

## 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 reaction to strep, not the infection itself (Swedo & Grant, 2005). When an infection happens, the body’s immune system makes a variety of proteins to help fight the bacteria. Some of these proteins are called antibodies and can be clinically measured. The exact way that causes the neuropsychiatric symptoms (OCD, tics, etc.) is not known.
- Other immune triggers have been also reported to worsen OCD and tics (like Lyme’s disease, influenza, mycoplasma, etc.) and because the connection of the immune system to the neuropsychiatric symptoms is not fully understood, little is known about the best treatments (which may be different from other kinds of OCD treatment.) Currently, there are no scientifically approved evaluation and treatment protocols leaving clinicians and parents guessing at the best options for having these children assessed.

### 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, Kurlan, & Leckman, 2010).
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) that is new or dramatically worse.
  - 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 hyperactive senses (such as sensitivity to clothing, noise, light, taste, etc.)
  - Noticeable decrease in handwriting or math skills
  - Frequent urination (especially when the child has an active infection)
3. Diagnosis of PANDAS should be discussed after symptoms first suddenly appear or severely worsen. Usually this change is severe and dramatic. Many parents can pinpoint a day or a week when behaviors changed.
4. In PANDAS children, a strep infection occurs before or at the time the OCD symptoms ramp up. Assuming the infection is adequately treated, the first symptoms generally improve within 4-6 weeks. The next OCD episode may last longer and may be triggered by a variety of immunological challenges such as 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 culture) 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. Ideally, ASO at symptom onset of <2 weeks duration and again 4-8 weeks later will provide support of a streptococcal trigger if a fourfold rise in titers is observed. In children with symptom onset exceeding four weeks before obtaining laboratory measures, an elevated ASO titer will add support but not provide proof that tic or OCD symptoms resulted from a streptococcal infection as 'strep throat' is very common in the school age in children. Due to the child's age and variation in response to the infection, a low blood level of ASO alone does not rule out PANDAS.
  - Other medical assessments will depend on clinical history and severity of presentation but may include other laboratory tests, EEGs, echocardiograms, etc.
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 (Storch, 2006).
- Selective serotonin reuptake inhibitor (SSRI) medicines are also effective for childhood OCD (SSRIs are standard medical therapies and many are FDA approved for childhood OCD). However, children presenting with PANDAS may be more sensitive to behavioral side effects (aggression, hyperactivity, sleep problems and even suicidal thinking) but may tolerate at smaller than usual starting doses. Some children with first episode OCD/PANDAS will have the symptoms improve gradually if the infection was treated. SSRI use should be discussed with a doctor in order to weigh the benefits against the risks.
- Consider having the child evaluated for fine motor deficits by an occupational therapist if handwriting or coordination skills have deteriorated.
- Ask for school accommodations as appropriate for ADHD, OCD, or fine motor skill symptoms.
- For some patients with severely disabling symptoms following infections, use of antibiotics as a prevention method may be considered (Snider, et. al., 2005). 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, increased risk for allergic reactions and alterations in the body's balance of healthy bacteria such as thrush and *C. difficile* infections.

### **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 streptococcal infections. Continued symptoms can be treated with standard OCD treatments (cognitive-behavior therapy and/or SSRI medication).
- 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.

**Authors:** Evelyn Stewart, MD, University of British Columbia, Vancouver, Canada  
Tanya Murphy, MD, University of South Florida, St Petersburg, FL