception, habit, executive 'logic based' thinking, emotions and the endocrine system.

“ The family and child are often traumatized, frightened and the sense of urgency is palpable. ”

Doctors often wonder if this syndrome is really just 'OCD or tic' disorders, or fussy eating. The type of profound change in the child and the effect on their family really goes far beyond a simple OCD or tic diagnosis. The family and child are often traumatized, frightened and the sense of urgency is palpable. If a parent suggests PANS or PANDAS, then consider this condition very carefully.

#### Physicians Network

There is now an established Physicians Network within the UK comprising of a number of neurologists, immunologists and psychiatrists as well as paediatricians, GP's and Drs from other medical specialities. Drs meet on a quarterly basis to discuss the detection, diagnosis and treatment of these conditions. If you wish to learn more about this or attend one of these meetings, please email us at [panspandasuk@gmail.com](mailto:panspandasuk@gmail.com)

## Appropriate first stage tests that may be considered

- Throat, nasopharyngeal or peri-anal swab to rule out strep on a 48 hour culture
- Initial bloods: U+E, LFT, FBC, ASOT, Anti-Dnase B Titres, IgG, IgA, IgM, ANA, Vit D3, Free T3, Free T4, TSH
- Tests to rule out other infections based upon medical and family history

## First stage treatments that may be considered

- Initiate treatment immediately – do not wait for test results
- Initial Antimicrobial therapy. Choose one of the following and administer orally for 14 days: Penicillin V, Amoxicillin, Co-amoxiclav, Cephalexin, Clindamycin, Azithromycin, Clarithromycin
- Follow up with patient to see if remission/improvement occurred. Consider continued antibiotic or prophylaxis
- Referral to paediatrician for ongoing treatment
- OCD often benefits from CBT or counselling

**This leaflet and other information can be downloaded from our website:**  
[www.panspandasuk.org/resources](http://www.panspandasuk.org/resources)