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What are PANS/PANDAS?anna.conkey2023-09-19T15:07:30-04:00 PANDAS is an acronym standing for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. This childhood disorder results from a Group A Streptococcal bacterial infection commonly referred to as "strep" or "strep throat." Following infection with strep, children with PANDAS syndrome develop severe physical, neurological, and psychological symptoms that interfere with their daily lives. Thankfully, we can treat this disorder in addition to alleviating the symptoms after the child has received a PANDAS diagnosis from a qualified health professional.What is the prevalence of PANDAS in the United States?Research from our network of parents and physicians, the PANDAS Network, suggests that 1 in 200 children in the United States alone have PANDAS. This is a staggering number, especially considering that many doctors, medical professionals, and clinicians do not recognize PANDAS as an autoimmune disease. Unfortunately, many children go untreated, sometimes experiencing debilitating symptoms for years until finding the cause and visiting a PANDAS specialist.What causes PANDAS? The science explained.The underlying cause of PANDAS is thought to be attributed to an autoimmune attack of healthy brain tissue after a strep infection.Video Summary of The Latest in PANDAS ResearchA video explaining the science of PANDASWhat is autoimmunity?Autoimmunity is a group of immune responses that attack our own healthy cells, tissues, and other normal body components. At the cellular level, autoimmunity is characterized by the presence of antibodies or T cells that attack healthy tissue. This phenomenon is present in all people at near undetectable levels, even in those who are healthy. Autoimmune diseases are only diagnosed when the immune system attack on healthy tissue resulting in physiological changes in the body.The role of autoimmunity in PANDAS disease?During a Group A Streptococcal (strep) bacterial infection, our immune system mounts an adaptive immune response to destroy the invading bacteria. This adaptive immune response involves making antibodies and strep-specific T-cells.In some instances, the antibodies that are made during the adaptive immune response inadvertently target the child's own healthy tissue in the brain. It is important to note that this "attack" does not destroy healthy brain tissue. Instead, the antibodies that bind our own self-tissue, termed autoantibodies, simply bind to different regions of the brain primarily resulting in abnormal neuronal signaling events.The abnormal signaling events caused by the autoantibodies provoke neurological issues such as cognitive and intellectual regression, and severe psychological abnormalities, collectively known as PANDAS. While there are still many unanswered questions about the PANDAS disease, we do understand what region of the brain is being targeted by autoantibodies.There is a physiological barrier that prevents toxic material from exiting the blood and entering the brain. This barrier is known as the blood-brain barrier. The blood-brain barrier protects fragile brain tissue from circulating pathogens and other potentially toxic substances.Evidence suggests that specific autoantibodies in the blood are able to cross the blood-brain barrier and bind various targets on the outside and inside of neurons in the basal ganglia and cause encephalitis (brain inflammation).Image of the Basal Ganglia (in orange)The basal ganglia are a group of subcortical nuclei located at the interior of the brain (shown above in orange). This brain region is primarily responsible for motor control, motor learning, and decision-making, combined with a sudden increase in emotional or behavioral instability. Stay up-to-date with the latest in PANDAS biomedical research.When do PANDAS symptoms appear after a strep infection?Symptoms typically present soon after a strep throat infection. However, the initial onset of symptoms may not appear for months in certain cases. So even if your child exhibits PANDAS symptoms long after a strep infection, they could still be experiencing PANDAS.Genetic predisposition to PANDAS?Additional factors for developing PANDAS may be related to genetic differences. Based on 100 self-reports from families, 70% reported both autoimmune illness and strep-related severity illness in their family. More research is being done in this area to investigate genetic links that may increase an individual's susceptibility to developing PANDAS.Scarlet fever and rheumatic fever are two illnesses caused by invasive Group A Streptococcus infections.Scarlet fever is typically followed by a sore throat or a skin infection caused by Streptococcus bacteria strains while rheumatic fever is a condition that can inflame the heart, joints, brain, and skin. Rheumatic fever is thought to be an autoimmune disorder in response to an earlier strep infection.Often children diagnosed with PANDAS have family members that have been previously diagnosed with either scarlet fever and/or rheumatic fever. This further suggests there are genetic predispositions to developing PANDAS.What are PANDAS signs and symptoms?Just as all immune systems are different, so are the signs and symptoms of PANDAS. Some of the characteristics of PANDAS include frequently exaggerated changes in mood, tics, obsessive-compulsive behavior, and the sudden onset of intense anxiety.These symptoms frequently go through cycles of onset, waning, and return. PANDAS children who are later reinfected with strep are susceptible to repeated spikes in disease severity.PANDAS and PANS/PANDAS falls under the umbrella of a disease called PANS (pediatric acute-onset neuropsychiatric syndrome). Both diagnoses include the abrupt, pre-pubescent onset of obsessions, compulsions, or tics. But PANDAS requires the association with streptococcal infection and PANS is associated with other infections, such as influenza or Lyme disease. Some other common symptoms of PANDAS or PANS are:Tics, which can be verbal—such as grunting—or jerking of the limbs or head/Depression, which can lead to suicidal thoughts and behavior, uncontrollable crying, or fear/Extreme rage or inability to control anger; breaking items and throwing objects/Sleep issues, including lack of sleep or excessive fatigue/Bedwetting/Restrictive eating or avoidance of food, which can cause extreme weight loss/Unusual gait, poor coordination, or degradation of handwriting/ OCD-like symptoms, such as repetitive actions, fear of germs, or developing habits and rituals that must be followed to avoid anxiety and panic/Behavioral abnormalities and personality changes/Sensory problems, like sensitivity to light and sound/Academic skill deterioration and mental regression/OCD and tics are often strong indicators when considering a PANDAS/PANS diagnosis. Among parents with diagnosed children, 37% reported OCD-like symptoms, 14% reported tics and 49% reported both. In fact, it is estimated that children with PANDAS/PANS may make up as much as 25% of children diagnosed with OCD and tic disorders, such as Tourette syndrome."How is PANDAS disease diagnosed?An accurate clinical diagnosis will consider the collection of signs and symptoms, lab test results, and your child's medical history. While there is no definitive test for PANDAS at this time, your provider can use several tests, including strep cultures, allergy tests, immunological tests, brain scans, and the Cunningham panel (a test that determines the likelihood that the patient's disorder is autoimmune in nature) among others to give your child a PANDAS diagnosis.Clinical diagnostic criteria for PANDAS/PANS are specific and consist of the following:The sudden, dramatic onset of obsessive-compulsive disorder or extremely restricted food intake.The simultaneous appearance of additional neuropsychiatric symptoms with acute, severe onset from at least two of the following seven categories:Irritability, aggression, or oppositional behaviors/Motor or sensory abnormalities/Emotional lability or depression/Behavioral (developmental) regression/AnxietyA decline in school performance/Somatic symptoms, such as sleep disturbances, increased urinary frequency, or enuresis/These symptoms are not better explained by another general medical condition or neurological disorder, such as Tourette's disorder, Sydenham's chorea, or Systemic Lupus Erythematosus. Learn the detailed signs and symptoms of PANDAS/PANS.Other medical disorders can present with signs and symptoms that are similar to PANDAS/PANS. Using various tests, your provider can help identify your child's symptoms and rule out other psychological, neurological, and medical conditions. Once your child receives a PANDAS/PANS diagnosis, they can begin treatment to target the underlying cause and begin the journey to symptom relief.How do you treat PANDAS disorder?The latest in treatment options.It is critical to treat PANDAS as soon as possible after symptoms appear. The earlier you start, the better the outcome will be because PANDAS symptoms may worsen over time without treatment. PANDAS treatment may consist of the following:Antibiotics, such as penicillin, augmentin, cephalosporins, or azithromycin/Prophylactic antibiotics can reduce the long-term recurrence of symptoms/Intravenous Immune Globulin (IVIG) is an intravenous solution of immunoglobulins that treats encephalitis, immune deficiencies, and other immune disorders. This has been shown to ease PANS-related symptoms in a recent clinical trial/Plasmapheresis removes harmful auto-antibodies from the blood to reduce PANDAS symptoms. Learn more about plasmapheresis from the PANDAS Physicians Network.You may consider other treatments in conjunction with these therapies, including tonsil removal, NSAIDs (like ibuprofen), steroids, or psychological interventions such as cognitive-behavioral therapy or exposure and response therapy (ERP). Specific treatment plans will depend on your child's symptoms, which you can discuss with your medical provider.How long does PANDAS disorder last?The duration of PANDAS differs between patients, the severity of symptoms, and how soon you begin treatment for the condition. PANDAS generally appears in childhood. According to 700 self-reports, the ages of onset were:1-3 years: 11%4-9 years: 69%10-13 years: 19%14+ years: only 1%According to current research, PANDAS is a pediatric disease caused by a strep infection, common in young children and demonstrated in the above prevalence rates. PANDAS/PANS symptoms seem to flare and remit throughout childhood and disappear in adulthood with proper treatment and symptom maintenance.Where can I find help for PANDAS disorder?PANDAS Network offers even more PANDAS resources here. These resources can help you on your journey as you heal your child and support them as they recover from PANDAS. From connecting you to other parents to keeping you up to date with the newest research and raising awareness for PANDAS, you can find helpful resources for interpersonal support and education about PANDAS/PANS.Additionally, PANDAS Network has special reports to aid parents and educators in learning more about getting help for PANDAS disorder and PANS. Click here to read stories from other PANDAS families, check out useful articles, and find U.S. physicians or international providers to receive help from medical professionals.How can I find a PANDAS specialist or doctor?Getting a PANDAS diagnosis and treatment for your child can be a challenge. After all, this is a relatively new, commonly misunderstood, and frequently misdiagnosed disorder. Your child's provider should be able to connect you with someone or refer you to another office that specializes in these types of childhood autoimmune disorders.If your provider cannot refer you to a specialist, PANDAS Network has a list of helpful resources, including a network of physicians who are dedicated to learning more about PANDAS and educating other medical professionals, at this link.Additionally, you can also discuss resources with other PANDAS parents online or in support groups to find a PANDAS specialist for your child.How can I support my child with PANDAS?Supporting your child when they are struggling with PANDAS symptoms can be difficult. The important thing is to try to be aware and understanding of the pain and confusion they are experiencing. Find a good medical provider who can help diagnose and treat your child promptly so they can reduce their symptoms quickly and have the best possible treatment outcome.You can also support children with PANDAS disease by advocating for them in your community. Talk to your family, friends, your child's school, neighbors, and other medical providers, and provide them with resources to learn about PANDAS/PANS and how to interact with and help other children with these conditions.While it may be frightening at times, know that you're not alone. Other parents are going through the same thing, and they are here to help you feel understood and supported in your family's PANDAS journey.If you're looking for additional resources and community support, join the PANDAS Network support group as a family or treating professional member. Symptoms and signs of PANDAS have been reported to vary widely from child to child and can involve a combination of psychological and neurological conditions. The symptoms are thought to start suddenly and occur in episodes. They seem to last for a few days or weeks, then go away and return.Psychological symptoms that have been reported to occur with PANDAS have included:Anxiety or depression.Bedwetting.Changes in mood or personality, especially sudden rage or irritability.Difficulty sleeping.Disinterest in food.Fidgeting and symptoms similar to attention-deficit/hyperactivity disorder (ADHD).Obsessive-compulsive disorder-like behavior.Separation anxiety.Tics similar to those of Tourette syndrome.Neurological symptoms that have been reported to be associated with PANDAS include:Changes in motor skills (muscle movements), such as problems with handwriting.Difficulty concentrating or learning.Poor performance in school.Reduced coordination.Sensitivity to light and sound.What causes PANDAS syndrome?Some believe that PANDAS occurs when your child's immune system produces antibodies to fight the bacteria that caused a strep infection. But the antibodies may also mistakenly attack healthy cells in other tissues because the cells mimic those of the strep infection. Some believe that antibodies affect tissues in your child's brain, leading to the psychological and neurological symptoms sometimes reported.Are PANS and PANDAS syndrome the same thing?PANS stands for "pediatric acute-onset neuropsychiatric syndrome." Some providers think PANDAS is a type of PANS. Both are thought to be related to a strep infection, whereas PANS is thought to result from other infections such as Lyme disease or influenza. Children and infections go hand-in-hand. They are more susceptible to catching infections as they play outside, go to school, and meet other kids. One common infection found in children is strep infection. Strep infections generally are transmitted in children when they come in contact with an infected person. 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