



New Jersey Center for Tourette Syndrome

AND ASSOCIATED DISORDERS, INC.

Collaborative Partnerships for the Tourette Syndrome Community

Faith W. Rice
Executive Director

FALL ISSUE

NOVEMBER 2011

Dear Friends,

Thanksgiving is right around the corner, and what better time to give thanks for the many wonderful happenings surrounding the New Jersey Center for Tourette Syndrome & Associated Disorders and the statewide TS community in general than right now!

In the next few days – expectedly before the holiday – Congressman Albio Sires of the 13th district (parts of Hudson, Essex, Union and Middlesex counties) will introduce proposed federal legislation in the U.S. Congress that contains anti-discrimination language, as well as potential support for collaborative research and treatment centers to benefit individuals and families with Tourette Syndrome across the nation.

NJ Center for Tourette Syndrome has been driving the effort behind this landmark legislation and has worked closely with the Congressman's office every step of the way. We are very pleased that Congressman Sires is moving forward with federal legislation and will share additional information as it becomes available.

This pending announcement, along with many of the other important items you will read in this newsletter, make this an exciting time for all of us!

Best wishes, Faith W. Rice, Executive Director

"STAND UP" MOVEMENT POSTER CONTEST



Dare to Dream
Student Leadership

Last month, NJCTS launched the "Stand Up" movement, which encourages all students – not just those with Tourette Syndrome – to stand up against bullying for themselves and others. As part of that movement, we have developed the slogan "Bullies Back Down When We Stand Up."

In order to better brand that slogan, we are initiating a poster contest – open to students of all ages statewide, not just those with TS – that we hope also will raise awareness and help all of us band together against bullying.

The rules for the contest are simple: Draw up a poster, with a maximum size of 11x17, which best conveys what "Bullies Back Down When We Stand Up" means to you. The contest will remain open until Jan. 15, 2012, and a winner will be chosen by April 15, 2012.

The winning poster will serve as a lightning rod in our school faculty and peer in-service presentations and will be prominently featured in the materials we distribute to schools, libraries and other partners. All of the submitted posters will be displayed at the Dare to Dream Student

Leadership Conference to take place Wednesday, May 23, 2012 at Raritan Valley Community College.

This conference, a partnership between New Jersey Department of Education and NJCTS, will be New Jersey's first symposium on student leadership for Tourette Syndrome, Obsessive Compulsive Disorder, Attention Deficit Disorder and Asperger's.

We urge you and your school to participate in this important conference. More information to follow in the coming weeks and months. If you wish to take part in the poster contest, please e-mail us at info@njcts.org and include "POSTER CONTEST" in the subject line. We will then send you more information on how to participate.

MEET THE NEWEST MEMBERS OF THE NJCTS TEAM

Jeff Weber - Our Communications and Public Relations Coordinator, Jeffrey M. Weber, has come to NJCTS after more than 11 years in the newspaper business as a reporter and editor for the Gannett-owned Courier News, Home News Tribune and MyCentralJersey.com publications. His last two years were spent as the health reporter, during which time he collaborated with NJCTS on several stories - including Wednesday is TS Day, Tim Howard and the Ghost Hunters. Jeff graduated from Rutgers University in 2000 with a bachelor's degree in Journalism and Mass Media and will graduate from Somerset Christian College in December with a bachelor's degree in counseling. In his spare time, Jeff, who lives in Pennsylvania with his wife, works with teenagers for his church fellowship's youth group.



Kirsten Graham - Our Outreach Coordinator, Kirsten L. Graham, is a graduate student at Fordham University. Kirsten will receive her master's degree in Mental Health Counseling this May and plans to pursue her PhD in Counseling Psychology. Kirsten graduated from Rutgers University in 2007 with a bachelor's degree in Psychology and minors in Sociology and Criminology. After earning her undergraduate degree, Kirsten worked for three years in UMDNJ's Therapeutic Day School/ Partial Hospitalization program for children and adolescents. Since starting at NJCTS last October, Kirsten has coordinated a number of outreach programs geared towards various professional groups throughout New Jersey. In her spare time Kirsten enjoys playing field hockey and traveling as much as possible.

CHECK OUT OUR NEWLY LAUNCHED BLOGS!

We are constantly searching for new, innovative ways to get the word out there about Tourette Syndrome and support those who need help in dealing with a diagnosis of TS. Our latest effort has been the successful launch of two weblogs, or "blogs," aimed at drawing in the expertise, opinions and accounts of the TS community.

On Nov. 7, we started TSParentsOnline (<http://www.njcts.org/tsparents>), a blog for parents of kids with Tourette Syndrome who want to share and connect. Then, on Nov. 14, we initiated Teens4TS (<http://www.njcts.org/teens4ts>), a blog for teenagers with Tourette Syndrome by teenagers with Tourette Syndrome. We encourage you to check out these blogs and jump in on the exciting conversation today!

75 DOCTORS ATTEND FIRST PATIENT-CENTERED GRAND ROUNDS AT SAINT PETER'S

On Oct. 20, NJCTS in collaboration with Saint Peter's University Hospital in New Brunswick hosted its first patient-centered grand rounds presentation and fourth overall patient-centered training seminar. The 70-minute grand rounds was facilitated by Lori Rockmore, Psy.D, clinical director for the NJCTS Tourette Syndrome Clinic at Rutgers University, and conducted in front of 75 pediatric physicians by Amanda Silvers, 16, of East Brunswick, and Steve Lindenbaum, 21, of Marlboro.

According to Dr. Bill Bernstein, Pediatric Grand Rounds Director at Saint Peter’s Children’s Hospital, “physician attendance at this grand rounds was high and feedback extremely positive. The attendees gained valuable insight into Tourette Syndrome and came away with a dramatically expanded perspective on the difficulties patients and their families face. I would strongly recommend all hospitals schedule this type of ‘family-centered’ grand rounds on Tourette Syndrome.”

SUPPORT GROUPS MEET AROUND THE STATE

We know it's important for TS parents to get the chance to listen and speak to each other about raising kids with this challenging disorder, and that's why Support Groups are a longstanding part of what we offer. Consider joining a group in your area. For more information on each of these meetings, please refer to our calendar at NJCTS.org:

- 11/28 Somerset/Hunterdon Counties – Somerset Medical Center, Somerville
- 12/1 Atlantic/Cape May Counties – Atlantic City Medical Center, Pomona
- 12/1 Morris/Sussex Counties – St. Clare's Hospital, Denville
- 12/27 Burlington/Camden Counties – Virtua Hospital, Marlton
- 1/10 Middlesex County – JFK Medical Center, Edison

WEDNESDAY WEBINARS TO LOOK AT HOARDING, EMOTION

Since 2008, we've shared information on TS with people in 48 states and 11 countries. Wednesday Webinars are available at no cost to families, educators, medical and mental health professionals. Professional development credits are available to qualified participants, and registration is required by visiting NJCTS.org under calendar, Wednesday Webinar Series. Here are our next two:

- 12/7 Hoarding, presented by Martin E. Franklin, Ph.D.
- 1/24 Emotion Regulation, presented by Julie Ryan, Ph.D.

Webinars are archived to NJCTS.org and can be downloaded for review at any time. We urge you to take advantage of this resource to better educate yourself on a variety of associated disorders and coping strategies.

INTRODUCING THE “I HAVE TOURETTE SYNDROME” CARD

Not everyone with TS has an easy time telling an inquisitive onlooker “I have Tourette Syndrome.” NJCTS is introducing a card – which can be carried in a pocket, wallet or purse and distributed – to help people better explain the condition of which 1 in 100 people show signs. Like a business card, it can be left, used as an introduction – any way you choose! It is available now by calling 908-575-7350.

SENSORY FRIENDLY FILMS CONTINUE WITH TWILIGHT AND THE MUPPETS

AMC Theatres and the Autism Society have teamed up to bring families affected by autism and other disorders, such as Tourette Syndrome, an opportunity to enjoy the cinema in a safe, accepting environment with the "Sensory Friendly Films" program. The next two films are “Twilight: Breaking Dawn – Part 1,” to be shown at 7 p.m. Wednesday, Nov. 30, and “The Muppets,” to be shown at 10 a.m. Saturday, Dec. 3, at seven AMC locations in New Jersey. For more information, please visit the Autism Society website at <http://www.autism-society.org/get-involved/events/sensory-friendly-films>.

VOLUNTEERS NEEDED FOR MAILINGS

Each month, we have thousands of pieces of mail that are sent out to families, businesses, educators and other outlets. We need your help in getting these important brochures, newsletters and flyers out to the public. If you live near our Somerville office and would like to help, please call 908-575-7350 today!

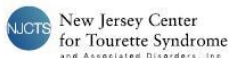
New card. See article inside this newsletter.

I have Tourette Syndrome

a neurological disorder that causes me to make uncontrollable movements and sounds. According to the *National Institutes of Health* 1 in 100 people show signs of this disorder, so it's much more common than you think.

For more information or to offer your support, call the *NJ Center for Tourette Syndrome* at 908 575 7350 or visit their website www.njcts.org.

Thank you for understanding.



Collaborative Partnerships for the Tourette Syndrome Community

908-575-7350 www.njcts.org

YOUR CONTRIBUTIONS MAKE A WORLD OF DIFFERENCE

Autumn marks the beginning of many workplace giving campaigns. Please be sure to designate NJCTS as the recipient of your contributions. If your workplace does not offer this type of program, you can choose to donate to NJCTS monthly through our website. Donating to NJCTS online is fast, convenient and secure. You can designate the funding to go to the program of your choice for one-time or monthly giving and you may make a gift to NJCTS in honor of someone special.

Visit NJCTS.org and simply click on the "Donate" option and you'll be guided through a simple form. Or mail us a check at the NJCTS address listed above. Giving to NJCTS is the only way to ensure your money will stay in New Jersey helping New Jersey families.

MATCHING YOUR GIFT

Did you know that many companies meet their philanthropic obligations through matching gift programs that recognize their employees' charities of choice? Check with your company's Human Resources or Payroll Department to see if they have a matching gifts program. If so, it could double or even triple your gift to NJ Center for Tourette Syndrome. We thank you on behalf of the NJ children and families we serve.

NEWS YOU CAN USE

While every child who acts up in class may not be suffering from Tourette's, it is important for parents and teachers alike to be aware that the disorder may be the source of some disruptive behavior. <http://www.almasyalyoum.com/en/node/510461>.

The Challengers, a Canadian TV concept that is in the early planning and development stages, is designed to be a one-hour docudrama series that inspires viewers by showcasing people – including those with Tourette Syndrome – who face obstacles but strive to achieve their goals. <http://www.theargus.ca/articles/ac/2011/10/challenge-accepted>.