

PANDAS Syndrome in the School Setting

By Kathy O'Rourke, MA

The members of our student assistance team (school nurse, learning consultant, principal, and guidance counselor) remained puzzled and perplexed. Nothing in our years of experience helped us connect a series of sudden and dramatic symptoms in young students. Capable parents struggled through worry and fear. Even the physicians of the identified children seemed to be at a loss to explain the remarkable changes in school behavior. Over a period of five years, these three notable cases mystified us all.

- A bright, well-adjusted third-grade girl who returned to school after a strep infection suddenly appeared acutely school phobic. The school psychologist ruled out the possibility of recent trauma, reporting that the “intact family was wonderfully close and supportive.” School friendships were numerous, with no identified social problems. The girl rated her teacher as a “favorite” and was not overwhelmed by missed schoolwork, which she described as “easy.” Yet morning after morning the child became intensely anxious, refused to get on the school bus, and had to be driven to school. She crouched in the car, sobbing and clinging to the seat. No amount of coaxing or prodding seemed to alleviate her severe yet unspecified anxiety.
- A first-grade boy returned to school in March after a strep-related illness and “out of the blue” began to exhibit unusual, uncontrolled vocalizations. He also twitched his head and made facial grimaces on and off throughout the day. The boy was clearly embarrassed, and tried to stifle the behaviors, which puzzled and frightened his classmates. Such tics and vocalizations commonly accompany Tourette’s syndrome, but this boy was seven years old and had never received any such diagnosis, in fact, had never exhibited any previous vocal or motor tics.
- A second-grade student returned to school after spring vacation. The child had contracted strep during a family vacation. This boy, previously studious and industrious in the classroom, became so hyperactive and disorganized that his teacher became quite alarmed. His inability to remain seated, resist calling out, and complete even simple tasks by himself were beyond comprehension.

I admit such cases are rare. Yet when they appear, the startling behavioral changes confound parents, educators, school nurses, physicians and even the children themselves. Recent studies at The National Institute of Mental Health and at Yale University and Brown University provide valuable insights into a newly discovered link that connects all three of our cases. They confirm a series of pediatric behavior problems that are triggered or intensified by streptococcal (strep) throat infections. The symptoms occur frequently



enough to constitute a syndrome called PANDAS (pediatric autoimmune neuropsychiatric disorders associated with strep infections). The symptoms include obsessive-compulsive disorder (OCD), motor or vocal tics, late-onset attention deficit/hyperactivity disorder (ADHD), separation anxiety disorder and marked personality changes. These behaviors begin for the first time, or intensify, after a strep throat infection and slowly lessen over time. The syndrome generally appears in children between of 4 and 10 (NIMH, 1999).

The identification of PANDAS symptoms in the school setting requires a cooperative effort. Any teacher who comes in contact with a child should be alert for sudden behavioral changes. Young children frequently exhibit striking behavior changes, including those due to trauma or significant life changes. Scrupulous observation and careful deliberation are sometimes needed to assess causes. Open and ongoing home — school communication may be essential. The school nurse, equipped with medical information, is in a valuable position to assist in the identification of possible PANDAS cases. She may be the significant professional in a school setting who is first able

to link a recent or recurring strep infection with sudden atypical behavior. The perceptive school nurse will also be able to identify and consider any variety of confounding medical symptoms. For instance, a marked intensification in the ADHD symptoms of a student after strep may be an indicator of PANDAS; however, increased hyperactivity *may* also be attributable to decongestant medications or inhalers prescribed during the infection.

Dr. Susan Swedo, Director of Behavioral Pediatrics at the National Institute of Mental Health, points out that although strep infection is very common, strep-triggered neuropsychiatric disorders are rare. Thus, the vast majority of children with strep are not at risk for developing PANDAS, particularly with prompt and effective treatment of the infection. Yet for a small number of youngsters who do suffer from PANDAS, parental and school awareness of the syndrome and its causes is critical. Evidence shows that some children form higher levels of antibodies against a strep infection. Through a process called *molecular mimicry*, these antibodies misidentify and attack healthy cells in the brain. This leads to inflammation of brain structures that regulate movement and motor control. The lag time between an initial streptococcal infection and the onset of PANDAS may be several months. Subsequent infections, however, often trigger symptoms within hours or a very few days (NIMH, 1999). Doctor Swedo urges doctors who examine children exhibiting an abrupt onset of OCD or tic symptoms to check them for strep, and if strep is present, to treat it with penicillin if possible. In some cases the OCD or tics will disappear when a child is treated for a strep throat, she said. A 10-day treatment with penicillin produced a decline in antineuronal antibody levels and the abatement of symptoms in any number of clinical studies (Academic Press, 1998; NIHM, 1999; Pharmaceutical Information Associates, 1994).

There are a variety of ways that PANDAS symptoms may present themselves in the school setting. According to Dr. Swedo, "A sweet, easygoing child suddenly may become impulsive and obsessed with things such as symmetry or bedtime fears. Math skills often decline and handwriting may suffer. One seven-year-old was recommended by his teacher for ADHD treatment after he suddenly manifested tics, vocalizations and hyperactive behaviors. His throat culture was positive for strep and serologic testing showed elevated levels of antineuronal antibody. He was treated with penicillin and a decline in the titer was accompanied by the alleviation of symptoms. His school performance improved and treatment for ADHD was no longer necessary." (Pharmaceutical Information Associates, 1994).

Children diagnosed with ADHD sometimes exhibit tics, which are generally believed to be side effects of their prescribed stimulant medication. Yet in at least two clinical trials, tics were shown to be associated with strep antibodies in the child's system. Treatment for 10 days with penicillin led to symptom cessation (Pharmaceutical Information Associates, 1994). PANDAS-related tics and obsessive-compulsive symptoms (washing, checking, repeating, counting, hoarding) can be *controlled* by the same kinds of medications as are used for other forms of OCD or tic disorders. However, the goal of current research stretches beyond basic symptom management to elimination and prevention.

A marked decline in PANDAS symptoms has been achieved with plasma exchange (PEX) a process that removes virtually all circulated

antibodies. Parents of children who received such treatments often reported, "My child's back to his old self again" or "Things are a lot easier now" (NIMH, 1999). In one study, children with pre-existing Tourette's syndrome, OCD or tics displayed greatly exacerbated symptoms after strep infections. A few of these children were able to discontinue all previously prescribed psychotropic medications after a plasma exchange (PEX). The study did not, however, support using PEX for all cases of tics or OCD (Tourette's syndrome links, 1999).

Physicians affiliated with Brown University have developed a blood test that searches for susceptibility to post-strep rheumatic fever. It is expected that the test will also pin-point children who are genetically predisposed to developing the repeated behaviors, movements, and vocalizations associated with strep-related PANDAS.

Research continues at The Tourettes/OCD Specialty Clinic at Yale, where children living in the New Haven area are currently being recruited for a study on the connection between tic/OCD acceleration and strep. "A strong genetic component is thought to be involved in OCD, Tourettes and tics, but what is inherited might actually be an inability of the immune system to distinguish between the brain's basal ganglia and the strep bacteria itself" (Pharmaceutical Information Associates, 1994).

An estimated 25–30 million Americans contact strep each year, and the number of strep infections worldwide continues to climb annually (Pharmaceutical Information Associates, 1994). As a result, ongoing PANDAS research is needed. The behaviors associated with PANDAS are perplexing to parents and problematic in the classroom. The combined efforts of Yale, Brown, and The National Institutes of Health may provide a rare opportunity for the early identification and aggressive treatment of a complex childhood disorder. School nurses need to familiarize themselves with current research as they strive to support success in the classroom. A simple trip to the pediatrician may lead to treatment and symptom relief for an identified student. The implications of current PANDAS research for suffering children, their parents, teachers and the school nurses who serve them all can only be termed very hopeful.

REFERENCES

- Academic Press, Daily Insight (1998). Online Internet. Retrieved July 12, 2001. Available: <http://www.academicpress.com/insight/00231998/grapha.htm>
- Bates, B. (1999). Plasmapheresis may benefit strep-related OCD. *Pediatric News*, 33(1), 28.
- National Institutes of Health (1999). Treatments reduce strep-triggered symptoms of OCD and tics in some children. Online. Internet. Retrieved July 10, 2001
- Pharmaceutical Information Associates (1994, Sept). Autoimmunity and neurological disorders. *Medical Sciences Bulletin Online*. Internet. Retrieved July 12, 2001
- Possible relationship between tic and OC symptoms and strep, (1999). Available: <http://www.info.med.yale.edu./chldstdy/tsocd/strep.htm>.
- Tourette's syndrome links.(1999) Online Internet. Retrieved July 11, 2001 Available: <http://www.tsagw1/tslinks.html>.
- Turner, S. (1997, Feb). Blood test can identify children with strep- related behavior disorder. The Brown University News Bureau Online. Internet. Retrieved July 18, 2001

ABOUT THE AUTHOR

Kathy O'Rourke, MA holds a master degree in counseling. She is the guidance counselor at Barclay Brook Elementary School in Monroe Township, N. J. and is a member of the student assistance team.