

Central Jersey FOCUS: Somerville nonprofit supports families dealing with Tourette's

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Lisa Rongo said that once her child was diagnosed with Tourette syndrome it was as if her family was "in a tunnel, and you feel like there's no way out." "We asked if there was anything we could do -- any resources," Rongo said. "The doctor looked at us and simply said, 'No.' Meanwhile you have a child looking up at you saying, 'Mommy, mommy, make it stop.'"

Now, Rongo helps families facing similar situations see light at the end of the tunnel. She is in charge of communications for Somerville's Tourette Syndrome Association of New Jersey Inc. -- a nonprofit organization that has grown into a nationwide, if not worldwide, leader in advocacy, education and support services for doctors, families, school districts and others.

The association trains doctors to recognize and treat the often misunderstood and misdiagnosed neurological syndrome that may affect as many as one in 200 children, said Faith Rice, executive director of the association.

Rice and Rongo met with Courier News editors last Thursday to discuss the associations' efforts. "Pediatricians just aren't educated or interested sometimes," Rice said. "The child is often diagnosed with something like OCD (obsessive compulsive disorder) -- even in schools, where children with TS are shuffled off to classes with special needs or behavioral problems."

Misunderstood symptoms

Rice, whose own child was diagnosed with Tourette syndrome in the early 1990s, said 26,000 schoolchildren in New Jersey have some form of the syndrome, which has wide-ranging symptoms that are often to blame for its misunderstanding. Tourette syndrome usually is accompanied by related disorders such as OCD, attention deficit disorder, depression, anxiety and learning disabilities, she added.

However, Rice said the truth is children with Tourette syndrome simply need a little understanding because their minds, though plagued by a disconnect of appropriate neurotransmitters that can outwardly cause uncontrollable physical movements or sounds, can comprehend and learn.

"People with (the syndrome) can lead very productive lives," Rice said. "People with

Tourette syndrome graduate high in their class, hold jobs and can become doctors."

The association is leading the charge for treatment and research for the Tourette syndrome. In 2000, the association partnered with Rutgers to create the New Jersey Center for Tourette Syndrome and Associated Disorders -- the only student-run clinic in the nation for Tourette patients and families.

Rice said the University of Medicine and Dentistry of New Jersey also has joined the center's treatment and research efforts.

"You can see families in individual or group settings here, getting support and treatment," Rice said. "It has really become an attractive program for Rutgers. It's grown to a point that there are waiting lists for students to get in because you learn so much, and it really is fascinating."

Ground-breaking research

Shortly after the center was created, Rice approached Jay Tischfield, a genetics researcher at Rutgers University, about his cell and DNA repository. Tischfield and his son have Tourette syndrome. This month, the public repository will be collecting samples from Tourette patients. It will be the first such collection in the world, Rice said.

Getting rid of the stigma about the condition also presents a challenge, Rice said. For instance, the disorder is widely known for the inappropriate language it can cause a patient to involuntarily shout, but Rice said only 5 to 15 percent of cases actually have the symptom.

The association, which Rice said started with a handful of volunteers in a basement office in 1988, appears to be making a significant difference for those with Tourette syndrome.

"I recently got a call from a woman who was gushing about her son graduating first in his class at a university," Rice said. "I didn't remember, but she said we got involved with the family when her son was in the fifth grade. The school wanted him removed to a school for emotionally disturbed children. We went in and educated the school and did it every year. "That's what we're about," she said.

What you can do

- For more about New Jersey Center for Tourette Syndrome programs or referrals, call (908) 575-7350 or visit www.njcts.org. The Tourette Syndrome Association of New Jersey in Somerville can also be reached at the above telephone number or www.tsanj.org

Tourette syndrome facts

- Dr. George de la Tourette, a French neurologist, first diagnosed a woman with the disorder in 1885.
- Boys get Tourette Syndrome three to four times more often than girls. It affects every race and nationality equally.
- Symptoms usually first appear at about 6 or 7 years old.
- The first symptom of the Tourette Syndrome is usually a facial tic such as rapidly blinking eyes or twitches of the mouth. Involuntary sounds like throat clearing and sniffing may be signs as well.
- Obscene language is not a typical symptom of the disease. The condition, called coprolalia, is manifested in fewer than 15 percent of syndrome patients.
- The cause of the symptoms is not known, although research suggests it stems from abnormal metabolism of the brain chemical, dopamine.
- Many people with Tourette syndrome experience improvement in their late teens or early twenties. Most get better, not worse, as they mature. People with Tourette syndrome have normal life expectancy and intelligence.
- There is no known cure for the disease.

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