



New Jersey Center for Tourette Syndrome

AND ASSOCIATED DISORDERS, INC.

NJCTS is a collaboration among TSANJ, Rutgers University
and health professionals throughout New Jersey

NJCTS Genetics Repository- A letter from the Executive Director

A little more than 5 years ago I saw an article in the *Star Ledger* about a scientist at Rutgers who received a \$26M grant to study mental disorders. I worked with that scientist and Rutgers University for 3 years to convince them that TS should be part of their research. As a result of that effort, in June of 2007 the NJCTS Sharing Repository collected its first sample from a New Jersey TS family and the TS repository (the only TS sharing repository for genetics research in the world) became a reality. During its first 18 months of operation the Repository screened families, collected blood and distributed samples to qualified researchers at Yale and Harvard among others.

This project has been supported for three years in part through a grant to NJCTS from the NJ Dept of Health. In December 2008 we recruited the University of Pennsylvania as the second collection site for our NJCTS Sharing Repository. We will soon be applying to the National Institutes of Health for funding to expand the TS repository to a select group of collection sites and researchers across the United States. The basis for that federal grant application is the success and size of our efforts here in NJ.

If you and your family have not yet participated in this research effort, I urge you to do so immediately. The greater the number of study participants, the greater the possibility of receiving federal funding.

Please email familystudy@biology.rutgers.edu to get started or contact me for additional information. The research is typically conducted at Rutgers (Piscataway), where you will meet with Dr. Robert King of the Yale University TS/OCD Clinic and a Rutgers scientist. However, there is the flexibility of having your blood sample drawn by your own doctor and the interview conducted by phone. It couldn't be easier!

Please help me accomplish our goal of obtaining federal funding for the NJCTS Sharing Repository. I urge you to be part of this effort to find better treatment and a cure for TS by emailing familystudy@biology.rutgers.edu or calling me TODAY! Your participation will make a difference. On behalf of the children and families we serve, I thank you.

A handwritten signature in blue ink, appearing to read 'Faith W. Rice'.

Faith W. Rice, NJCTS Executive Director

Preparing For Your Child's Future- NJCTS Offers a Guide

Attorney Lori Wolf helped navigate us through the issues special needs parents need to take into consideration when estate planning during our February 4 webinar. (In case you missed it, or would like to hear it again, "Estate Planning for Special Needs Children" is available in our archived webinars at www.njcts.org) Ms. Wolf suggests parents prepare a letter of intent to instruct guardians on how to properly handle your children's affairs in the event of your death. Please find Ms. Wolf's outline of suggestions at www.njcts.org. This framework is designed to help all parents develop a care plan that takes their children's comfort and continuum of care into consideration.

IEP Interview Checklist – A Useful Tool for Parents

Education Consultant Sandra L. Romano offers her suggestions on how to successfully negotiate your annual IEP meeting with school administrators. Her checklist covers what to do before, during and after your conference with your child's special education team. The suggestions, available on our website, are designed to help you maintain an effective working relationship with school representatives.

North Jersey Families- Save the Date for TS Presentation

In case you missed the “State-of-the-art Treatments for Tourette Syndrome and Associated Disorders” in November, NJCTS is hosting another presentation for north Jersey families. The date will be announced soon and the event will take place at Bergen Regional Medical Center in Paramus. NJCTS Sharing Repository Executive Director Jay Tischfield, Ph.D. will discuss genetics and Tourette Syndrome research. Dr. Robert King of the Yale University Child Study Center TS/OCD will provide an overview of current treatments and therapies for TS. Onsite appointments will be available for anyone interested in participating in the NJCTS Genetics Study.

Golf Outing to Support NJCTS- Save the Date June 3, 2009

Please be sure to save the date for a member-initiated golf outing to support NJCTS. The event will be held June 3, 2009 at Olde York Country Club in Chesterfield in celebration of our **Wednesday is TS Day** awareness campaign. Plan to come out and be part of the fun. More information will be available in the coming weeks.

Changes to Camp Bernie- Camp Counselors Wanted

Calling all teens: If you've been attending our annual family retreat at Camp Bernie we need your help. This year we want the weekend to be run by our member families and we'd like teens to counsel and mentor our younger members. This would entail some group leadership like organizing games and activities. Interested families with teens 16 and older should contact the NJCTS office. This year's event is June 5-7. Mark your calendar and visit www.njcts.org for a registration form.

In-service Presenters Needed

We are currently recruiting people with education and medical backgrounds to help us deliver in-service training to teachers and mental health professionals across New Jersey. If you are interested in learning more about this exciting opportunity, please give us a call at 908-575-7350

Youth Ambassador Training for Teens with TS

NJCTS is gearing up to offer Youth Ambassador Training in 2009. This comprehensive program will give teens the opportunity to learn important leadership skills like public speaking, peer mediation and conflict management. The process will focus on self-esteem building with the goal of equipping TS youth to become stronger advocates. If you would be interested, please contact the office at info@njcts.org or call 908-575-7350.

Postal rates are going up in May- Give us your e-mail address now!

If you haven't already, please give us your e-mail address so that we can continue to send you information on TS as it becomes available. We need to save money on postage costs, especially since postal rates are going up in May, and every dollar we save can be put back into our family support, education and advocacy programs will make a difference. Help us help you by e-mailing us today at info@njcts.org.

Wednesday Webinars – Feb 25 and March 18

Our Wednesday Webinar series continues on February 25 with “Special Education and the Law” presented by attorney Rebecca Spar. This webinar will focus on how school-age children with Tourette Syndrome and Associated Disorders may be eligible for services under the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act. Ms. Spar will also discuss modifications that can be made to your child’s education program. On March 18, attorney Randi Kochman will lead a webinar on employment rights for individuals with Tourette Syndrome and Associated Disorders. Webinars take place from 7:30-8:30 p.m. To register visit our website at www.njcts.org.

Professional Development Workshops on TS and Associated Disorders

NJCTS is offering several educator workshops this Spring through partner colleges across the state. Please encourage your child’s teachers, administrators, social workers and counselors to attend these sessions. Professional development credits are offered. Families are also urged to attend.

March 3	County College of Morris- 6-9 p.m. Presenter: Julie Swenson, M.Ed. CSW Cost: \$38 Register: www.ccm.edu
March 28	Bergen County College, 10-1 p.m. Presenter: Ann Deutsch, MSN Register: www.bergen.edu Course: SD759 Cost: \$45
March 30	Ocean County College, 4-7 p.m. Presenter: Janine Howley, MA Register: www.ocean.edu Cost: \$59
April 7	Camden County College, Cherry Hill Campus Presenter: Cheryl Ludwig, MA, CCC-SLP Register www.camdencc.edu/ce Course: CE.EDU.012-41 Cost: \$35

Volunteers Needed

NJCTS is looking for additional volunteers to help in the following areas:

- Camp Bernie Family Retreat Committee
- Appel Farm Family Retreat Committee
- Mailings
- Fundraising
- Helpline

Contact Us

NJCTS Office – 908-575-7350 info@njcts.org
NJCTS Sharing Repository- familystudy@biology.rutgers.edu
NJCTS Rutgers TS Clinic- 732-445-6111 ext. 930

February/March Calendar of Events

- Feb. 12- Seminar: Undergraduate Social Work, Richard Stockton College of NJ, Pomona
- Feb. 13- Faculty In-service, Atlantic County Special Services, Mays Landing
- Feb. 13- Faculty In-service, Delran High School, Delran
- Feb. 19- Atlantic/Cape May County Family Support group, Atlantic City Med. Ctr, Pomona (TSANJ)
- Feb. 25- Wednesday Webinar: "Special Education and the Law" Presenter: Rebecca Spar, Esq.
7:30-8:30 p.m.
- Mar. 3- Educator Workshop: County College of Morris
Cost: \$38- Register at www.ccm.edu
- Mar. 9- Faculty In-service, Hawes Elementary School, Ridgewood
- Mar. 10- Middlesex/Union County Family Support Group, JFK Hospital Institute, Edison (TSANJ)
- Mar. 17- Monmouth/Ocean County Family Support Group, Jersey Shore University Hospital, Neptune 7-8:30 p.m.
(TSANJ)
- Mar. 18- Wednesday Webinar Series: "Tourette Syndrome and Associated Disorders in the employment industry: Your rights under 'New Jersey Law Against Discrimination' and 'Americans with Disabilities Act.'" Presenter: Randi W. Kochman, Esq. 7:30-8:30 p.m.
- Mar. 19- Mercer County Family Support Group, RWJ Hamilton Center for Health & Wellness, Mercerville
7-9 p.m. (TSANJ)

FOR MORE INFORMATION ON ANY OF THESE EVENTS VISIT WWW.NJCTS.ORG OR CALL 908.575.7350