

## PANDAS Fact Sheet

### What is PANDAS?

- The term 'PANDAS' is short for 'Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus' (The word streptococcus is often shortened to 'strep'.)
- A child can be diagnosed with PANDAS when:
  - Obsessive Compulsive Disorder (OCD) or tic symptoms suddenly appear for the first time, OR
  - The symptoms suddenly get much worse, AND
  - The symptoms occur during or after a strep infection in the child.
- PANDAS is caused by the body's immune system reaction to strep, not the infection itself. When an infection happens, the body's immune system makes proteins to fight the bacteria. These proteins are called antibodies. It is believed that PANDAS may be similar to another disorder called Sydenham's chorea, where antibodies to strep infections can attach to some nerve endings in the brain and cause symptoms to appear.
- Because the exact way that PANDAS affects the body is not fully understood, neither are the best treatments (which may be different from other kinds of OCD treatment.) This means that treatment for PANDAS is still debated by researchers and clinicians.

### Diagnosing PANDAS:

1. Children with PANDAS are initially diagnosed with Obsessive Compulsive disorder or a tic disorder. OCD and tic symptoms in PANDAS are similar to those in the classic forms of childhood OCD and tic disorders (Murphy, Herbstman, & Edge, 2005).
2. PANDAS first appears in childhood from age 3 to puberty. In addition to OCD or tics, these children may have some or all of the following symptoms:
  - Sudden unexplainable rages (also called emotional lability)
  - Personality changes
  - ADHD (Attention Deficit Hyperactivity Disorder)
  - Anorexia (often because of a fear of choking, or fear of throwing-up)
  - Nervous system disorders such as tics or other rapid, jerky movements
  - Age inappropriate behaviors (such as bedtime fears/rituals, loss of impulse control)
  - Separation anxiety
  - Defensiveness caused from hyper-active senses (such as sensitivity to clothing, noise, light, taste, etc.)
  - Noticeable decrease in handwriting or math skills.
3. Diagnosis of PANDAS should be discussed after symptoms first suddenly appear or severely worsen. One way that symptoms severity can be measured is through an OCD symptom checklist called the CY-BOCS (Children's Yale-Brown Obsessive Compulsive Scale.) If a child has an average increase of 18 or more points in their CY-BOCS score, it can be called a severe worsening of symptoms. Many parents can pinpoint a day or a week when behaviors changed.
4. In PANDAS children, a strep infection occurs before the start of symptoms. If treated, the first symptoms generally improve within 4-6 weeks. The next PANDAS symptoms may last longer and may be triggered by another strep infection, or by other bacterial or viral infections (ear infections, sinusitis, pneumonia, meningitis, impetigo) making a diagnosis more difficult.

#### 5. Lab Tests:

- A throat swab (rapid and cultured) to test for strep can be done when symptoms first appear.
  - If the throat swab does not show any signs of strep, a blood test for an antibody called ASO (Anti-Streptolysin O) can also be done up to 6 weeks after onset.
  - However, a high blood level of ASO alone does not confirm PANDAS. Nor can a low blood level of ASO alone rule out PANDAS.
6. PANDAS is not the only immune system disease that may initially cause OCD to appear suddenly. Other disorders may need to be ruled out. They include: Lyme Disease, Thyroid Disease, Celiac Disease, Lupus, Sydenham Chorea, Kawasaki's Disease, and acute Rheumatic Fever.

#### **Treatment:**

- Strep infections are treated with antibiotics.
- Cognitive Behavioral Therapy (CBT), specifically Exposure & Ritual Prevention (ERP) therapy, has been shown to help PANDAS patients and their families.
- Selective serotonin reuptake inhibitor (SSRI) medicines are also effective for childhood OCD (SSRIs may work well in some children but, in others, OCD symptoms may actually get worse and more serious problems such as aggression, hyperactivity, sleep problems and even suicidal thinking can occur. This was shown to be the case in a small PANDAS study (Storch 06)) Because of this, SSRI use should be discussed with a doctor in order to weigh the benefits against the risks.
- For some patients with severely disabling symptoms following infections, use of antibiotics as a prevention method may be considered (Leonard and Swedo 2001). Future studies are required to develop guidelines for which PANDAS patients should receive this treatment. This is due to the concern that antibiotic use may lead to the evolution of drug-resistant germs.

#### **Key Points**

- PANDAS is a proposed kind of OCD that occurs in childhood following the body's reaction to infection.
- It is thought to be the body's immune reaction to infection, not the strep infection itself that causes symptoms.
- A high blood level of a strep antibody alone does not confirm PANDAS. Nor can a low blood level of a strep antibody alone rule out PANDAS.
- PANDAS should be managed with early antibiotic treatment for strep infections. Continued symptoms can be treated with standard OCD treatments (cognitive-behavior therapy and/or SSRI medication). Closely watching a child's reaction to SSRIs is important as they can cause severe behavioral problems, including suicidal thoughts.
- PANDAS symptoms will only stop once an infection is fully treated. Doctors should perform follow-up throat cultures and check family members before assuming an infection is no longer present.

#### **More Information**

The PANDAS Foundation <http://www.pandasfoundation.org>

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