



TSANJ and Partners Provide Family Support and Research Opportunities for Managing Tourette Syndrome

Tourette Syndrome (TS) is an inherited neurological disorder characterized by involuntary motor and vocal tics. It usually appears by the time a child is 6 or 7 years old, affects all races and nationalities and boys are affected three to four times more often than girls. Tourette is much more than just tics. It is most often accompanied by obsessive compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), depression, panic attacks, generalized anxiety disorder and sometimes learning disabilities. Few professionals have expertise in treating TS, according to Faith Rice, Executive Director, Tourette Syndrome Association of New Jersey, Inc. (TSANJ).

One in 200 children exhibit at least partial symptoms of the disorder. For many of these children, the disorder is undiagnosed and, therefore, not fully treated. "A lot of people are being treated for mental health issues, such as OCD, ADHD, depression or panic attacks, when these individuals could actually have TS. We believe that there are large numbers of children in New Jersey's urban areas and in the DYFS system who have probably been labeled as emotionally disturbed or otherwise classified when they may actually have TS," Rice said.

"It is so critical that medical and mental healthcare providers receive proper education and training to recognize, properly treat and refer children and adults who have TS. Pediatricians and other primary healthcare providers should coordinate care with a psychiatrist or other

mental health provider and, if the patient is a child, the school child study team should be involved. When these clinicians collaborate, the children and adults will receive the services they need to deal with this often devastating disorder," Rice added. With a constant focus on these needs, her objective is to provide such training to medical and mental health professionals to assist them in diagnosing and treating TS, as well as providing education and support for New Jersey families who are dealing with TS.

Rice established TSANJ after a seven year long struggle of helping her son cope with symptoms before finally being diagnosed with TS. The lack of medication or guidance regarding his needs and the lack of available services shocked Rice. Determined that something needed to be done, she established TSANJ to guide coordinated services for families and professionals and to educate the public on this often misdiagnosed and misunderstood disorder. One example of TSANJ's offerings is a group services program that TSANJ established in 1999 in partnership with Rutgers' Graduate School of Applied and Professional Psychology (GSAPP), providing a variety of psychological services.

Rutgers-TSANJ Therapeutic Program and Research Initiatives

The Rutgers-TSANJ Therapeutic Program is the nation's only standalone, doctoral student-run clinic for individuals with TS and their families. The program offers individual counseling, social skills groups for children with TS, sessions for siblings and workshops for parents. Families are referred to the program from TSANJ, Rutgers University, surrounding communities, schools and human services agencies throughout the state.

And now, with a \$125,000 grant awarded in 2006 from the Rutgers' Academic Excellence Fund, the Rutgers-TSANJ program is expanding its multidisciplinary scope and research focus. "The award also provides funding for the Rutgers Graduate School of Applied and Professional Psychology to study pioneering, computer-assisted neuro

and bio-feedback treatments that show promise in mitigating the tics and other symptoms of TS," according to Rutgers University's *Focus* (May 9, 2007). TSANJ also is collaborating with Rutgers' Department of Genetics to facilitate research to develop more effective treatments and hopefully, a cure. The Rutgers University Cell and DNA Repository is collecting genetic samples from New Jersey residents with TS and from their families. These samples will be stored in the nation's first sharing repository of human tissue for TS research and made available to qualified scientists around the world to further research into this genetic disorder.

A Larger Collaboration Takes On Varied, Broad-Reaching Initiatives

Rice has recently established another meaningful collaboration, The New Jersey Center for Tourette Syndrome and Associated Disorders (NJCTS), another one-of-a-kind organization in the United States. NJCTS is an umbrella organization which incorporates community practitioners, the Rutgers University Cell and DNA Repository, Rutgers Graduate School of Psychology and the University of Medicine and Dentistry of New Jersey to provide a range of services and opportunities for professionals, and individuals with TS and their families:

- Diagnoses and treatment
- Coordinated care, advocacy, education and support programs for families
- Opportunities for research on causes, treatments and cures
- Training for medical and mental health professionals and educators to develop the next generation of professionals, which includes in-service training at colleges, hospital grand rounds and professional conferences, and onsite training for medical and mental health professionals.

TSANJ Also Offers Training for Schools, Police Departments and More

While overseeing and enhancing these various programs, Rice also strives to build awareness of TS and associated disorders and fight stigma against these illnesses through training programs. Primarily delivered as in-services, training is available for staff in public and private schools, colleges

and universities, residential facilities, police departments and other community organizations. In addition, TSANJ offers a help-line and physician referral services. According to Rice, the school inservice program is one of TSANJ's strongest programs, training more than 30,000 New Jersey educators over the past 11 years. TSANJ is registered with the New Jersey Department of Education as a Professional Development Provider. TSANJ also offers

peer intervention services and has established partnerships with 14 New Jersey colleges to deliver workshops on TS. Their support groups are hospital based and cover all 21 counties. For more information on TSANJ and NJCTS, call 908-575-7350, write to info@tsanj.org or visit www.tsanj.org.