NJCTS NEWS

This Wednesday and Every Wednesday is TS Day. Get Involved. Get an Education. Get Help.

September 2008

New Jersey Center for Tourette Syndrome and Associated Disorders, Inc.

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

All across New Jersey Wednesday is TS Day!

A growing number of communities are pledging support for the 28,000 New Jersey children and families dealing with Tourette Syndrome. Several mayors have issued proclamations directly acknowledging and congratulating the efforts of New Jersey Center for Tourette Syndrome (NJCTS) which offers support services, medical referrals, training programs and the world's first TS DNA Sharing Repository.

Proclamations were issued in Newark, Camden, Trenton and Wildwood in conjunction with "Wednesday is TS Day at the Ballpark!" celebrations throughout the summer . Spreading the message to thousands of baseball fans helped solidify the "Wednesday is TS Day!" campaign.

"By recognizing our 'Wednesday is TS Day!' effort, city leaders are taking a proactive step in standing up for adequate healthcare for the underserved, expanding public and professional acceptance as well as supporting a safe-haven for this vulnerable population," said NJCTS Executive Director Faith Rice,
"These proclamations and support of 'Wednesday is TS Day' speak volumes to the importance of fair treatment to those with neurological disorders and the need for access to quality healthcare for all New Jersey residents. We're delighted we can work together to put TS at the center of these important issues."

Trenton Mayor Doug Palmer presents NJCTS with a proclamation supporting the "Wednesday is TS Day" campaign. He is flanked by educator and TS parent Cheryl Ludwig and NJCTS Executive Director Faith Rice.

"Wednesday is TS Day" in Newark thanks to this proclamation delivered on behalf of Mayor Cory Booker at a Newark Bears game.

Newark Mayor Cory Booker, Trenton Mayor Doug Palmer, Camden Mayor Gwendolyn Faison and Wildwood Mayor Earnest Troiano have joined a growing number of officials standing up to raise Tourette Syndrome awareness, and these latest proclamations echo the efforts of U. S. Congressman Albio Sires (D-NJ), and State Sen. Kip Bateman to establish every Wednesday as a day of advocacy on behalf of people with TS.

Educator Workshops

NJCTS Educator Workshops offer professional development training for educators on Tourette Syndrome and associated disorders. Visit the *Calendar of Events* page on NJCTS.com for presentation times and more information.

Sept. 25– Mercer County College
West Windsor Campus
Presenter: Cheryl Ludwig, MA
CCC-LSP XCP262

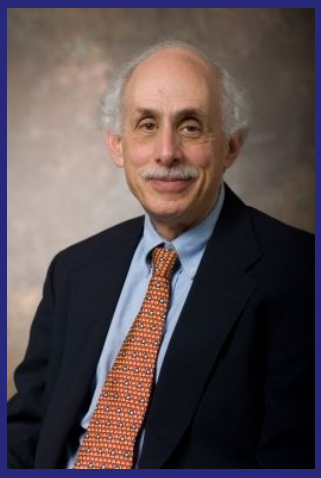
Sept. 26– Raritan Valley
Community College
Presenter: Janine Howley, MA
CRN11626 AH402-01

Oct. 4– Brookdale Community College
Presenter: Janine Howley, MA
XEECG 516 CT

Oct. 25– Bergen Community
College
Presenter: Ann Deutsch, MSN
SD759

Oct. 26– Ocean County College
Presenter: Janine Howley, MA
SRED 107-01
Library Building Rm. L017

Nov. 7– Warren County
Community College
Presenter: Rob Zambrano, Psy.D.
EDU 8682 A1



Dr. Robert King will talk about new TS therapies on September 19th.

State-of-the-art treatments for Tourette Syndrome

As part of the Rutgers University genetic study of Tourette Syndrome, Dr. Robert A. King will present recent clinical advances in medication and other state-of-the-art treatments for TS and other associated disorders. He will also describe Rutgers University's ongoing genetic research study. The presentation will be followed by a question and answer session and refreshments will be provided.

Dr. King is Medical Director of the Tourette/OCD/Anxiety Disorder Clinic at the Yale University Child Study Center where he is also Professor of Child Psychiatry. He is the author of numerous scientific papers and is the author of the *American Academy of Child and Adolescent Psychiatry's Practice Parameter on Assessment and Treatment of Childhood OCD.*

Space for this presentation is limited. For more information, directions and to reserve your seat, please call 732-445-1145 or e-mail your name and phone number to familystudy@biology.rutgers.edu.

Families are welcome. Registration is free, but mandatory. Deadline for reservations is September 15th.

TS Webinar series returns for professional credit in September

Wednesday Webinars return this fall with an exciting line-up of presentations. Educators, social workers and nurses can earn professional development and CEU credits for attending these in-service webinars.

On September 24 and October 1, *An Educator's In-Service Modules 1 & 2* will provide insights on what every school professional needs to know about Tourette Syndrome and coping strategies for helping TS children in the educational environment. These presentations will be conducted by Ann Deutsch, MSN; Janine Howley, MA; and Cheryl Ludwig, MA, CCC-SLP. Both webinars will take place from 7:30-8:30 p.m.

On October 29, Dr. Lori Rockmore, Clinical Director of the NJCTS TS Clinic at the Rutgers University Graduate School of Applied and Professional Psychology, will present *Mental Health Treatment for Individuals with TS: Does it Work?* from 7:30–8:30 p.m.

S M T W T F S

Wednesday is TS Day!
WEBINARS

Click "Register for a Webinar" under the *Wednesday is TS Day* link on our website, www.njcts.org to sign-up and for more information.

WEDNESDAY IS TS DAY WEAR

Sign up for:	Size	Price
☐ TS Day T-shirt Youth S/M/L/XL		$12
☐ TS Day T-shirt Mens M/L/XL		$12
☐ TS Day T-shirt Ladies M/L/XL		$12
☐ TS Day Hat Youth Size	One Size	$10
☐ TS Day Hat Adult Size	One Size	$10
☐ TS Day Car Magnet	One Size	$10

# of Items: _____

Total: _____

☐ I'd like to make a donation to NJCTS Amount: _____

Method of Payment
☐ Check
☐ Cash

Name

Address

Phone

Signature

NJCTS
50 Division Street
Suite 205
Somerville, NJ 08876

New Jersey Center for Tourette Syndrome and Associated Disorders, Inc.

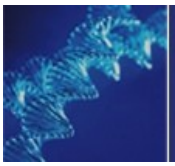
What are *you* wearing?

Put it on...

Don't just say "Wednesday is TS Day," wear it. Help New Jersey Center for Tourette Syndrome help shatter the stigma around TS and help educate those who don't know the signs and symptoms of this disorder.

Wednesday is TS Day!

Families with Tourette Syndrome are encouraged to take part in this exciting genetic study led by Dr. Jay Tischfield and Dr. Gary Heiman at Rutgers University.



New Jersey Center for Tourette Syndrome Sharing Repsitory

Research has revealed that Tourette Syndrome (TS) has a strong inherited component, and in recent years, the disorder has been linked to specific genes but these may account for only rare forms of TS.

To further research into genetic factors contributing to Tourette Syndrome, the Rutgers University Department of Genetics working with NJCTS established the New Jersey Center for Tourette Syndrome Sharing Repository.
Housed at Rutgers University, the TS Sharing Repository collects and stores information and DNA from individuals with TS and their families. Opened in 2007, this is the world's first TS DNA repository which encourages research into Tourette Syndrome by making samples available to qualified researchers across the globe.

The ultimate goal of this study is to identify genetic (inherited) factors that play a role in causing TS and related disorders such as Chronic Tics (CT), Obsessive-Compulsive Disorder (OCD) and Attention Deficit Hyperactivity Disorder (ADHD).

Identification of genetic factors that predisposes individuals to TS could increase understanding of the basic causes, possibly leading to the development of new methods for treatment, or perhaps even prevention of onset of this disorder in some individuals.

The Sharing Repository functions as a bank and processing center. Simply, they recruit and evaluate interested individuals with TS and, if possible, their relatives and a blood sample is drawn. The information is stored in a coded way to keep their identity a secret.

In the future, this data could become part of the National Institutes of Health Repository at Rutgers University as a national resource.

You've got what it takes!

If you (and your family) agree to participate in this study, you will be asked to complete a survey questionnaire and to come to Rutgers University in Piscataway to do the following:

1. Review your responses on the survey questionnaire with a member of the research team. This interview should take between 30-60 minutes.

2. Answer questions about your family members. If you agree, we may ask for your permission to contact some of your relatives to invite them to also participate.

3. Have a sample of your blood drawn. The amount of blood to be drawn from a vein in your hand or arm is the amount typically drawn during a routine medical exam. The purpose of this blood sample is to examine whether specific segments of DNA or genes are associated with Tourette Syndrome and related behaviors.

If you would be willing to talk to a member of the professional staff, please e-mail your name, phone number and best time to be reached to:

familysudy@biology.rutgers.edu

DONATE THROUGH UNITED WAY

September marks the United Way's annual charitable giving campaign. This movement allows an easy way to donate to your favorite cause. Please remember you can support the programs and services of New Jersey Center for Tourette Syndrome though the United Way by designating NJCTS as the recipient when you sign-up. Please urge your friends and family members to give on behalf of the 28,000 New Jersey kids with TS.

Be sure to include our organization name, address and telephone number which are listed on the front and back of this newsletter.

Family2Family

NJCTS Family2Family provides parents and children an opportunity to socialize and exchange strategies and life skills for dealing with TS and its associated disorders. The next meeting is scheduled for October 12 in the Pompton Plains area. A gathering in Vineland is slated for later this year.

New therapy options

The TS Clinic at the Rutgers Graduate School of Applied and Professional Psychology (GSAPP) is marking another successful season. Not only is there a waiting list for families looking to receive services, but there is now a waiting list for doctoral students to enter this program. NJCTS and Rutgers University recognize the need for more clinicians specializing in TS and have developed the nation's only stand-alone student-run TS clinic and doctoral training program. To meet family demands, NJCTS is establishing a satellite TS clinic.

The Tourette Syndrome Program at Rutgers University will be conducting groups for children, parents, and siblings of children with Tourette Syndrome at **St. Clare's Hospital** in Morris County. The plan is to run three different groups at the same time: one for children with TS, one for their parents, and one for their siblings.

The Children's Group is designed to help children with TS work on the specific issues that often come with a diagnosis of TS. The groups are intended to provide a supportive environment where children and adolescents can learn about living with TS and meet peers who also have TS.

In the Parent Group, the parents of children with TS are invited to meet other parents of children with TS in a psychoeducational group that will facilitate discussion on various topics that relate to raising a child with TS.

In the Siblings Group, siblings of children with TS will work on skills that allow them to empathize with their siblings and to cope with having a neurological disorder within their family.

The groups will be held at St. Clare's Hospital and run by staff affiliated with the Tourette Syndrome Program at Rutgers University and the New Jersey Center for Tourette Syndrome.

RUTGERS
Graduate School of Applied and Professional Psychology
Center for Applied Psychology

The 90-minute groups will be offered weekly beginning in late September or early October. The groups will continue for 10 weeks. The fee for a family to participate in the groups is a flat rate of $200. All family members are welcome to individually participate in one of the three groups.

If you are interested, please contact GSAPP at 723.445.6111 and discuss your availability.

A decision about what evening and which meeting room the group will take place will be based on family response. A representative from the Tourette Syndrome Program at Rutgers will then contact you with information to see if you want to sign up for the groups.

New therapeutic groups for families with TS in the Morris County area. Call the Rutgers University TS Clinic at 732.445.6111 ext. 27 for more information or to register.

Back to School Strategies for Parents

Family Support Groups will be focusing on strategies for making the transition back to school in September.

On September 9, the Middlesex/Union County Family Support Group will meet at 7 p.m. at the JFK Hospital Neuroscience Institute located at 65 James Street in Edison.

Monmouth and Ocean County Family Support Group will meet on September 16 at Meridian Life Fitness Center at Jersey Shore Hospital, 2020 Highway 33 in Neptune. The meeting begins at 7 p.m.

Families from the Mercer County area are invited to join the Family Support Group meeting at RWJ Hamilton Center for Health and Wellness at 3100 Quakerbridge Road in Mercerville. That meeting will be held on September 18 at 7 p.m.

The Somerset/Hunterdon County Family Support group meets on September 22 at 7 p.m, at Somerset Medical Center at 110 Rehill Avenue in Somerville. The meeting will take place in Conference Rooms A & B.

Family support groups meet on a regular basis as a way for TS parents to network and learn about coping strategies for children with TS and associated disorders. Visit NJCTS.org for details.

Helpline Help Wanted

'Hablas Espanol?' If so... NJCTS needs you!

Each year NJCTS receives thousands of phone calls to its Helpline. Often the callers are parents looking for assistance in dealing with their child's newly diagnosed case of Tourette Syndrome.

While we do our best to accommodate every call, we do have a need for English and Spanish-speaking volunteers.

Volunteers would serve a few hours a month from home and receive basic training on how NJCTS handles call volume, member requests and medical referrals.

If you are able and interested in serving, please contact the NJCTS office at 908.575.7350 or e-mail info@njcts.org.

Thank you for your consideration and efforts to make help available to everyone dealing with TS.

On the road with NJCTS

NJEA THE BEACON FOR PUBLIC EDUCATION
Helping Students Develop 21st Century Skills

New Jersey Center for Tourette Syndrome will continue its outreach to New Jersey school professionals this fall.

On October 29th, NJCTS will be at the 17th annual School Health Conference at Pines Manor in Edison offering support and information to school nurses and other health professionals. NJCTS returns to the New Jersey Education Association annual convention in Atlantic City November 6-7.

If you are attending these events, please be sure to stop by our booth.

We are excited to promote all the services NJCTS has to offer and invite you to join us as a booth volunteer to help spread information and support for making a difference in the lives of children with TS.

Two family retreats in 2009

Get your calendars ready as 2009 is shaping up to be a fun year.

Thanks to a grant from Hoop-A-Paluza, NJCTS is pleased to announce a second family retreat opportunity. The fall retreat is slated for Columbus Day weekend 2009 at Appel Farm Arts and Music Center in Salem County.

We'll keep you posted with the exact dates and other important information in the months ahead.

Our annual retreat at Camp Bernie is scheduled for early June 2009. This experience is a favorite among NJCTS families and we're looking forward to both events.

If you are not on our mailing list, and would like to be, make sure to contact the office at 908.575.7350.

Thanks to a grant from Hoop-A-Paluza, Inc., there will twice as much fun at NJCTS retreats in 2009!

Doctor Seeks TS "Life Stories"

Including Yours...

Older adults who have lived successfully with mild, moderate or severe Tourette Syndrome (TS), are wanted for a New Jersey -based study. They are people with stories to tell about resilience, courage, strengths, and creativity. Such stories, from older adults with TS, gathered from in-depth interviews and guided autobiographies, can benefit younger generations and facilitate new insights for researchers not trained in gerontology.

Dr. Lisa Cox, Associate Professor of Social Work and Gerontology, at The Richard Stockton College of New Jersey, is studying how genetic traits and life-course experiences are linked to physical and emotional health in later life. She is particularly focusing on older adults (55+) who have been living with Tourette Syndrome (TS) for a long time. Dr. Cox is a long-standing member of our organization, and is particularly interested in meeting and talking with individuals with TS.

Despite difficulties in school, on the job and with friends, Dr. Cox believes people with TS have demonstrated resilience by adapting their own coping mechanisms. She wants to learn more about individuals' strategies, and what challenges they face as they consider career longevity, retirement, health care and long-term needs.

Instead of standard "yes or no" questions, Dr. Cox wants to collect stories through an in-depth interview.

If you are interested in sharing your experiences, write, e-mail or call Dr. Cox. Information shared will be kept confidential and it is expected that the stories of older adults with TS will help inform medical professionals, teachers and social workers. In turn, this information will be used to help professionals develop essential skills for the continuum of care for aging adults with Tourette Syndrome.

STUDY ON TS AND AGING

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Time to spare? Show you care!

Do you have a few hours to spare? How about once a month? As you know New Jersey Center for Tourette Syndrome is a busy organization. Right now we are in need of teachers, social workers and others with a background in education to join us as in-service presenters.

We can also use a hand from time to time with some light clerical work. This opportunity is ideal for students seeking public service credits for school or scouting groups; parents who want to meet other TS parents; retirees and anyone willing to give a few hours for a great cause. If you're interested, please contact the NJCTS office at 908.575.7350 or write info@njcts.org.

The "Wednesday is TS Day" message in action as worn by our wonderful volunteers at the Newark Bears game on July 30th.

Of course, the easiest way you can help is by making sure we have your current contact information. Make sure you're getting updates and information as well as an electronic copy of NJCTS News; subscribe by visiting our website at www.njcts.org.