

PANDAS and PANS



PANDAS is an abbreviation for Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections. This describes a group of children who have OCD and/or tic disorders such as TS, whose symptoms are abruptly provoked or worsened by streptococcal infections such as 'strep throat' and scarlet fever. Some of the children who were originally described were rather more ill than usually seen at the start of TS with other symptoms and additional significant changes in brain function.

One of the ways the body fights infections is with proteins in the blood called antibodies that attach to bacteria and destroy them. Patients with PANDAS have antibodies in their blood which also attack a part of the brain called the basal ganglia, a part that normally helps control movement. It is not definitely known that these antibasal ganglia antibodies do cause harm. Around 25% of people with TS but not PANDAS also have these antibodies, compared to about 3% of people who do not have TS - so testing for antibodies in the blood is usually not very useful.

It is difficult to prove streptococcal infections are an important cause of TS for many patients as a high proportion of children in general have been infected at some point. A major Europe-wide research project called EMTICS is investigating the link between streptococcal infection and TS.

PANDAS has been partially superseded by the term PANS (also known as CANS) which stands for Paediatric or Childhood Acute-Onset Neuropsychiatric Syndrome. PANS includes cases that would have previously fitted the definition of PANDAS.

PANS differs in that it does not require the presence of tics or streptococcal infection, although the majority of PANS cases do have tics. PANS is defined by the sudden onset of OCD or severely restricted food intake in association with several other emotional, behavioural and intellectual problems.

This area remains scientifically controversial. As PANS does not require the presence of an infection, or not specifically streptococcus, there could be a variety of other causes. A sudden onset of TS does sometimes occur and whilst infections may be relevant in some cases, in many it is not proven. A sudden change in a child alone cannot be assumed to be due to a streptococcal infection. There is not yet good evidence to show that children should be given antibiotics or other treatments that affect the immune system. There could also be risks of long term antibiotic treatment. The EMTICS study includes an investigation into using antibiotics but results are not yet available.

As there is some uncertainty around PANS and PANDAS, advice and diagnosis from different doctors can vary and experiences recorded by families on the internet can unfortunately be misleading. Assessment should be by a doctor with experience in TS.

This information was written by Dr Jeremy Stern, Dr Helen Simmons, Professor Eileen Joyce and Professor Andrea Cavanna, December 2018.