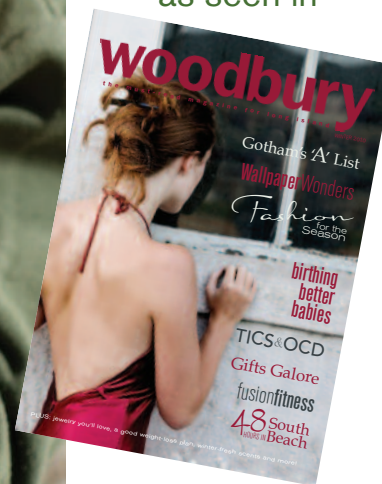


A mother's  
instinct told  
her this was  
not tics but  
something else



as seen in



# Could It Be PANDAS?

## When Tics and Obsessive Compulsive Disorder Are Misdiagnosed

by mary ellen renna, m.d., pc

Medicine is an ever-changing art with the best scientists and doctors working to conquer new diseases. There are however, times when parents are the protagonists in the evolving story of a disease. That is the case with a relatively under diagnosed problem that occurs in children who are suffering from PANDAS. This of course does not represent those cuddly black and white bears but is an acronym for pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections. This relatively new syndrome had its start in 1998 when parents noted behavioral changes surrounding a recent diagnosis of strep throat in their children. The observation led by parents carried over to the medical literature as psychiatrists and pediatricians started to take notice. Since that time, many articles have been written supporting the disease and its etiology while others have not supported the disease. A medical controversy does exist but the children who have suffered from PANDAS also exist to tell their stories.

Consider Spencer a 5-year-old boy who just started kindergarten 3 months ago. He adjusted well but his mom noticed a new habit he started to engage in which worried her. She first noted it while he was doing his homework practicing his letters. He would periodically take his left hand, bring it up to his mouth and blow into his palm. She called the teacher to ask if she noted anything different about Spencer's behavior in school but the teacher thought he

was an angel in class. After the blowing stopped, he started to move his head to the left with a sudden jerky movement. He was seemingly unaware of his movements as his mom asked him to stop doing it several times without improvement. She called the pediatrician who diagnosed him with motor tics probably from the stress of starting a new school. He assured her this was very common, not to worry, it would pass and not to make a big deal about it. Over the following 2 months he continued to jerk his head always to the left; so much so the teacher called the mom and asked what was wrong with her son? She told him he has tics and to ignore him. The mother's instinct told her that this was not tics but something else so she decided to search for help.

Robert is an 11-year-old pre-pubertal boy who started to have thoughts about sexual encounters. All he could think about was girls and sex which at first did not seem unusual for a young boy. However Robert himself became concerned when he started to have trouble focusing in school and suddenly a straight A student became a C student. He went to his mom to talk about his concerns of, as he put it, his obsessive thoughts. His mother called the pediatrician who recommended she seek psychiatric help for her son and he might have OCD or obsessive compulsive disorder.

Darla is an 8-year-old girl in 2nd grade who started to become disruptive in class. It was the middle of the winter and up until this



## Discover truer, richer colors. And performance without compromise.

Proprietary Color Lock® Technology delivers truer hues and richer colors with exceptional durability. Quite simply the finest paint we've ever made™.

**Benjamin Moore**



benjaminmoore.com

**Willis The Paint Place & Design Center**  
**35 Mineola Ave**  
**Roslyn Heights/NY/11577**  
**516-621-3772**

©2010 Benjamin Moore & Co., Limited. Aura, Benjamin Moore and the triangle "M" symbol are registered trademarks, licensed to Benjamin Moore & Co., Limited.

point she had been a model student. The teacher noted that she would suddenly jump out of her seat to get a tissue or grab a pencil without asking. She also noted that her work was not as good as it used to be and her grades were slipping. She called her mother who also noted an increase in her "activity" but thought she was bored being inside with the cold weather. She asked Darla if there was any problem. She said she was fine except for a sore throat she had 2 weeks ago. The mom took Darla to the pediatrician who did a strep test and diagnosed her with strep throat. He prescribed penicillin for 10 days. After the 10 day course, the mom noted a dramatic decrease in her activity level. Before she was unable to sit through a television show where now she was back to her normal self. The mother called the pediatrician to inquire if there was any link to the strep infection and her activity and he told her it was all a coincidence.

The last scenario involves Charlie, a 10-year-old boy who started with a fever for 3 days. His mom was about to take him to the doctor but the fever disappeared and he was acting fine. After 2 months he started to have fever again but this time he started to have unusual arm movements as if he was a dancer. His arms would flow around his body and he was unable to control the movements. He also started to have some facial grimacing. His family became very concerned so his mom took him to the pediatrician who noted a new heart murmur along with the unusual new movements. She told the mom that Charlie was experiencing something called Sydenham's chorea, a neurological phenomenon associated with

His arms  
would flow  
around his  
body and he  
was unable  
to control the  
movements.

Rheumatic Fever. After conducting lab tests, the doctor was able to confirm a diagnosis of Rheumatic Fever. He was seen by a cardiologist and has been treated with long term penicillin prophylaxis with only minor heart issues as a residual.

Talking about Sydenham's chorea is critical to help with understanding how it is possible that a group A streptococcal infection (strep throat) can cause the myriad of symptoms in PANDAS. Sydenham's chorea is a well known neurological phenomenon associated with acute rheumatic fever. It causes facial tics, behavior changes, facial grimaces, uncontrollable body movements, emotional lability and poor school performance. There is no doubt that acute rheumatic fever is associated with a streptococcal infection. There is also no doubt that Sydenham's chorea is one manifestation of acute rheumatic fever. We know that strep infections cause an antibody immune response to the bacteria. These antibodies produce an autoimmune type of response that results in all the manifestations of acute rheumatic fever including the neurologic symptoms.

In Spencer's, Robert's and Darla's case each one of them was subsequently diagnosed with a strep throat that was treated with antibiotic. The initial treatment course allowed dramatic improvement of the symptoms but as time went on the symptoms returned. In the case of Robert the psychiatrist opted to do some blood work which included testing for antibodies to strep. He found that even though Robert was treated he still had very high levels of different types of antibodies in his blood. This astute psychiatrist diagnosed Robert with PANDAS.

# SCHLESSINGER EYE & FACE

AESTHETIC EYELID SURGERY | FACIAL REJUVENATION  
SPECIALIZING IN OPHTHALMIC PLASTIC SURGERY



David A. Schlessinger, M.D., F.A.A.C.S.  
Board Certified, American Board of Ophthalmology  
Member, American Academy of Cosmetic Surgery

Botox  
Juvederm  
Sculptra  
Restylane  
Microdermabrasion  
Chemical Peels  
Laser Skin Resurfacing  
Intense Pulsed Light  
Eyelid & Facial Plastic Surgery

ASK ABOUT THE  
*liquid facelift*

*the eyelid  
specialist*

*Call now*  
complimentary consultation

516.496.2122  
Woodbury | Hauppauge  
schlessingereyeandface.com

Spencer and Darla took several years to diagnose with their symptoms waxing and waning. It was Darla's mother who persisted with the notion that every time her daughter got strep throat her behavior deteriorated and after she was treated she seemed to improve. Finally she sought out the advice of a specialist who easily made the diagnosis. Spencer unfortunately was diagnosed with Tourette's syndrome and was treated with medication to stop his tics. He was not diagnosed with PANDAS until his neurologist dropped his insurance and the mom was forced to see a new neurologist who tested all his patients diagnosed with Tourette's for PANDAS.

The association between strep throat and the onset of neurological symptoms occurs more frequently in families with a history of autoimmune diseases. This results from the genetic makeup of an individual to be more prone to producing antibodies that not only attack the infection but also attack cellular membranes in the body. In the case of PANDAS the neurological problems stem from an area in the brain called the basal ganglia. It has been postulated that the strep antibodies cross react with the cell membranes in the basal ganglia causing an inflammatory reaction and subsequent abnormal behaviors. The diagnostic criteria for PANDAS includes the presence of tic disorder or OCD, presentation before the onset of puberty, waxing and waning symptoms and an association with a group A beta hemolytic infection.

Once the criteria are met for the diagnosis of PANDAS, the treatment remains an area of disagreement amongst experts. While it is crucial to treat any child who has a strep infection, the presence of antibodies against strep only signifies that the body was exposed to strep in the recent past and does not necessarily indicate an active infection. If a child does not test positive for strep via a throat culture, most institutions and organizations do not recommend treating with antibiotics even if the antibody blood test confirms a recent exposure. However it is clear from clinical experience that some children can and do respond to antibiotic treatment but long

term use of antimicrobials is not needed. The current recommendation is to treat only the symptoms if no active infection is present i.e. SSRI's for OCD symptoms. The disease will wax and wane as the antibodies to the streptococcal bacteria rise and fall in relation to exposure or infection. It is important for your pediatrician to be aware of the syndrome as he/she should be the one to diagnose a patient since it is a clinical diagnosis. There are specialists involved in the care of patients with PANDAS and your doctor can make a referral to a qualified specialist experienced with this diagnosis if needed. There are ongoing trials using plasma exchange or intravenous immunoglobulin therapy for severe cases of strep related OCD or tics. These modalities should only be used at research centers where a team of physicians can diagnose and monitor response to these invasive treatments.

**T**his article serves as a reminder to parents that if your instinct is telling you something is wrong with your child you need to pursue it despite what one doctor may be advising you. Another reminder is to recognize that all neurologic abnormalities may not be what they appear to be but instead be something more easily treated. So any child who presents with a sudden onset of ADHD should be worked up for PANDAS which merely involves a simple blood test. If your child suddenly starts to have eye twitching or blinking it is wise to look for a recent strep infection. Sudden onset of OCD like symptoms should also raise some red flags as well as strange body movements. Lastly, any child who has been diagnosed as having Tourette's syndrome deserves a PANDAS workup. The key to helping children with this diagnosis is awareness of the disease. |

To reach a North Shore based PANDAS liaison who provides families with information and specialist support, please call Stefanie Weiss at 516-641-7926.

Mary Ellen Renna M.D. FAAP is a Physician Nutrition Specialist and Senior/Founding Partner in the pediatric practice of Renna, Sachse and Shapiro, MD, PC and can be reached at 516.677.9658.