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PANDAS

Questions and Answers



PANDAS—Questions and Answers

Overview

What is PANDAS?

PANDAS is short for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. A child may be diagnosed with PANDAS when:

- Obsessive compulsive disorder (OCD) and/or tic disorders suddenly appear following a strep infection (such as strep throat or scarlet fever); or
- The symptoms of OCD or tic symptoms suddenly become worse following a strep infection.

The symptoms are usually dramatic, happen “overnight and out of the blue,” and can include motor and/or vocal tics, obsessions, and/or compulsions. In addition to these symptoms, children may also become moody or irritable, experience anxiety attacks, or show concerns about separating from parents or loved ones.

What causes PANDAS?

The strep bacteria are very ancient organisms that survive in the human host by hiding from the immune system as long as possible. It hides itself by putting molecules on its cell wall so that it looks nearly identical to molecules found on the child’s heart, joints, skin, and brain tissues. This hiding is called “molecular mimicry” and allows the strep bacteria to evade detection for a long time.

However, the molecules on the strep bacteria are eventually recognized as foreign to the body and the child’s immune system reacts to them by producing antibodies. Because of the molecular mimicry by the bacteria, the immune system reacts not only to the strep molecules, but also to the human host molecules that were mimicked; antibodies system “attack” the mimicked molecules in the child’s own tissues.

Studies at the NIMH and elsewhere have shown that some cross-reactive “anti-brain” antibodies target the brain—causing OCD, tics, and the other neuropsychiatric symptoms of PANDAS.

Could an adult develop PANDAS?

PANDAS is considered a pediatric disorder and typically first appears in childhood from age 3 to puberty. Reactions to strep infections are rare after age 12, but researchers recognize that PANDAS could occur, though rarely, among adolescents. It is unlikely that someone would experience these post-strep neuropsychiatric symptoms for the first time as an adult, but it has not been fully studied.

It is possible that adolescents and adults may have immune-mediated OCD, but this is not known. The research studies on immune-mediated OCD at the NIMH are restricted to children.

Signs and Symptoms

How is PANDAS diagnosed?

The diagnosis of PANDAS is a clinical diagnosis, which means that there are no lab tests that can diagnose PANDAS. Instead, health care providers use diagnostic criteria for the diagnosis of PANDAS (see below). At the present time the clinical features of the illness are the only means of determining whether or not a child might have PANDAS.

The diagnostic criteria are:

- Presence of obsessive-compulsive disorder and/or a tic disorder
- Pediatric onset of symptoms (age 3 years to puberty)
- Episodic course of symptom severity (see information below)
- Association with group A Beta-hemolytic streptococcal infection (a positive throat culture for strep or history of scarlet fever)
- Association with neurological abnormalities (physical hyperactivity, or unusual, jerky movements that are not in the child's control)
- Very abrupt onset or worsening of symptoms

If the symptoms have been present for more than a week, blood tests may be done to document a preceding streptococcal infection.

Are there any other symptoms associated with PANDAS episodes?

Yes. Children with PANDAS often experience one or more of the following symptoms in conjunction with their OCD and/or tics:

- ADHD symptoms (hyperactivity, inattention, fidgety)
- Separation anxiety (child is "clingy" and has difficulty separating from his/her caregivers; for example, the child may not want to be in a different room in the house from his or her parents)
- Mood changes, such as irritability, sadness, emotional lability (tendency to laugh or cry unexpectedly at what might seem the wrong moment)
- Trouble sleeping, night-time bed-wetting, day-time frequent urination or both
- Changes in motor skills (e.g. changes in handwriting)
- Joint pains

What is an episodic course of symptoms?

Children with PANDAS seem to have dramatic ups and downs in the severity of their OCD and/or tics. OCD or tics that are almost always present at a relatively consistent level do not represent an episodic course. Many children with OCD or tics have good days and bad days, or even good weeks and bad weeks. However, children with PANDAS have a very sudden onset or worsening of their symptoms, followed by a slow, gradual improvement. If children with PANDAS get another strep infection, their symptoms suddenly worsen again. The increased

symptom severity usually persists for at least several weeks, but may last for several months or longer.

My child has had strep throat before, and he has tics, OCD, or both. Does that mean he has PANDAS?

No. Many children have OCD and/or tics, and almost all school-aged children get strep throat at some point. In fact, the average grade-school student will have two or three strep throat infections each year.

PANDAS is considered as a diagnosis when there is a very close relationship between the abrupt onset or worsening of OCD and/or tics and a strep infection. If strep is found in conjunction with two or three episodes of OCD, tics, or both, then it may be that the child has PANDAS.

What does an elevated anti-streptococcal antibody titer mean? Is this bad for my child?

The anti-streptococcal antibody titer (amount of molecules in blood that indicate a previous infection) is a test that determines whether the child has had a previous strep infection.

An elevated anti-strep titer means the child has had a strep infection sometime within the past few months, and his or her body created antibodies to fight the strep bacteria.

Some children create lots of antibodies and have very high titers (up to 2,000), while others have more modest elevations. The height of the titer elevation doesn't matter and elevated titers are not necessarily bad for your child. They are measuring a normal, healthy response – the production of antibodies to fight off an infection. The antibodies stay in the body for some time after the infection is gone, but the amount of time that the antibodies persist varies greatly between different individuals. Some children have "positive" antibody titers for many months after a single infection.

When is a strep titer considered to be abnormal, or "elevated"?

The lab at National Institutes of Health considers strep titers between 0-400 to be normal. Other labs set the upper limit at 150 or 200. Since each lab measures titers in different ways, it is important to know the range used by the laboratory where the test was done— just ask where they draw the line between negative or positive titers.

What if my child's doctor does not understand or does not want to consider PANDAS?

Please note: NIMH does not evaluate the professional qualifications and competence of individual health care providers listed on these websites. The resources are provided for general informational purposes only. NIMH does not intend to provide specific medical advice on its websites, but rather to help visitors better understand mental health and disorders. NIMH will not provide specific medical advice and urges you to consult with a qualified mental health or health care provider for diagnosis and for answers to your personal questions.

Treatment

What are the treatment options for children with PANDAS?

Treatment with Antibiotics

The best treatment for acute episodes of PANDAS is to treat the strep infection causing the symptoms (if it is still present) with antibiotics.

- A throat culture should be done to document the presence of strep bacteria in the throat.
- If the throat culture is positive, a single course of antibiotics will usually get rid of the strep infection and allow the PANDAS symptoms to subside.

If a properly obtained throat culture is negative, the clinician should make sure that the child doesn't have an occult (hidden) strep infection, such as a sinus infection (often caused by strep bacteria) or strep bacteria infecting the anus, vagina, or urethral opening of the penis. Although the latter infections are rare, they have been reported to trigger PANDAS symptoms in some patients and can be particularly problematic because they will linger for longer periods of time and continue to provoke the production of cross-reactive antibodies.

The strep bacteria can be harder to eradicate in the sinuses and other sites, so the course of antibiotic treatment may need to be longer than that used for strep throat.

Tips for Parents or Caregivers

Sterilize or replace toothbrushes during and following the antibiotics treatment, to make sure that the child isn't re-infected with strep.

It might also be helpful to ask a health care provider to perform throat cultures on the child's family members to make sure that none are "strep carriers," who could serve as a source of the strep bacteria.

How can you manage neuropsychiatric symptoms of PANDAS?

Children with PANDAS-related obsessive-compulsive symptoms will benefit from standard medications and/or behavioral therapies, such as cognitive behavioral therapy (CBT). OCD symptoms are treated best with a combination of CBT and a selective serotonin reuptake inhibitor (SSRI) medication, and tics respond to a variety of medications.

Children with PANDAS appear to be unusually sensitive to the side-effects of SSRIs and other medications, so it is important to "START LOW AND GO SLOW!!" when using these medications. In other words, clinicians should prescribe a very small starting dose of the medication and increase it slowly enough that the child experiences as few side-effects as possible. If PANDAS symptoms worsen, the SSRI dosage should be decreased promptly. However, SSRIs and other medications should not be stopped abruptly, as that could also cause difficulties.

What about treating PANDAS with plasma exchange or immunoglobulin (IVIG)?

Plasma exchange or immunoglobulin (IVIG) may be a consideration for acutely and severely affected children with PANDAS. Research suggests that both active treatments can improve global functioning, depression, emotional ups and downs, and obsessive-compulsive symptoms. However, there are a number of side-effects associated with the treatments, including nausea, vomiting, headaches, and dizziness.

In addition, there is a risk of infection with any invasive procedure, such as these. **Thus, the treatments should be reserved for severely ill patients, and administered by a qualified team of health care professionals.**

Should an elevated strep titer be treated with antibiotics?

No. Elevated titers indicate that a patient has had a past strep exposure but the titers can't tell you precisely when the strep infection occurred. Children may have "positive" titers for many months after one infection. Since these elevated titers are merely a marker of a prior infection and not proof of an ongoing infection it is not appropriate to give antibiotics for elevated titers. Antibiotics are recommended only when a child has a positive rapid strep test or positive strep throat culture.

Can penicillin be used to treat PANDAS or prevent future PANDAS symptom exacerbations?

Penicillin does not specifically treat the symptoms of PANDAS. Penicillin and other antibiotics treat the sore throat caused by the strep by getting rid of the bacteria. In PANDAS, research suggests that it is the antibodies produced by the body in response to the strep infection that may cause PANDAS symptoms, not the bacteria itself.

Researchers at the NIMH have been investigating the use of antibiotics as a form of prophylaxis or prevention of future problems. At this time, however, there isn't enough evidence to recommend the long-term use of antibiotics.

My child has PANDAS. Should he have his tonsils removed?

Current research does not suggest that tonsillectomies for children with PANDAS are helpful. If a tonsillectomy is recommended because of frequent episodes of tonsillitis, it would be useful to discuss the pros and cons of the procedure with your child's health care provider because of the role that the tonsils play in fighting strep infections.

Clinical Trials

What are clinical trials?

Clinical trials are part of clinical research and at the heart of all medical advances. Clinical trials look at new ways to prevent, detect, or treat disease. Treatments might be new drugs or new combinations of drugs, new surgical procedures or devices, or new ways to use existing treatments. The goal of clinical trials is to determine if a new test or treatment works and is safe. Clinical trials can also look at other aspects of care, such as improving the quality of life for people with chronic illnesses.

How do I find clinical trials for PANDAS?

Around the Nation and Worldwide

NIH conducts clinical research trials for many diseases and conditions, including PANDAS. The ClinicalTrials.gov website has a searchable registry and results database of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health care professionals.

Search NIH Clinical Research Studies

The NIH maintains an online database of clinical research studies taking place at its Clinical Center, which is located on the NIH campus in Bethesda, Maryland. Studies are conducted by most of the institutes and centers across the NIH. The Clinical Center hosts a wide range of studies from rare diseases to chronic health conditions, as well as studies for healthy volunteers.

Join a National Registry of Research Volunteers

www.researchmatch.org/ is an NIH-funded initiative to connect people who are trying to find research studies with researchers who are seeking people to participate in their studies. It is a free, secure registry to make it easier for the public to volunteer and to become involved in clinical research studies that contribute to improved health in the future.