



## New Jersey Center for Tourette Syndrome

AND ASSOCIATED DISORDERS, INC.

Collaborative Partnerships for the Tourette Syndrome Community

Faith W. Rice  
*Executive Director*

**NEW YEAR'S ISSUE**

**JANUARY 2012**

Dear Friends,

Happy New Year! I hope you and your family had the very best of holiday seasons. 2012 is off to a great start for NJCTS, and I want to share with you some of the extraordinary happenings that are taking place.

On Dec. 20, New Jersey Congressman Albio Sires (D-NJ13) introduced federal legislation, the Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2011 with bill number H.R. 3760, that – if passed – would provide for the expansion, intensification and coordination of the programs and activities of the National Institutes of Health (NIH) with respect to Tourette Syndrome and would specifically establish regional centers of excellence around the country.

Another breakthrough: The NJCTS Sharing Repository at Rutgers University has been federalized and named the National Institute of Mental Health Sharing Repository. At the same time, the NJCTS Sharing Repository received federal funding to establish 20 additional sites around the world to collect DNA samples from individuals with TS and their families based on the model established by NJCTS.

NJCTS also is busy coordinating a series of events that will benefit everyone in the New Jersey TS community – a poster contest to brand the anti-bullying message included in our faculty and peer trainings; a collaboration with New Jersey Department of Education to hold the first-ever “Dare to Dream” conference for students with and TS, OCD, ADHD and Asperger’s on May 21; and the annual TS Awareness Day on April 29 at the Somerset Patriots’ baseball stadium in Bridgewater. More information on all of these activities appears below and at [www.njcts.org](http://www.njcts.org).

Best wishes to all,  
Faith W. Rice, Executive Director

### FEDERAL TOURETTE SYNDROME LEGISLATION INTRODUCED

The Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2011, with bill number H.R. 3760, may be the most important thing to happen in the TS community in the past 40 years. If passed, the bill would amend the Public Health Service Act to provide for the expansion, intensification and coordination of TS research programs and activities.

New Jersey Congressman Albio Sires (D-NJ13) worked closely with NJCTS Executive Director Faith W. Rice; Dr. Jay A. Tischfield, Director of the Human Genetics Institute at Rutgers University; and other



NJCTS leadership to craft this legislation. The bill is being examined by the House Energy and Commerce Committee, which will consider it before sending it on to the House of Representatives or Senate as a whole.

A primary purpose of this legislation is to establish regional centers of excellence across the country to conduct research into the cause, diagnosis, early detection, prevention, control and treatment of Tourette Syndrome and associated disorders.

Please support this groundbreaking legislation and make your opinion known by visiting <https://www.popvox.com/bills/us/112/hr3760> and casting your vote! More information about this legislation also is available by visiting [www.njcts.org](http://www.njcts.org).

## NJCTS SHARING REPOSITORY GETS FEDERALIZED, RECEIVES FUNDING

Since its inception in 2007, the NJCTS Sharing Repository at Rutgers University has collected genetic samples from individuals with TS and their families for study by scientists around the world.

Thanks to a federal grant and a new name – the National Institute of Mental Health NJCTS Sharing Repository – Dr. Tischfield and his colleagues worldwide will be able to collect DNA samples from individuals with Tourette and their families at more than 20 sites in the United States, Europe and Asia. All samples collected will be sent to the NJCTS Sharing Repository on the Rutgers campus to be processed, stored and made available to qualified researchers across the globe to work toward better treatments and a cure.

Tischfield, who for 40 years has been doing research on mental disorders, says that getting more cell samples to study is critical to moving the research forward. This story recently was picked up 2011 Online Journalism Award for Excellence winner NJ Spotlight and can be viewed by visiting [www.njspotlight.com/12/0105/0113](http://www.njspotlight.com/12/0105/0113).

## NJCTS PARTNERS WITH DEPARTMENT OF EDUCATION ON MAY 2012 CONFERENCE



*Dare to Dream*  
*Student Leadership*

NJCTS is thrilled to partner with the New Jersey Department of Education to offer the first ever Dare to Dream Student Leadership Conference that targets the community of New Jersey high school students with Tourette Syndrome, OCD, ADHD, Asperger's Syndrome and associated neurological disorders.

This conference, which will take place from 9:30 a.m. to 1:30 p.m. May 21 at Rutgers University, will feature presentations from individuals with neurological disorders who have demonstrated exemplary self-advocacy and leadership qualities.

Anticipated topics will address the transition from high school to college and from college to the workplace, how to self-advocate in an IEP meeting, student rights in the college setting and insight on how to be an effective leader and advocate – specific to the student living with these neurological conditions.

The conference will include break-out sessions that provide information to parents and an open-mic session where students are encouraged to share their personal stories and successes. We are currently seeking submissions!

Students are encouraged, with the help of their school or teacher, to propose additional topics for breakout sessions or to consider contributing their musical and other talents for our keynote presentations and opening ceremonies. More information is available by calling Melissa Fowler at 908-575-7350 or by visiting

<http://njcts.org/wordpress/wpcontent/uploads/2011/12/DareToDreamConference2012.pdf>.

## "BULLIES BACK DOWN WHEN WE STAND UP" POSTER

### POSTER CONTEST:

#### *Bullies Back Down When We Stand Up*

**WHAT:** New Jersey Center for Tourette Syndrome Bullies Back Down When We Stand Up poster contest to help brand the "Stand Up" movement, which encourages students to take a stand against bullying for themselves and others, and help kick off the Dare To Dream Student Leadership Conference on May 21, 2012, at Rutgers University

**WHO:** New Jersey students in grades 7 through 12

**WHEN:** Now through March 1, 2012, with the winner being chosen on or about March 22, 2012, and announced publicly at the conference.

**CONTEST DETAILS:** Create a poster on 11x17 white poster board that best conveys what Bullies Back Down When We Stand Up means to you. The winning poster will be featured on the official conference T-shirt, displayed at the conference and supported for use in NJCTS school faculty and peer in-service presentations and printed materials that NJCTS distributes to schools, libraries and other partners.

**HOW TO PARTICIPATE:** Visit [www.njcts.org/postercontest](http://www.njcts.org/postercontest) for the official contest rules and the official contest registration form, which must be submitted with all entries. For further information, please call 908-575-7350 or e-mail [info@njcts.org](mailto:info@njcts.org) and include POSTER CONTEST in the subject line.

**ABOUT THE CONFERENCE:** A partnership between the New Jersey Department of Education and NJCTS, Dare To Dream will be New Jersey's first symposium on student leadership for Tourette Syndrome, Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder, Asperger's Syndrome and other associated disorders.

The conference will feature presentations from students and adults with neurological disorders who have demonstrated exemplary self-advocacy and leadership skills. There will be breakout sessions and keynote presentations.



New Jersey Department of Education partners with NJCTS to bring first Dare to Dream Symposium on Student Leadership for those affected by neurological disorders.

**NJCTS New Jersey Center for Tourette Syndrome and Associated Disorders, Inc.**  
50 Division Street, Suite 205, Somerville NJ 08876  
908-575-7350 [www.njcts.org](http://www.njcts.org)

Collaborator/Donor/Partner for the Tourette Syndrome Community

Please visit our newest online resources: TSParents/Childer blog - [www.njcts.org/blogparents](http://www.njcts.org/blogparents) TSPeers/TS blog - [www.njcts.org/blogpeers](http://www.njcts.org/blogpeers)

NJCTS has launched the "Bullies Back Down When We Stand Up" Poster Contest, which will be used to brand our anti-bullying message and augment our faculty and peer in-service presentations, webinars, as well as other printed materials.

This contest – for all public, private, parochial and homeschooled New Jersey students in grades 7 through 12 – will run through 4 p.m. March 1. All entries must be forged on 11x17 white poster board, be original works of art and depict what "Bullies Back Down When We Stand Up" means to you.

The winning entry will be incorporated into the official T-shirt for the Dare To Dream Student Leadership Conference. But before you get started on your design, there are some rules and regulations, so please visit [www.njcts.org/postercontest](http://www.njcts.org/postercontest) to read more about the contest, its purpose, other prizes associated with it and to download a registration form.

This poster, available by visiting [www.njcts.org](http://www.njcts.org), tells you all you need to know about the "Bullies Back Down When We Stand Up" Poster Contest.

## TOURETTE SYNDROME AWARENESS DAY WITH THE PATRIOTS

Weekends fill up fast in the springtime, so be sure to set aside the afternoon of April 29 for what we hope will be the event of the season: Tourette Syndrome Awareness Day!

Hosted by the five-time Atlantic League champion Somerset Patriots, Tourette Syndrome Awareness Day will include an official TS Awareness Day proclamation from New Jersey Gov. Chris Christie, as well as recognition of NJCTS scholarship winners, the Educator of the Year and the Healthcare Provider of the Year.

Tickets to TS Awareness Day are available now only through NJCTS for only \$10, with all proceeds going to help NJCTS continue to provide programs for the TS community. Group sales and corporate sponsorship opportunities also are available. To purchase tickets, please call 908-575-7350 or visit [www.njcts.org/ts-awareness-day-2012.php](http://www.njcts.org/ts-awareness-day-2012.php).



## THANK YOU FOR MAKING THE NJ WALKS FOR TS-MENDHAM A SUCCESS!

NEW JERSEY



WALKS FOR TS

Our second annual New Jersey Walks for TS event on Nov. 19 at Borough Park in Mendham was a rousing success. But it would not have happened without your support! So we want to thank you for taking part in the walk and working hard to raise funds that will benefit NJCTS and its many top-notch, one-of-a-kind programs and services.

Your participation and ongoing support are very much appreciated, and we look forward to our third annual Mendham Walk in November 2012 and hope that you and your family will join us.

## TEEN GIVES IN-SERVICE PRESENTATION TO STUDENTS

Emily Fleischman, 17, has been collaborating with NJCTS to give in-service presentations to elementary school students for the past two years. Her latest presentation was Dec. 15 at the Roosevelt School in River Edge.

The River Dell High School junior stressed in her presentation to about 140 fifth- and sixth-graders that bullying of anyone should not be tolerated and fielded nearly 20 questions about several different topics pertaining to Tourette Syndrome.

She had answers for queries such as "How old you were you when you first had Tourette Syndrome?" "Where did you get it from?" "How do you control it?" and "Have you been made fun of for it?" That last question enabled her to sum up her presentation in two succinct sentences: "We should never make fun of people because of their differences, especially when it's something that they cannot control. People with TS are just the same as all of you."

To schedule a faculty or peer in-service presentation at your school or for questions about the program, please call 908-575-7350.



## KOWALKSI FAMILY ENJOYS TIME WITH TIM HOWARD



While NJCTS and the TS community were taking part in the Mendham Walk on Nov. 19, the Kowalski family was "across the pond," enjoying time with Everton soccer goalkeeper Tim Howard, which they earned by winning the Team Up With Tim Howard raffle last June.

The Kowalskis traveled to Liverpool, England, to see Howard play for his English Premier League team, Everton, against Wolverhampton. Howard and Everton won 2-1, but it was what took place before and after the game that gave the Kowalskis their greatest thrill.

Howard had lunch with the Kowalskis, during which their oldest daughter, Tess, told Howard about her idea to bring a NJ Walks for TS event to the Princeton area this year. He was so inspired by Tess' courage that he got her a signed shirt from his team to raffle at the walk. Howard also talked about his tics and what it was like for him growing up with Tourette Syndrome.

For more on the Kowalskis' experience with Howard, visit the [www.njcts.org](http://www.njcts.org) Newsroom or our TSParentsOnline blog at [www.njcts.org/tsparents](http://www.njcts.org/tsparents).

## 2012 NJCTS CHILDREN'S SCHOLARSHIP

Each year, NJCTS awards scholarships to graduating New Jersey high school seniors with Tourette Syndrome. This year's submission deadline is April 5, and all applicants must complete an application -- available by visiting [www.njcts.org/2012-scholarship](http://www.njcts.org/2012-scholarship) -- and meet the following criteria: be a New Jersey citizen, be planning to attend a college or trade School on a part- or full-time basis, provide a record of high school grades to date and submit an essay of 1-2 pages describing how Tourette Syndrome has played a part in your life.

## 2012 EDUCATOR AND HEALTHCARE PROVIDERS OF THE YEAR

NJCTS is seeking nominations from its membership for its 2012 NJCTS Healthcare Professional and Educator of the Year awards. The awards were established to recognize a healthcare professional and an educator in New Jersey who have made a significant difference in the life of a child with Tourette Syndrome. For more information and an application, please visit [www.njcts.org/2012-nomination](http://www.njcts.org/2012-nomination). All nominations must be received by April 5.

## FAMILY RETREAT WEEKEND AT CAMP BERNIE 2012 – REGISTER NOW

Our annual family retreat at Camp Bernie will take place June 8-10, 2012, and registration is open now! We encourage you to get your family signed up for what always proves to be a fun-filled weekend. Registrations forms are available by visiting [www.njcts.org/2012-camp-bernie](http://www.njcts.org/2012-camp-bernie).

Right now, we still are in the planning stages and could use your help in making it even better. We need parent volunteers to run/supervise activities such as volleyball games and treasure hunts, and also are seeking a professional who can share his or her experiences with the campers. Can you help out? If so, give us a call at 908-575-7350 or tell us how you would like to volunteer on your registration form.

## 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:

01/23	Somerset/Hunterdon Counties – Somerset Medical Center, Somerville
02/02	Atlantic/Cape May Counties – Atlantic City Medical Center, Pomona
02/02	Morris/Sussex Counties – St. Clare's Hospital, Denville
02/28	Burlington/Camden Counties – Virtua Hospital, Marlton
03/13	Middlesex County – JFK Medical Center, Edison

For more information on each of these meetings, and to learn more about our new adult support group in the New Brunswick area, please refer to our calendar at [www.njcts.org](http://www.njcts.org). Also, we are looking for volunteers to be a coordinator for other regional hospital-based support groups. If you are interested, please call 908-575-7350.

## WEDNESDAY WEBINARS LOOK AT EMOTION AND OCD

01/25 Julie Ryan, Ph.D., presents "Emotion Regulation: How to Help Your Child Understand Their Emotions and Reduce the Tantrums" <https://www1.gotomeeting.com/register/243487104>.

02/29 Allen H. Weg, Ed.D., presents "The Bee Trap" Storytelling as a therapeutic modality in the understanding and treatment of OCD <https://www1.gotomeeting.com/register/903521392>.

## YOUR CONTRIBUTIONS MAKE A WORLD OF DIFFERENCE

Many corporations and individuals designate funds for nonprofit organizations such as NJCTS for their giving campaigns. Please consider designating NJCTS as the recipient of your contributions. There are many different ways to donate to NJCTS, including monthly to the program or activity of your choice on [www.njcts.org](http://www.njcts.org) via PayPal. You also may make a gift to NJCTS in honor of someone special. Donating online to NJCTS is fast, easy and secure, and giving to NJCTS is the only way to ensure your money will stay in New Jersey helping New Jersey families.

Unilever, Schering-Plough, AT & T, Prudential, Aetna, Chevron

*A fun filled weekend for TS kids and their families*

# TS Family Retreat at Camp Bernie

## June 8-10, 2012

This is a fun weekend for the whole family. Come join us for our Family Retreat at Camp Bernie. **The deadline for registration is May 11, 2012.**

- Do you want to meet other families who "get it"?
- Do you think your TS child would enjoy making friends that already understand what they are going through?
- Talent show Saturday night. Bring your props.
- Friday night campfire. Smores and glow paraphernalia
- Archery
- Canoeing Crafts & much more

If you've never been to an NJCTS Family Retreat, visit our homepage ([www.njcts.org](http://www.njcts.org)), select "For Families" and choose "Family Retreats" to view a short video of what our retreat program has to offer. YMCA Camp Bernie is located in scenic Hunterdon County and has been the site of our retreats for six years.

Through a grant from the Hoop-A-Paluzza, Inc., we can offset much of the cost of camp but we are asking for a donation of \$100 for a family of 4 or less, \$125 for families of 5 or 6 and \$150 for families with more than 6 people. (If the cost of attending is prohibitive to you, please call the NJCTS office at 908-575-7350.)

**Don't chance forgetting. Register now! Deadline May 11, 2012**

**Yes, our family will be attending the TS Family Retreat at Camp Bernie**

Family Name: \_\_\_\_\_ Phone #: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

E-mail: \_\_\_\_\_

Total number of campers: \_\_\_\_\_ Vegetarian meals needed? Y \_\_\_\_\_ N \_\_\_\_\_ Donation Enclosed: \_\_\_\_\_

Campers Names: \_\_\_\_\_

*(Please include the ages of all minors)*

T-shirts: Youth size: \_\_\_\_\_ Small \_\_\_\_\_ Medium \_\_\_\_\_ Large  
(indicate quantity) Adult Size: \_\_\_\_\_ Small \_\_\_\_\_ Medium \_\_\_\_\_ Large \_\_\_\_\_ XL \_\_\_\_\_ XXL \_\_\_\_\_ 3X

I'd like to help with: \_\_\_\_\_

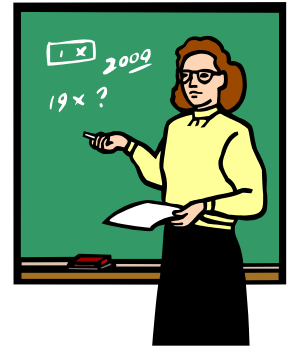
*(Examples: Pre-event planning, crafts, talent show, signs/posters, registration, t-shirt distribution, campfire, etc.)*

\_\_\_\_\_ Count me in for "Cabin Mom/Dad" responsibilities include emergency contact coordination and post-camp cabin cleanout.

**Return this registration form by Wednesday May 11, 2012 to NJCTS, 50 Division Street, Suite 205, Somerville, NJ, 08876. For additional information, call 908-575-7350 or e-mail [info@NJCTS.org](mailto:info@NJCTS.org).**



**2012**  
**HEALTHCARE PROFESSIONAL OF THE YEAR**  
**OR**  
**EDUCATOR OF THE YEAR**  
**NOMINATION FORM**



The New Jersey Center for Tourette Syndrome & Associated Disorders (NJCTS) is seeking nominations from its membership for its 2012 NJCTS Healthcare Professional and Educator of the Year Awards. The awards will go to a healthcare professional and to an educator in New Jersey who has made a significant difference in the life of a child with Tourette Syndrome.

**Please check appropriate box.**

**Health Care Professional**

If you wish to nominate a doctor, nurse, psychologist or other healthcare professional, please use the form below and return it to NJCTS, 50 Division Street, Suite 205, Somerville, NJ 08876. Also, please attach a statement of 500 words or less, explaining why you believe this person should be honored as NJCTS' 2012 Healthcare Professional of the Year.

**Education Professional**

If you wish to nominate a teacher, guidance counselor or other education professional in the school your child attends, please use the form below and return it to NJCTS, 50 Division Street, Suite 205, Somerville, NJ 08876. Also please attach a statement of 500 words or less, explaining why you believe this person should be honored as NJCTS' 2012 Educator of the Year.

Your Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_

Child's Name: \_\_\_\_\_ Age: \_\_\_\_\_ Grade: \_\_\_\_\_

Nominee's Name: \_\_\_\_\_

Nominee's Address: \_\_\_\_\_

School Name (if applicable) \_\_\_\_\_

School Address: (if applicable) \_\_\_\_\_

All nomination forms must be received at the NJCTS office by **April 5, 2012**:

NJCTS, 50 Division Street, Suite 205, Somerville, NJ 08876.

If you need an additional nomination form please go to [www.njcts.org/2012-nomination](http://www.njcts.org/2012-nomination).



New Jersey Center for Tourette Syndrome

AND ASSOCIATED DISORDERS, INC.

50 Division Street Suite 205 Somerville, NJ 08876

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*Collaborative Partnerships for the Tourette Syndrome Community*

908-575-7350 [www.njcts.org](http://www.njcts.org)

## NEWS YOU CAN USE

NJCTS has been in the news a lot lately. Here are a few of the most prominent links that have made their way to the Internet:

The NJCTS Genetics Sharing Repository at Rutgers University is now the National Institute of Mental Health NJCTS Genetics Sharing Repository. <http://www.njspotlight.com/stories/12/0105/0113/>

New Jersey Congressman Albio Sires (D-NJ13) has introduced federal Tourette Syndrome legislation that would help establish more centers for excellence such as NJCTS.

<http://njtoday.net/2012/01/04/nj-congressman-introduces-legislation-for-tourette-syndrome/>

Teenagers from New Jersey, across the nation and around the world are helping others understand more about TS thanks to NJCTS' Teens4TS blog. <http://www.radicalparenting.com/2012/01/05/teens-helping-people-learn-about-tourette-syndrome/>