

NIMH researchers offer update on strep-linked mental disorder

In 1996, researcher Susan Swedo reported evidence that the bacteria that cause strep throat can also, in some cases, cause Tourette's syndrome and obsessive-compulsive disorder (OCD) (see ARRI 10/3). Swedo and colleagues at the National Institute of Mental Health have now reported on the first 50 children they have identified with strep-linked Tourette's, OCD, and related mental symptoms.

The researchers have named their newly identified syndrome PANDAS, short for "pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections." The PANDAS symptoms seen in their group of patients, Swedo et al. say, are triggered by strep infections in childhood (typically before puberty) and onset is "acute and dramatic." The disorder is more common in boys than in girls. After the first attack of PANDAS, symptoms wax and wane, with exacerbations usually following bouts of strep or other illnesses.

In addition to tics and OCD, the researchers say, symptoms seen in children with PANDAS include hyperactivity, impulsivity, distractibility, mood swings, separation anxiety, bedtime rituals, cognitive deficits, and oppositional behaviors. "The children with PANDAS exhibited a peculiar 'squirminess' in which the children tried very hard to sit still but constantly wriggled and fidgeted in their chairs," the researchers say, noting that "the symptoms met criteria for ADHD [attention deficit hyperactivity disorder] except that the onset frequently occurred after age six."

The researchers speculate that in susceptible children, strep infection triggers an autoimmune disorder causing PANDAS symptoms, after which "subsequent symptom exacerbations can be triggered by viruses, other bacteria, or noninfectious immunologic responses." They have been testing immune system therapies on their PANDAS patients, and reported positive results in their 1996 study.

"Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections: clinical description of the first 50 cases." Susan E. Swedo, Henrietta L. Leonard, Marjorie Garvey, Barbara Mittleman, Albert J. Allen, Susan Perlmutter, Sara Dow, Jason Zamkoff, Billinda K. Dubbert, and Lorraine Lougee; *American Journal of Psychiatry*, Vol. 155, No. 2, February 1998, pp. 264-271. Address: Susan Swedo, Child Psychiatry Branch, NIMH, Bldg. 10, Room 4N224, 9000 Rockville Pike, Bethesda, MD 20892-1381.

FC: Mechanical support ineffective

Facilitated communication (FC) is a technique in which a facilitator physically aids a disabled individual in typing messages, generally by supporting the typist's shoulder, arm, or wrist. The technique is highly controversial because none of the 50 studies conducted to date have demonstrated valid communicative ability in the handicapped subjects.

Some researchers have suggested that a mechanical device could provide the same physical support as a human facilitator, while removing the possibility of facilitator influence. In theory, such a support also could help students transition to independent typing.

To test this idea, Stephen Edelson, Bernard Rimland, and colleagues evaluated the effectiveness of a mechanical FC device designed by one of the researchers (Donald Billings). The device consists of an easel that positions a keyboard correctly; a strong steel spring clamped to a desktop; and, attached to the spring, a T-bar to steady the arm and an arm support on which the typist's arm or wrist can rest. A Velcro restraining band also is available when additional control is needed.

Edelson and colleagues tested the mechanical hand support with six nonverbal autistic subjects, all reported to be moderately or highly skilled at FC. The subjects, who ranged in age from 5 to 31, had received prior training in reading, language, and communication.

The researchers first evaluated the subjects' ability to use standard FC, to type independently, and to use the mechanical device without training. (Subjects were asked to point to pictures, numbers, and letters, and to copy words by typing on a letterboard or keyboard.) The subjects then received eight weeks of training in using the mechanical FC support. After the training period, the researchers again evaluated the subjects' ability to type independently or with the mechanical support.

To provide the best chance for subjects to succeed, the researchers selected subjects with considerable experience with FC; used a highly trained and experienced facilitator (study co-author Carol Berger) to train the subjects in using the mechanical device; and used a device designed and constructed by a skilled machinist also experienced in FC.

"The results of this study were clearly negative," Edelson et al. report. "There was no evidence of communicative ability enhanced by use of the specially designed hand-support system, despite our having done ev-

erything we could to increase the likelihood of finding positive results." The researchers note that in an informal study continuation, four subjects and three additional participants

used the device for an entire semester with no positive results.

"Although this study was not an attempt to evaluate FC per se," the researchers say, "the results are consistent with every controlled study on FC in that no evidence

was found of consistent, useful, or spontaneous communication using this method."

"Evaluation of a mechanical hand-support for facilitated communication," Stephen M. Edelson, Bernard Rimland, Carol Lee Berger, and Donald Billings; *Journal of Autism and Developmental Disorders*, Vol. 28, No. 2, 1998, pp. 153-157. Address: Stephen M. Edelson or Bernard Rimland, Autism Research Institute, 4182 Adams Avenue, San Diego, CA 92116.

IVIG therapy tested

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surgery, while it can sometimes cure LKS, can only be performed on a minority of children with the disorder.

Because of concerns about steroids' long-term effects, Lieven Lagae et al. tested IVIG therapy on a young patient who previously had been treated with steroids during two periods of regression. The patient had progressed a third time, losing his speech and becoming unresponsive. IVIG therapy (400 mg/kg/day for 3 consecutive days) had a dramatic effect, the researchers report, even though treatment had to be discontinued due to illness. "About 1 week later," the researchers say, "[the boy's] comprehension improved dramatically and soon he began to use short sentences again." In addition, the boy's IQ rose significantly. The child's current stable period has lasted for 18 months, during which his behavior and learning skills have improved markedly.

"Intravenous immunoglobulin treatment of children with autism," Audrius Plioplys; *Journal of Child Neurology*, Vol. 13, Feb. 1998, pp. 79-82. Address: Audrius Plioplys, Div. of Neurology, Mercy Hospital and Medical Center, Stevenson Expressway at King Dr., Chicago, IL 60616.

—and—

"Successful use of intravenous immunoglobulins in Landau-Kleffner syndrome," Lieven G. Lagae, Jon Silberstein, Phillippe L. Gillis, and Paul J. Casaer; *Pediatric Neurology*, Vol. 18, 1998, pp. 165-168. Address: Lieven Lagae, University Hospital Gasthuisberg, Division of Pediatric Neurology, Herestraat, B 3000 Leuven, Belgium.