



NJCTS

IN REVIEW

**NJCTS CHANGING**  
**LIVES**  
**2012**

**Collaborative partnerships for the Tourette Syndrome community**

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## Mission Statement

The New Jersey Center for Tourette Syndrome & Associated Disorders, Inc. is a not-for-profit organization committed to the advocacy of children and families with Tourette Syndrome and its associated disorders. Dedicated to delivering high-quality services to these individuals, the Center recognizes the importance of educating the public, medical professionals and teachers about this disorder through programs and affiliations with public schools, health centers and universities. To ensure that individuals with Tourette Syndrome are contributing members of their communities and society at large, the Center is committed to leading the promotion and development of diagnostic and treatment therapies, and actively supporting research for a cure.

### WHAT IS TOURETTE SYNDROME?

Tourette Syndrome (TS) is an inherited neurobiological spectrum disorder characterized by the childhood onset of uncontrollable vocal and physical tics. It's estimated that about 1 in 100 children and adults exhibit symptoms of TS. Kids and families with TS frequently report feelings of isolation from being ostracized or bullied.

Tics can include head jerking, eye blinking, facial grimaces, jumping, spinning, sniffing, throat clearing, squealing, barking and more.

Vocal tics can also include echolalia involuntary repetition of what someone else has just said, the involuntary repetition of one's own words and the most infamous and problematic vocal tic: coprolalia, which is the involuntary utterance of curse words, ethnic or racial slurs. This symptom is present in only 5 percent of cases. Here are some other facts about TS:

- Appears when a child is 6 or 7 years old
- Affects all ethnic groups
- Boys are affected 3 – 4 times more often than girls
- Lifelong condition – course unknown – no cure
- No standard treatment protocol
- Average time from onset to diagnosis is still 7 years
- Psychological, social, educational, physical impact
- Associated Disorders: Attention Deficit Disorder, Obsessive Compulsive Disorder, learning disabilities, panic attacks, depression, generalized anxiety disorder, sleep disorders
- Under-represented in medical texts
- Misunderstood by the public and professionals
- Underdiagnosed by the medical community
- Misrepresented by the media
- Misunderstood by educators

“TS has a complex, often subtle range of manifestations that cut across professional disciplines, affecting mental health and social functioning (anxiety, depression, OCD), learning and school adaptation (vulnerability to ADHD, learning difficulties, stigmatization) and motor coordination as well as neurological functioning. Treatment and educational planning involves special expertise and resources, often unavailable even in good primary care medical and mental health settings, to coordinate behavioral and family interventions, educational assessment and planning, school consultation and advocacy and to provide consultation to clinicians, parents and educators, as well as more traditional services such as pharmacotherapy and long-term case management.”

~DR. ROBERT KING,  
YALE CHILD STUDY CENTER, YALE TS/  
OCD CLINIC

# Legislative Outreach

## Awareness grows across New Jersey and nationally for federal TS bill

One of the most important events to happen to the TS community in the past 40 years took place in 2011: Federal legislation for Tourette Syndrome was introduced by U.S. Congressman Albio Sires (D-NJ8). Titled the Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2011 with bill number H.R. 3760, the legislation was reintroduced to the new Congress in early 2013.

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

disorders such as OCD, ADHD, anxiety and depression. If passed, this legislation could change the way TS is viewed, researched, advocated and much more. It would amend the Public Health Service Act to provide for the expansion, intensification and coordination of the programs and activities of the National Institutes of Health (NIH) with respect to Tourette Syndrome.

In 2012, this bill – originally introduced in the House of Representatives – also was introduced as Senate companion bill S. 2321 by New Jersey Senator Robert Menendez with the following statement: “This legislation builds on current NIH activities on Tourette Syndrome in two important ways. First,

the bill expands and intensifies data collection on TS to improve information on the prevalence of the disease. Secondly, the bill establishes Centers of Excellence to undertake extensive research into the causes, treatments, diagnosis and preventions of TS. This legislation is necessary for those suffering from TS and those looking for a cure. I am proud to ally with the New Jersey Center for Tourette Syndrome & Associated Disorders on this important issue.”

NJCTS, the nation’s first center of excellence for TS, was established in 2004. New Jersey now leads the nation in supporting the needs of children and families dealing with TS, an often misunderstood and misdiagnosed

inherited neurological disorder characterized by repeated involuntary movements and uncontrollable vocal sounds called tics.

“New Jersey has changed the face of TS research, education and support through partnerships and collaborations,” NJCTS Executive Director Faith W. Rice said. “We are pleased that Senator Menendez and Congressman Sires helped take this important legislation to the next level by introducing it to the Senate and the House of Representatives and advocating on behalf of the 1 in 100 children nationwide who show symptoms of Tourette Syndrome.”



From left, Leslie and Tim Kowalski, and their daughters Paige and Tess, joined Congressman Rush Holt (D-NJ12), Amanda and Barbara Silvers, and NJCTS Executive Director Faith Rice for a meeting at Congressman Holt’s West Windsor office in April to encourage him to sign on as a co-sponsor for the federal TS legislation.



Dr. Jay A. Tischfield, the director of the Human Genetics Institute at Rutgers University, and NJCTS Executive Director Faith Rice met with Congressman Frank Pallone Jr. (D-NJ6) to talk about federal TS legislation.



Marc and David Brummer met with Senator Frank Lautenberg in July to call to the Senator’s attention the importance of having federal TS legislation.

# Legislative Outreach

“This is legislation worthy of support, and I am proud to be a co-sponsor. With more data collection and better coordination of Tourette Syndrome programs and activities at NIH, we can help enhance the lives of so many people.”

~ CONGRESSMAN *RODNEY FRELINGHUYSEN*

NJCTS, along with several of its member families and Board of Directors, met with a majority of New Jersey’s Congressional Representatives and U.S. Senators in 2012 to discuss the federal TS legislation introduced by Congressman Albio Sires (D-NJ8):

## APRIL

- Representative Rush Holt (D-NJ12), with the Kowalski and Silvers families at the Congressman’s West Windsor office
- Senator Robert Menendez, with NJCTS Executive Director Faith W. Rice at the National Resource Center for Hispanic Mental Health Awards Gala in Newark

## MAY

- Representative Leonard Lance (R-NJ7), with about 20 Somerset County families in a roundtable discussion at the Somerville Public Library

## JUNE

- Representative Frank Pallone Jr. (D-NJ6), with Dr. Jay A. Tischfield of Rutgers University at the Congressman’s New Brunswick office
- Representative Rodney Frelinghuysen (R-NJ11), with the Stanley family and NJCTS Board President Tim Omaggio at the Congressman’s Morristown office

## AUGUST

- Representative Jon Runyan (R-NJ3), with the Baldwin family at the Congressman’s Mount Laurel office
- Senator Frank Lautenberg, with the Brummer and Roncati families at the Senator’s office in Newark

## NOVEMBER

- Representative Frank LoBiondo (R-NJ2), with the Baldwin family at the Congressman’s Mays Landing office



*From left, NJCTS Board President Tim Omaggio, Jerome Stanley, T.J. Stanley, Congressman Rodney Frelinghuysen (R-NJ11), NJCTS Executive Director Faith Rice and Lee Stanley met at Congressman Frelinghuysen’s office in June to discuss the federal TS legislation.*



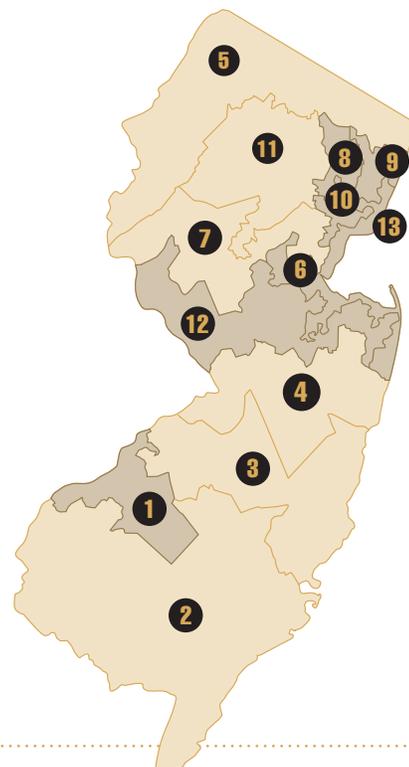
*The Baldwin family (Scott and Carolyn, along with their son, Eric, and daughters, Anna and Sara) joined NJCTS Executive Director Faith Rice for a November meeting with Congressman Frank LoBiondo (R-NJ2) at his office in Mays Landing to talk about how federal TS legislation can benefit the 1 in 100 children and adults with TS.*

# Legislative Outreach

## NJCTS FAMILIES SPEAK OUT

One in 100 New Jersey children are affected by Tourette Syndrome. Their families are seeking differences that can be made in their children's lives. The Collaborative Academic Research Efforts for Tourette Syndrome Act (bill H.R. 3760) was introduced to do just that. It seeks to amend the Public Health Service Act to provide for the expansion, intensification, and coordination of the programs and activities of the National Institutes of Health with respect to Tourette syndrome. H.R. 3760 was not passed into law, but it has been reintroduced as H.R. 146 in 2013. The following comments by NJCTS families to their Congressional Representatives via the legislative website POPVOX helped in getting the bill reintroduced:

- 1 From New Jersey's 1st District (Rep. Robert Andrews):** "My son has TS and daily life for him, which we take for granted, is a struggle. A bill like this will bring into his life access to things that are not within his grasp right now. It is a very frustrating road I walk in trying to get the required help for my child, as all I hear mostly is 'You don't qualify for this or that because you are not citizens or haven't worked long enough.' So I support any bill that would make my son's life richer and better."
- 2 From New Jersey's 2nd District (Rep. Frank LoBiondo):** "I have three children with Tourette Syndrome. Their ages are 13, 12 and 9. My children face many obstacles every day because of their Tourette Syndrome. We are constantly making modifications to their 504 plans in school and seeking out the best medical treatments. The New Jersey Center for Tourette Syndrome has been a huge help, but there is still an incredible need for continued research and education."
- 3 From New Jersey's 3rd District (Rep. Jon Runyan):** "I have been involved in TS research for years and the support of our legislators is what we need to get to the next level. There are more people in the nation that suffer from TS than anyone thinks. This research can help all of those that have TS."
- 4 From New Jersey's 4th District (Rep. Chris Smith):** "My son has Tourette Syndrome and it has taken a toll on him and our family every day for the last 11 years. I do feel that this disease crosses over to many other psychiatric illnesses and getting control of this disorder could help many others with OCD, ADD, ADHD, Generalized Anxiety Disorder and Depression. Please, I cannot urge Congress strongly enough to help my son and the many like him who suffer daily."
- 7 From New Jersey's 7th District (Rep. Leonard Lance):** "In my own family and in my professional practice as a psychotherapist, the devastating effects of this condition that is still misunderstood and mishandled in the schools and community at large."
- 8 From New Jersey's 8th District (Rep. Albio Sires):** "Congress, your total support of H.R. 3760 is so important to my grandson, who suffers from Tourette Syndrome. Our academic community needs to become educated about this disorder in order for these individuals to get the special attention that is needed to teach them and the awareness their classmates need to live in harmony."
- 11 From New Jersey's 11th District (Rep. Rodney Frelinghuysen):** "I have a 12-year-old daughter who was diagnosed at the age of 10 and who struggles every day. Those who have only heard of Tourette Syndrome do not understand the disorder itself and usually when it is brought up, it is used in a joking manner. This is due in big part to the lack of education and understanding of the disorder. More research is needed to identify the causes and help in the controlling the symptoms."
- 12 From New Jersey's 12th District (Rep. Rush Holt):** "I watch my bright and beautiful daughter struggle with tics and the co-morbid disorders of Tourette Syndrome each and every day. This condition has a severe impact on the person with the disability as well as the entire family unit. Individuals not familiar with this medical condition have no idea of life with Tourette Syndrome or its impact on daily life for the individual or their family. It can have an impact on social relationships, educational opportunities and a huge economic impact."



# Educational Outreach

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## TS clinic at Rutgers University continues to grow

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**T**ourette Syndrome Clinic at Rutgers University is a collaboration between NJCTS and the Graduate School of Applied and Professional Psychology (GSAPP). Facilitated by clinical director Dr. Lori Rockmore, Psy.D and augmented by Drs. Stanley Messer, Shawn Ewbank and Lewis Gantwerk, the clinic is the nation's only standalone university-based student clinician program for individuals and families with TS. The program facilitates a TS practicum for doctoral-level students, who are trained in assessment and diagnostic techniques; understanding, diagnosis and management of TS and co-morbid disorders; Cognitive Behavioral Therapy (CBT) for TS and co-morbid conditions; and manualized approaches to CBT.

Clinical services include assessment; individual psychotherapy, which is administered by Dr. Ewbank and the doctoral students under Dr. Rockmore's direct supervision; parent skills training; group psychotherapy; and neuropsychological assessment and cognitive remediation. Research activities include creating a de-identified database for use in future research projects at GSAPP and for other institutions looking to do research in the area of TS, as well as "Comprehensive Behavioral Intervention for Tics: A Study on Efficacy in a Clinical Care Setting."

In 2012, several TS practicum students screened families at NJCTS' annual Family Retreat Weekend at YMCA Camp Bernie for participation in research. They also gave talks about the importance of social skills and how TS can affect not only the individuals who have it, but also the families and friends surrounding them (pictured below).



Shawn Ewbank  
*TS Clinic Assistant  
Supervisor*



Lewis Gantwerk  
*Executive Director Center  
for Applied Psychology  
(retired April 2012)*



Stanley Messer  
*Dean of Rutgers GSAPP*



Lori Rockmore  
*TS Clinic Supervisor*



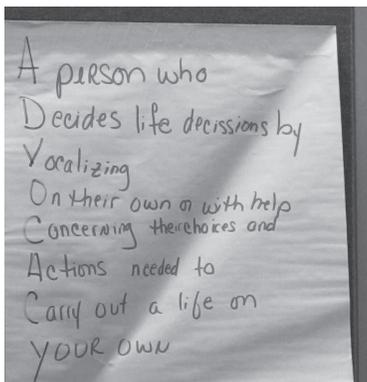
# Educational Outreach

## Dare To Dream Student Leadership Conference, May 21 at Rutgers University

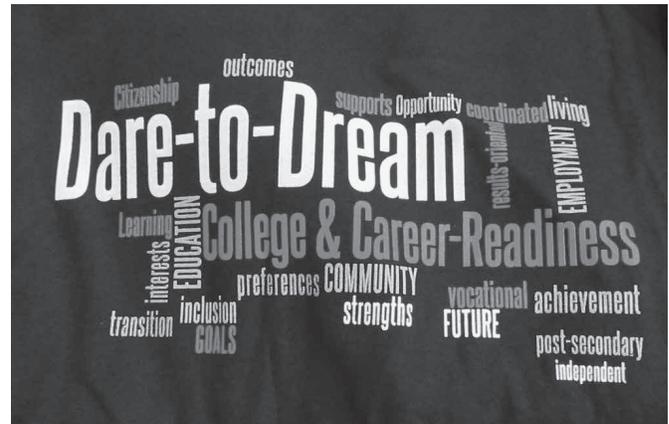
Statewide education outreach is one of NJCTS' primary goals in terms of helping families affected by TS. The Center's Education Outreach Program took a giant leap forward in 2012 by partnering with the New Jersey Office of Special Education to host the first Dare To Dream Student Leadership Conference for New Jersey high school students living with neurological conditions such as Tourette Syndrome, OCD, ADHD, Asperger's Syndrome and other associated disorders.

This unique opportunity, which took place May 21 at Rutgers University's Busch Campus Center, was centered on students in transition and focused on the importance of student self-advocacy and leadership while featuring presentations from students and young adults with neurological disorders who have those life-essential skills. Through a variety of concurrent breakout sessions, the several hundred attendees gained valuable insight into the transition process from student to adult. There also were peer-led workshops on goal-setting, self-discovery and planning for the future. Joining the many students in attendance was a host of teachers and special educators.

The conference's keynote speaker was Sue Conners, a noted Tourette Syndrome author and presenter whose primary message was that there isn't anything out there that should stop a student affected by neurological disorders – that each one has the necessary intensity, intelligence and desire to fulfill their dreams and overcome all adversity. Also taking the podium were Montclair State University sophomore Katie Delaney, who spoke about "Voice of Experience;" "The Junction," a small group of special-needs students who performed a variety of musical and artistic numbers; 14-year-old South Plainfield student and NJCTS Peer Advocate Tommy Licato, who noted that "different is the new normal"; and East Brunswick High School senior Amanda Silvers, who relayed her success in discussing TS with medical and education professionals around the state, as well as fellow students.



*Advocacy was a big theme at the Dare To Dream Conference, and students learned how to better self-advocate at one of the breakout sessions.*



*This was the design for the T-shirts*



*NJCTS Peer Youth Advocates Tommy Licato, left, Sarah Ethridge and Amanda Silvers, right, join NJCTS Education Outreach Coordinator Melissa Fowler at the Dare To Dream Conference*

**"I can do anything I want to, and you can do anything you want to. It's the power of positive thinking."**

*~NORTHERN VALLEY REGIONAL HIGH SCHOOL  
STUDENT RICHARD LIZZI*

# Educational Outreach



*Soccer superstar Tim Howard, who hails from North Brunswick, N.J., delivered the opening message at the Dare To Dream Student Leadership Conference*



*Members of "The Junction," a small school of special-needs students, perform a song during the Dare To Dream Conference.*

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**"We could not be more pleased with the turnout for this Dare To Dream Conference. Each of the students in attendance learned some valuable life lessons, the most important of which being that no matter what condition they might have, they have the tools necessary to succeed in life."**

*~NJCTS EDUCATION OUTREACH CONSULTANT MELISSA FOWLER*

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*Steven Lindenbaum, an NJCTS volunteer and 23-year-old teaching assistant, helped many students maximize their experience at the Dare To Dream Conference.*



*Students from "The Junction" group had a great time expressing their talents at the Dare to Dream Conference.*

# Educational Outreach

## Educator In-Service Program

**N**JCTS offers on-site in-service programs for educators, guidance counselors, child study teams, administrators and support staff. These sessions are designed to inform and enlighten professionals about TS and co-occurring disorders such as OCD, ADHD, learning disabilities, depression, anxiety and the impact they can have on a child's school performance. The workshops also provide educators with specific classroom strategies and accommodations that can have a positive impact on a student's academic success. Our presenters are teachers, school nurses or other professionals with education or medical backgrounds. Most presenters have first-hand knowledge of TS.

Schools from all over the state continued to ask for educator in-services to be presented at their school in 2012, and NJCTS once again rose to the occasion. Educator in-service presentations are set up by our Education Outreach Coordinator, Melissa Fowler, MA, M.Ed. Melissa has amplified our program content, developed new initiatives within the education community to reach students with TS and associated disorders, and expanded NJCTS' reach to schools in all corners of the state. The 2012 in-service presentations took place at 20 different locations – including multiple presentations at several locations – throughout the year and were facilitated by Joelle Beecher-McGovern, Ph.D.; Ann L. Deutsch, MSN; Mariann Fimbel; Melissa Fowler, MA, M.Ed.; Janine Howley, MA; Tracy Lederman; Cheryl Ludwig, MA, CCC-SLP; Dr. Richard Zakreski, Psy.D.; and Robert Zambrano, Psy.D.



*Joelle Beecher-McGovern, Ph.D.*



*Ann L. Deutsch*



*Melissa Fowler*



*Bob Happich*



*Janine Howley*



*Tracy Lederman*



*Cheryl Ludwig*



*Richard Zakreski*



*Robert Zambrano*

### PARTICIPATING SCHOOLS IN 2012

**HAMILTON ELEMENTARY SCHOOL** – Bridgewater  
**WASHINGTON ELEMENTARY SCHOOL** – Turnersville  
**TERRILL MIDDLE SCHOOL** – Scotch Plains  
**RIVER PLAZA ELEMENTARY SCHOOL** – Red Bank  
**EAST BRUNSWICK HIGH SCHOOL** – East Brunswick  
**QUEEN CITY ACADEMY CHARTER SCHOOL** – Plainfield  
**CHATHAM HIGH SCHOOL** – Chatham  
**HOWELL MIDDLE SCHOOL** – Howell  
**THOMAS JEFFERSON SCHOOL** – Turnersville  
**LAFAYETTE SCHOOL** – Chatham  
**INDIAN HILL SCHOOL** – Holmdel  
**READINGTON MIDDLE SCHOOL** – Readington  
**LOPATCONG MIDDLE SCHOOL** – Lopatcong  
**MONTGOMERY UPPER MIDDLE SCHOOL** – Montgomery  
**WHITMAN ELEMENTARY SCHOOL** – Turnersville  
**HAWKSWOOD ELEMENTARY SCHOOL** – Eatontown  
**MEMORIAL MIDDLE SCHOOL** – Fair Lawn  
**KNOLLWOOD SCHOOL** – Fair Haven  
**ECLC OF NEW JERSEY** – Chatham  
**WARREN MIDDLE SCHOOL** – Warren

# Educational Outreach

## Peer In-Service Program

Since NJCTS' inception, peer in-service presentations have been sensitive to the social needs of all students with challenges or disabilities. We have built our program on the foundations of empathy and fair treatment to break the stigma and bullying often attached to TS and its associated disorders. NJCTS, a longtime member of the New Jersey Anti-Bullying Coalition, incorporates our tried and true message of acceptance and advocacy for one's self and others into everything we do.

To that end, NJCTS offers on-site, age-appropriate peer in-service to present information about TS to classmates of an individual TS student, or to the general student population. This workshop is presented by a trained professional who leads student attendees in several activities designed to broaden their knowledge and understanding of TS. Prior to the presentation, parents of the student with TS are consulted about how the information will be presented to their child's classmates. At the request of the student's parents, our presenter will discuss the workshop directly with the TS student and answer any questions he/she may have about the workshop content. Our presenters are teachers, school nurses or have a medical background, and most have first-hand knowledge of TS.

### PARTICIPATING DISTRICTS IN 2012

**HOLMDEL SCHOOL DISTRICT** – presented by Dr. Robert Zambrano, Psy.D

**TURNERSVILLE SCHOOL DISTRICT** – presented by Tracy Lederman

**HOWELL SCHOOL DISTRICT** – presented by Dr. Robert Zambrano, Psy.D

**MONTGOMERY SCHOOL DISTRICT** – presented by Mariann Fimbel

**FAIR HAVEN SCHOOL DISTRICT** – presented by Joelle Beecher-McGovern, Ph.D.

**FAIR LAWN SCHOOL DISTRICT** – presented by Melissa Fowler, MA, M.Ed.

## Lecture Series

In 2012, NJCTS introduced a Lecture Series at which trained professionals – many of whom have presented Educator and Peer In-Services – discuss Tourette Syndrome and its associated disorders with faculty and students at colleges and universities around New Jersey, as well as other educational venues. The program received a warm welcome in 2012, with presentations taking place at the following venues:

- Kean University in Union
- Ocean County College in Toms River
- New Jersey Council for Exceptional Children in Trenton
- Rutgers University in Piscataway
- Raritan Valley Community College in Branchburg
- Graduate School of Applied and Professional Psychology in Piscataway
- Montclair State University in Montclair
- Monmouth University in West Long Branch

## Conferences

Each year, NJCTS takes part in myriad education conferences throughout the state – at which thousands of teachers and other school support staff receive materials and are exposed to information about Tourette Syndrome and its associated disorders. The biggest school conference of the year, the New Jersey Educators Association Conference in Atlantic City, was canceled by Hurricane Sandy, but NJCTS was present at the following conferences in 2012:

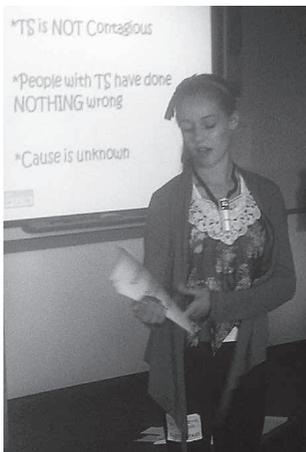
- School Nurses Convention in New Brunswick
- ARC of Ocean County in Lakewood
- ARC of Camden County in Camden
- School Health Conference in Somerset
- Somerset County Disabilities Expo in Somerville
- NASW Conference in Atlantic City
- Latino Psychological Association Conference in New Brunswick

# Educational Outreach

## Youth Advocate Program

In 2012, NJCTS renamed its student-led in-service program as the Youth Advocate Program, which equips teenagers to provide information about Tourette Syndrome and the co-morbid disorders to classmates of an individual TS student or to the general student population. These presentations foster understanding, sensitivity and tolerance of TS and its symptoms by describing the symptoms, causes and effects of the disorder. In addition, these presentations work to displace the myths and stereotypes that are often attributed to TS and contain a strong anti-bullying message. Student presenters may or may not have TS or one of the co-morbid disorders themselves, though all have first-hand experience with one or most of these disorders. Student-led in-service presentations are appropriate for all age groups and are used in the school setting, for sports leagues, scout troops, camps, religious groups or after-school programs.

## SARAH ETHRIDGE



*2012 National Youth Ambassador Sarah Ethridge of Chatham gives a Youth Advocate Presentation to faculty members at Lafayette Elementary School in her hometown.*

NJCTS' most prolific Youth Advocate presenter in 2012 was National Youth Ambassador Sarah Ethridge, a student at Chatham High School. Ethridge was on a mission, delivering

PowerPoint presentations to students and/or faculty at Chatham Middle School, Lafayette Elementary School, Warren Middle School, New Providence Middle School, Deerfield Middle School and Chatham High School. All told, Ethridge spoke to more than 1,000 individuals through the Youth Advocate Program in 2012.

While her message to the many students to whom she spoke reflected her own path – learning more about TS so that she could become confident in telling others about it – the information for teachers, several of whom had taught her at one point, was more direct: “Be understanding. Talk to your students. Spread the word to other teachers and students so that everyone has an understanding of what Tourette Syndrome is and what

it isn’t.” Each time, the faculty in attendance responded – almost in unison – with an attitude of “this is something we need to do in order to better serve our special needs students.”

Jim Donough, a fifth-grade teacher at Lafayette Elementary School in Chatham, was adamant in his belief of how education professionals should respond when faced with having a student with Tourette or an associated disorder in their classroom: “Sarah’s presentation reminded me of the constant need to be aware, be sensitive and have that dialogue – with parents and with our students,” he said. “I don’t think we have (anyone with Tourette right now), but if we do, we will be prepared to be sensitive and have a dialogue with the student and the parents.”

Also presenting as Youth Advocates in 2012 were:

Tess Kowalski  
of Plainsboro

Tommy Licato  
of South Plainfield

Amanda Silvers  
of East Brunswick

Emily Fleischman  
of Fort Lee

One of Licato’s presentations, at Grant School in South Plainfield, led to a fellow student boldly stepping out to talk about his own battle with TS – a first for the Youth Advocate Program.

“Be understanding. Talk to your students. Spread the word to other teachers and students so that everyone has an understanding of what Tourette Syndrome is and what it isn’t.”

# Educational Outreach

## NJCTS Children's Scholarship Award

Each year, NJCTS awards scholarships to graduating New Jersey high school seniors with Tourette Syndrome with the Children's Scholarship Award. All applicants must complete an application 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 to 2 pages describing how TS has played a part in your life. Since 2003, NJCTS has awarded more than 200 scholarships to graduating high school seniors.

Meet the 2012 scholarship winners, who were selected for academic achievement, community involvement and accomplishments as an individual with Tourette Syndrome:

### FIRST-PLACE WINNER:

**Richard J. Schorr-Coben**, a graduate of East Brunswick High School

### SECOND-PLACE WINNER:

**Thomas J. Stanley**, a graduate of Ridge High School

### HONORABLE MENTION WINNERS:

**Melissa F. Chayt**, a graduate of Pascack Valley High School

**Michael R. Ehrhardt**, a graduate of North Brunswick High School

**Sean A. Fahey**, a graduate of Randolph High School

**Joseph P. Flanagan**, a graduate of Seton Hall Preparatory School

**Mallory A. Greenberg**, a graduate of Collier High School

**Harrison D. Kaminsky**, a graduate of Randolph High School

**Brian D. Krakower**, a graduate of Fair Lawn High School

**Troy W. Kurilew**, a graduate of South Plainfield High School

**Jesse J. Magliulo**, a graduate of Old Bridge High School

**Katherine M. Muentener**, a graduate of Voorhees High School

**Lucas J. Paige**, a graduate of Verona High School

**Cody C. Stoia**, a graduate of the Academy at Swift River in Massachusetts

## Educators of the Year

Since 2003, NJCTS has awarded 13 Educator of the Year awards – in some years, such as 2012, there has been more than one winner – to New Jersey teachers and support staff who have demonstrated exemplary work, patience and skill with students who have Tourette Syndrome.



*Grace Hawruk and Stacy Gottesman*

### **Stacey Gottesman, DePaul Catholic High School:**

When DePaul Catholic High School student Grace Hawruk missed a sizeable chunk of last year after having surgery, she fell behind in a lot of her classes. Spanish II wasn't one of them, however – thanks to Stacey Gottesman. Gottesman, who has been teaching Spanish at DePaul for the past 12 years, gave Hawruk a lot of support – visiting Hawruk

at home, helping Hawruk catch up on missed work, providing tutoring during the week and ensuring Hawruk would not feel lost and would be properly equipped to succeed at the highest level. She also made Hawruk feel comfortable in class, especially when Hawruk had to tic. Those accommodations helped Gottesman win a 2012 NJCTS Educator of the Year Award.



*Erin Miskell and Anita Riccardelli*

### **Anita Riccardelli, Good Shepherd Academy:**

Once a student progresses on to the next grade – especially in elementary school – whatever interaction that student had with his or her teacher usually ends. But when Erin Miskell graduated from Anita Riccardelli's first-grade class at the Good Shepherd Academy, it was not the last time she had contact with Riccardelli. And in Miskell's case, that's a very good thing. Riccardelli, known for doing whatever she can to help her students succeed, went above and beyond the call of duty – continuing to

aid Miskell's educational development throughout her second-grade year. For her exemplary service, Riccardelli was named a 2012 NJCTS Educator of the Year.

# Medical Outreach

## Patient-Centered Medical Education



*Tommy Licato has the ears of family practice resident physicians during a Patient-Centered Medical Education presentation at JFK Medical Center in Edison.*

**N**JCTS works with hospitals throughout New Jersey and the greater New York and Philadelphia areas to present grand rounds and workshop trainings for doctors, nurses and other health care providers. This program, which in 2012 was coined the Patient-Centered Medical Education program after a successful pilot run in 2010 and 2011, allows teenagers with Tourette Syndrome and their families to discuss TS and their experience with groups of family practice and pediatric resident physicians. In some cases, these presentations are done in tandem with a TS expert. These educational sessions consist of a one-hour conference in which one or two adolescents with TS, and their parents,

describe their experience with the condition at school, at home and in the community.

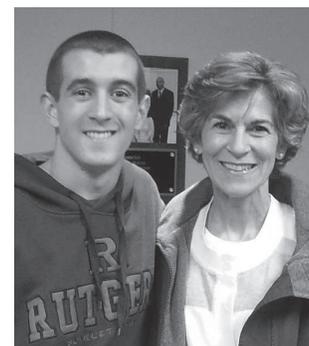
The presentations focus on the experience of initial diagnosis, on quality of life and on encounters with physicians and the health-care system. The goal of this project is to help physicians enhance their understanding of the perspectives, stresses and needs of patients with neurological disorders and their families and to improve interpersonal and communication skills in patient encounters. Many of these sessions are open to community professionals as well.

Presenting families in 2012 included the Cannizzaro, Kowalski, Licato, Hawruk, Friedrich, Silvers and Ethridge families. Our most prolific

presenter in 2012 was Tommy Licato, who spoke with Drew Friedrich at Goryeb Children's Hospital in Morristown and on his own at JFK Medical Center in Edison. Tommy's presentation at JFK went over particularly well: "I think the residents really enjoyed hearing directly from Tommy about his experience," said Dr. Anne Picciano, the Associate Director of the JFK Family Medicine Residency Program. "It's always very helpful to put a human (and especially such a young human) face on disorders the residents normally just read about. Tommy is a terrific ambassador! It's also good to know we have such a great resource in the NJCTS so close to home."

At Goryeb, the words of Licato and Friedrich helped the

pediatric residents learn about Tourette in a way a textbook and countless hours in medical school simply could not offer. According to Chief Pediatric Resident Shobhit Jain, the expectations of his staff not only were met in terms of learning objectives, they were exceeded – with medical students and residents asking numerous questions and receiving a host of new, valuable information. "Even with the prevalence of TS being so high, not many of us feel very comfortable diagnosing the children of this condition due to the vague manifestations that it can present with," he said. "I learned a whole new perspective of the condition, which cannot be described in written words in the books that we spend years reading."



*Michael and Elizabeth Cannizzaro teamed up to discuss Tourette Syndrome with family practice resident physicians in a Patient-Centered Medical Education presentation at CentraState Medical Center in Freehold.*

# Medical Outreach

NJCTS has facilitated Patient-Centered Medical Education sessions at the following New Jersey hospitals:

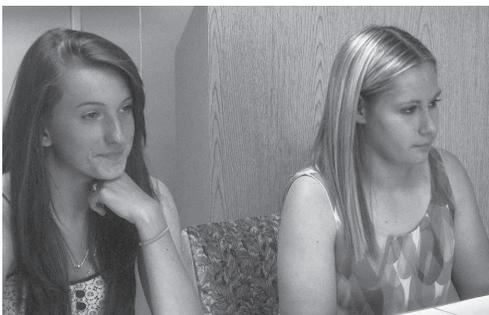
Bergen Regional Medical Center  
Bristol-Myers Squibb Children's Hospital  
CentraState Medical Center  
Children's Specialized Hospital  
Cooper University Hospital  
Goryeb Children's Hospital  
Jersey Shore Medical Center  
JFK Medical Center  
Kennedy Memorial Hospital  
Monmouth Medical Center  
Newark Beth Israel Medical Center  
New Jersey Medical School  
Overlook Medical Center  
Robert Wood Johnson University Hospital  
Saint Barnabas Medical Center  
Saint Clare's Hospital  
Saint Mary's-Hoboken University Medical Center  
Saint Peter's University Hospital  
Trinitas Hospital  
University of Medicine and Denistry of New Jersey  
Virtua Hospital



*Drew Friedrich and Sarah Ethridge address pediatric resident physicians at Goryeb Children's Hospital in Morristown during a Patient-Centered Medical Education presentation.*

“Our institution had an outstanding experience hosting a ‘family-centered’ Pediatric Grand Rounds on Tourette Syndrome, working with the New Jersey Center for Tourette Syndrome and Associated Disorders. 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 that you consider scheduling this type of ‘family-centered’ Grand Rounds on Tourette Syndrome at your institution.”

*~DR. BILL BERNSTEIN, PEDIATRIC GRAND ROUNDS ACTIVITY DIRECTOR AT THE CHILDREN'S HOSPITAL AT SAINT PETER'S UNIVERSITY HOSPITAL*



*Grace Hawruk and Amanda Silvers deliver a Patient-Centered Medical Education presentation at Jersey Shore Medical Center in Neptune.*

# Medical Outreach

## Symposiums & conferences

For the third straight year, NJCTS participated in an Atlantic Health Symposium at Overlook Medical Center in Summit. Dr. Stuart Green, associate director of the Overlook Family Medicine Residency Program who helped NJCTS develop its Patient-Centered Medical Education program in 2011, headlined the Center's participation in the event – discussing how medical professionals can empower their patients as experts, educators and advocates of their health care. Augmenting Dr. Green's presentation were NJCTS Advocate of the Year Marc Brummer and his wife, Suzanne Klar, who spoke about the many difficulties they faced while

trying to navigate the health-care system as parents of two sons with Tourette Syndrome. Their story – and the plight of many TS families – was best summed up by Dr. Green: “Most of the work in managing care needs to be done by patients when they are not in our facilities, and I believe that as professionals, our only chance of reaching the heights we aspire to reach lies in meeting the rising expectations of patients.”

TS families from South Jersey in November returned to the RIPA Center at Cooper University Hospital in Voorhees for a symposium featuring Dr. Martin Franklin, associate professor of Clinical Psychology and Clinical Director of the Center for the Treatment and Study



Dr. Stuart Green of Overlook Medical Center talks about Tourette Syndrome during an Atlantic Health Medical Symposium.

of Anxiety at the University of Pennsylvania School of Medicine, and Dr. Gary Heiman, Principal Investigator of the Tourette International Collaborative (TIC) Genetics Group at Rutgers University. Dr. Franklin spoke

about Habit Reversal Therapy and its use to manage tics, while Dr. Heiman discussed the importance of participating in the NJCTS Cell and DNA Sharing Repository at Rutgers University – particularly highlighting the work of Dr. Robert King, who comes to Rutgers University each month to interview families interested in taking part in the genetics sharing program.

NJCTS also took part in several statewide health fairs in 2012, including ones in Newton and Plainfield in August, as well as a Disabilities Awareness Night at the Newbury School in Howell as part of Tourette Syndrome Awareness Week. The Center also had a strong presence at the National Association of Social Workers Convention in Atlantic City, with hundreds of social workers gaining easy access to important information about TS.



These women help spread the word about Tourette Syndrome at the National Association of Social Workers Conference in Atlantic City.

# Medical Outreach/Family Support

## Physician Referral List (PRL)

The Physician Referral List (PRL) list is comprised of more than 200 neurologists, psychiatrists, psychologists, counselors and social workers who have expertise in treating Tourette Syndrome. The list, available through NJCTS Helpline, support group coordinators, school in-service presenters and office staff, is compiled from bi-annual interviews with clinicians and recommendations from our members as well as other clinicians.

Our referral is a direct link for families to medical professionals across the state who treat TS, ADHD, OCD, anxiety and depression. Our Physician Referral List is a critical aspect of our work at NJCTS, and we are constantly updating and developing it to provide the best, most up-to-date information on clinicians who have interest and expertise in TS and its co-occurring disorders.

The Physician Referral List also is used to inform doctors and other medical workers of scholarly articles related to TS, such as "Histidine Decarboxylase and Tourette Syndrome" in the New England Journal of Medicine and "NJCTS Sharing Repository: Methods and Sample Description" in BMC Medical Genomics. Here are samples of the topics we shared with the PRL in 2012:

- **Randomized trial of behavior therapy for adults with Tourette Syndrome**, Wilhelm et al., 2012, Archives of General Psychiatry
- **Clinical features of tic-related obsessive-compulsive disorder: results from a large multicenter study**, Gomes de Alvarenga et al., 2012, Cambridge University Press
- **Executive functions in uncomplicated Tourette Syndrome**, Eddy, Rickards, & Cavanna, 2012, Psychiatry Research
- **Smile and laughter induction and intraoperative predictors of response to deep brain stimulation for OCD**, Haq et al., 2011, Neuroimage
- **Clinical course of Tourette Syndrome**, Bloch & Leckman, 2009, Journal of Psychosomatic Research

For information on access to the Physician Referral List, e-mail us at: [info@njcts.org](mailto:info@njcts.org).

## SUPPORT GROUPS

NJCTS knows it's important for TS parents to get the chance to listen, learn and speak to each other about their experiences raising kids with Tourette and associated disorders, and that's why support groups are a long-standing part of what we offer. Support groups met at hospitals all around the state on a bi-monthly basis throughout 2012. If you didn't get the chance to check one out, consider joining one of the following groups in your area:

### **Somerset/Hunterdon Counties**

Somerset Medical Center, Somerville

### **Atlantic/Cape May Counties**

Atlantic City Medical Center, Pomona

### **Morris/Sussex Counties**

St. Clare's Hospital, Denville

### **Burlington/Camden Counties**

Virtua Hospital, Marlton

### **Middlesex County**

JFK Medical Center, Edison

*For more information:*

Call: 908-575-7350

E-mail: [info@njcts.org](mailto:info@njcts.org)

Visit our calendar: [www.njcts.org/calendar.php](http://www.njcts.org/calendar.php)

Visit our Facebook page: [www.facebook.com/TouretteSyndrome](http://www.facebook.com/TouretteSyndrome)

# HELPLINE 732-972-4459

When a family member is diagnosed with Tourette Syndrome, NJCTS provides a roadmap for services, support and clarity. One of the ways that is accomplished is through our helpline, which is manned by a dedicated group of volunteers and loyal staff. Calls are received at 732-972-4459 from doctors, teachers, newly diagnosed families and others needing information and support.

# Family Support

## 8th annual NJCTS Family Retreat Weekend – the best weekend of the year

A perfect mixture of fun, education and advocacy has been the name of the game for the past eight years during the annual NJCTS family retreat weekend at picturesque Hunterdon County's YMCA Camp Bernie in Port Murray. Children and teenagers with Tourette Syndrome and their families once again had plenty of reasons to flock to the June retreat – a host of exciting activities, the chance to meet other families who “get it” when it comes to Tourette, the opportunity to make new friends and time for listening to experts, therapists, support group leaders

and volunteers talk about various subjects pertaining to TS.

Representatives from the NJCTS Cell and DNA Sharing Repository at Rutgers University were on hand to screen families for participation in genetic research. Graduate students from the Rutgers Graduate School of Applied and Professional Psychology also gave several valuable talks about the importance of social skills and how TS can affect not only the individuals who have it, but also the families and friends surrounding them – a theme that numerous families in attendance echoed when asked about their camp experience.

“It’s just such a wonderful, supportive, relaxed environment for the children. They can be free to try things that they ordinarily wouldn’t do in an environment where they will not be judged or pressured,” said Allissa Letts, who attended with her husband, Eric, and 16-year-old son, David. “It gives us a chance to chat with other families who are experiencing the same challenges. We get to share how we’ve handled it and hear how they’ve handled it, and it’s just fantastic.”

The family retreat weekend would not have been possible without our wonderful volunteers and partners from Rutgers University, including:

William Benson  
Joe Connerty  
Alycia Davis  
Dr. Meir Flancbaum  
Harry Hubert  
Tess Kowalski  
Amy Kranzler  
Marilyn Lamarca  
Liz Lamarca  
Steven Lindenbaum  
Dominic Mocerri  
Anthony Restifo  
Kim Rice  
Mike Rice  
Juliet Robinson  
Jamyne Shelton-Pelosi  
Matt Sullivan  
Nawei Sun  
Donna Tischfield



The Perez family had a blast and drew closer together during the 2012 Family Retreat Weekend.

# Family Support



The “big swing” is one of the most popular activities among children and adults at the Family Retreat Weekend.



The rock climbing wall is a hit with the many teenagers who attend the Family Retreat Weekend.



Andy Friedrich had a host of kids playing volleyball with him throughout the weekend at Camp Bernie.



Allissa Letts and her daughter enjoy some quiet time paddling on Camp Bernie’s lake.



The archery range provided plenty of bonding time for families at the annual Camp Bernie retreat.

“We just love being around everyone. We call them our TS tribe. We have a lot of fun together as a family. We’ve progressed from all four of us being together all the time to the kids running off with the kids they knew from the year before. They have these connections with kids they might only see once a year. It’s a safe place where there’s a lot of freedom and a lot of closeness. We wouldn’t miss it.”

~ LESLIE KOWALSKI



The Bonaguide sisters couldn’t be separated during this past Family Retreat Weekend, even though there is quite a bit of separation between their ages.

# Family Support

## Wednesday Webinars

The Wednesday Webinar Series, which debuted in 2008, aims to bring the strength and information of world-class seminars electronically to families, educators and medical professionals in the disabilities and mental health communities. In 2012, NJCTS' webinars reached more than 2,300 people – 66 percent of whom were school or medical professionals – in 43 states, the District of Columbia and the countries of Canada, the Virgin Islands, Guatemala, Belgium and the Netherlands

The topics of interest included emotion regulation, dealing with Tourette Syndrome in the classroom, educational rights, texting and technology, eating and sleep disorders, and anxiety.

During these webinars, questions often are broached and subsequently answered concerning understanding behavior modification therapy, family coping strategies and techniques for success in school, peer relationships, in the workplace and in the community.

Presentations are delivered by practicing professionals including neurologists, psychiatrists, psychologists, nurses, teachers and attorneys. Viewers have the opportunity to ask questions during the presentation and have access to a web-based chat room where they can post additional questions to topic-speaker. Credits are offered to qualified professionals and all webinars are archived for continued viewing.



Dr. Hue-Sun Ahn



Dr. Lawrence W. Brown



Susan Connors



Dr. Michael M. Osit



Dr. Julie L. Ryan



Dr. Allan H. Weg



Dr. Michael C. Zarabi

### 2012 WEBINARS

JANUARY 25:

**Emotion Regulation:**

Strategies for Children and Adolescents Experiencing Irritability and Difficulties Managing Their Emotions

FEBRUARY 29:

**OCD in Children and Adolescents:** Guidelines for Parents and Educators

MARCH 28:

**Sleep and Developmental Disabilities:** Lessons for All Children

APRIL 11:

**Managing Tourette Syndrome in the Classroom**

APRIL 26:

**Anxiety and the Undergraduate:** Common Difficulties Due to Anxiety and How Post-Secondary Educators Can Help

MAY 23:

**Understanding Eating Disorders and How to Intervene**

JULY 18:

**Chronic Illness:** Psychological and Educational Impact

AUGUST 15:

**Educational Rights, Part 1** - Your Child's Educational Rights and Options

AUGUST 22:

**Educational Rights, Part 2** - Denial of Services and Discipline Issues

SEPTEMBER 19:

**Generation Text:** Raising Well-Adjusted Kids in an Age of Instant Everything

“Additional resources (like webinars) are helpful to remain current as educators. We are lifelong learners, and being aware of issues will help best meet the needs of students in my care due to the ever-changing society we live in. These webinars are a wonderful way to stay connected.”

~ PARTICIPANT IN THE “OCD IN CHILDREN AND ADOLESCENTS” WEBINAR

# Family Support

## Social Media and Blogs

In 2012, NJCTS' social media platforms took a gigantic step forward in terms of relevance, quality and quantity of information, availability to readers worldwide, and exposure. The biggest achievement was seeing the organization's website, [www.njcts.org](http://www.njcts.org) become mobile-friendly so that users of iPhone, Android and other widely used cellular and computer devices could access a litany of NJCTS content in an easy-to-read, professional fashion. NJCTS' primary social media platforms – website, blogs, Facebook and Twitter – were viewed by hundreds of thousands of people from every corner of the globe. Some of what they saw included:

### NJCTS.org [www.njcts.org](http://www.njcts.org)

 NJCTS' website features resources for families – help for kids in school, awards and scholarships, information about family retreats, a full calendar of activities and much more – as well as educational and medical professionals. A complete list of support groups, links to TS resources and a history of NJCTS are just a few of the other features of the website, which receives as many as 124,000 page hits each month from people all over the world. Visitors also can find multiple ways to contact NJCTS, obtain downloads of information, explore opportunities to donate and sign up for Wednesday Webinars, seminars, blogs, advocacy events and more. In 2012, NJCTS added a rotating “carousel” of important events, as well as a scrolling breaking news & events section for the latest news pertaining to the organization's efforts and outreach.

### Facebook [www.facebook.com/TouretteSyndrome](http://www.facebook.com/TouretteSyndrome)

 NJCTS' presence on the social media giant has increased over the past year, and its following has seen a subsequent bump – since the end of 2011, the page has more than doubled in its number of participants, views, likes, shares and comments. NJCTS' Facebook page features information about the organization, a calendar of events, photographs from important events such as the NJ Walks For TS program and Tourette Syndrome Awareness Month, and information from the local, national and international TS community. The page also hosts the TSParentsOnline blog.

### Twitter <http://twitter.com/NJCTS>

 NJCTS uses this social media platform to inform not only the TS community, but people from all walks of life all over the world, about its programs, services, events and accomplishments. Since the end of 2011, NJCTS' Twitter account has welcomed SIX times as many followers, as more and more people logged on to read streams of information from the NJ Walks For TS program, statewide education outreach and peer advocacy initiatives, access links to TS resources, repost TS tweets to their followers and more.

### BLOGS:

**TSParentsOnline** [www.njcts.org/tsparents](http://www.njcts.org/tsparents)

**Teens4TS** [www.njcts.org/teens4ts](http://www.njcts.org/teens4ts)



TSParentsOnline and Teens4TS are online communities for parents and teenagers affected by Tourette Syndrome from all over the world.



These blogs regularly feature touching stories, brilliant ideas, personal experiences, bright hopes and legitimate dreams of people who want nothing more than for someone else to identify with what they are going through. In 2012, the blogs received nearly 40,000 hits on its more than 500 posts from all over the United States and countries such as Canada, England, Germany, Belgium, the Netherlands and Australia. Some of the most popular topics include education, bullying, relationships, diagnosis, medication and diet.

REFERRALS AND SERVICES FOR KIDS, FAMILIES  
AND PROFESSIONALS DEALING WITH TS

908.575.7350



New Jersey Center for Tourette Syndrome  
AND ASSOCIATED DISORDERS, INC.

Collaborative Partnerships for the Tourette Syndrome Community



# Awareness & Advocacy

## Members of the TS community make a marked impact



### ADVOCATE OF THE YEAR

**Marc Brummer**, a Livingston native and proprietor of the famous Hobby's Deli in Newark, has been an integral part of the NJCTS community for more than a decade, giving the organization guidance on a wide array of platforms, offering support to countless TS individuals and families, and making scores of kids and their parents laugh and feel welcome as a centerpiece of the annual Family Retreat Weekend at YMCA Camp Bernie. For those efforts, Brummer was named NJCTS' 2012 Advocate of the Year.

An NJCTS Advocate is a person whose dedication and actions improve awareness and help break the stigma of TS by informing the public, medical professionals and educators about Tourette and by supporting kids and families living with Tourette. Brummer, along with his wife, Suzanne, also has been the focal point of NJCTS' signature Patient-Centered Medical Education program – giving a detailed, heartfelt account of what it is like to be a parent of a child (or in their case, two children) with Tourette Syndrome to dozens of doctors and health-care professionals across the state.



### YOUTH ADVOCATE OF THE YEAR

**Emily Fleischman**, a Fort Lee resident and senior at River Dell High School, has been a consistently growing force in the NJCTS community over the past several years – particularly in 2012, giving student-led peer in-service presentations to fifth- and sixth-graders at several North Jersey elementary schools and synagogues, writing and illustrating a children's book about Tourette Syndrome and regularly posting well-read topics on the popular Teens4TS blog. For those efforts, she was named NJCTS' first annual Youth Advocate of the Year.

The Youth Advocate of the Year Award was established in 2012 to recognize a teenager whose contribution makes a difference to New Jersey's Tourette Syndrome community. Another way Fleischman achieved that distinction was through her personally illustrated and written children's book, "Emily's Tic," which talks about life as a kid with TS – including her own challenges of facing bullying – and features a Tourette Syndrome fact sheet, information about NJCTS and Fleischman's personal message of why advocacy for Tourette is such a big part of her life. It has been available on Amazon.com since February 2012.



### NJCTS HITS AIRWAVES ON NEWS 12'S "TO YOUR HEALTH"

Tourette Syndrome and the New Jersey Center for Tourette Syndrome was featured as the main segment on News 12 New Jersey's "12 To Your Health" show, hosted by Dr. Derrick DaSilva, on August 4 and 5, 2012. Taking part in this segment on TS was Dr. Tolga Taneli, a child and adolescent psychiatrist at the New Jersey Medical School in Newark, and NJCTS Youth Advocate of the Year Award winner Emily Fleischman. Taneli answered questions such as "What is Tourette Syndrome?" "What are the symptoms?" and "How is it treatable?" Fleischman discussed her personal experience with Tourette, her connection to NJCTS, her book, "Emily's Tic" and questions such as "When did you first notice you might have had Tourette Syndrome?" "What is having TS like?" "Have you dealt with ignorance or negative reactions from your peers?" and "What do you recommend for other young people with Tourette?" The 15-minute segment was seen 6 times over a two-week span on the cable news network, which serves most of New Jersey.

# Awareness & Advocacy

## TS Awareness Day with the Somerset Patriots, April 29

As part of the first annual Tourette Syndrome Awareness Week, the Somerset Patriots Baseball Club welcomed several hundred members of the New Jersey Tourette community as part of an exciting TS Awareness Day on April 29, 2012, at TD Bank Ballpark in Bridgewater. NJCTS and its member families took part in many fun activities. Ethan Lederman, 12, of Howell, threw out the first pitch; Sarah Ethridge, 14, of Chatham, sang the National Anthem; various families told their personal stories in a pregame ceremony; and kids were allowed to run the bases after the game. Two of NJCTS' Youth Advocates, Amanda Silvers and Josh Klapper, also had special experiences. Amanda's story was chronicled by the Courier News and Home News Tribune, while Klapper got to meet Patriots manager Sparky Lyle and receive a signed baseball.

NJCTS also had a table at the event, at which many of the more than 5,000 people who attended the game stopped to pick up information about the organization and learn more about Tourette Syndrome. Proceeds from the event's ticket sales, as well as a 50/50 drawing, benefitted NJCTS' statewide education outreach and peer advocacy programs. The Somerset Patriots also contributed a generous donation as part of the TS Awareness Day festivities.



*Ethan Lederman throws out the first pitch as part of TS Awareness Day on April 29, 2012, at TD Bank Ballpark in Bridgewater.*



*The Levitt family and their friends enjoy the beautiful sunshine and the Somerset Patriots baseball game on TS Awareness Day.*



*Many of the more than 5,000 people in attendance at TD Bank Ballpark for TS Awareness Day stopped by NJCTS' table to learn more about Tourette Syndrome.*

# Awareness & Advocacy

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## TS Awareness Week and Month reach all corners of NJ

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As a prelude to Tourette Syndrome Awareness Month, which annually takes place May 15 to June 15, NJCTS hosted its first Tourette Syndrome Awareness Week from April 23 to 29, 2012. The Center made its presence known around the state during this important week of awareness and advocacy, with the following events offering just a taste of the programs and services offered on a daily, weekly, monthly and yearly basis to New Jersey's TS community:

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- In Scotch Plains, Youth Advocates Tess Kowalski and Josh Klapper teamed up to give a presentation about Tourette Syndrome to Klapper's fifth-grade class at Terrill Road Middle School in Scotch Plains. The students were taught how to be better advocates on behalf of those with Tourette.
- In Somerville, a dozen Somerset County residents affected by TS took part in a roundtable discussion with Congressman Leonard Lance (R-NJ7) – one of the original co-sponsors of the CARE for Tourette Syndrome Acts of 2011 and 2013. Congressman Lance fielded a host of questions during the hour-long session.
- Also in Somerville, the Letts family of Hillsborough – with assistance from New Jersey Senator Christopher “Kip Bateman” – helped NJCTS obtain its yearly Tourette Syndrome Awareness Month proclamation from Governor Chris Christie. The family also had the opportunity to share its experience with the Senator.
- In Piscataway, Rutgers University graduate students in the Tourette Syndrome Practicum Program learned more about the clinical side of Tourette during seminars by Dr. Meir Flancbaum, Dr. Abba Cargan and NJCTS in-service presenter Tracy Lederman at the Graduate School of Applied and Professional Psychology.
- In Trenton, the NJCTS Cell and DNA Sharing Repository at Rutgers was honored with a Joint Legislative Resolution celebrating the fifth anniversary of the scientific institution, which – according to the resolution – is “renowned as an appropriate venue for citizens of this state with Tourette Syndrome to contribute valuable data, genetic samples and material to help researchers worldwide to study causes and to work toward better treatment and a cure.”

- And in Branchburg and New Brunswick, a series of lectures and presentations helped a host of college educators discover new and improved ways to meet the needs of students with TS and associated disorders. The events took place at Raritan Valley Community College and Rutgers' Graduate School of Education.



*From left, Hillsborough teen David Letts, Senator Christopher “Kip” Bateman, NJCTS Executive Director Faith Rice and NJCTS Board President Tim Omaggio receive the 2012 TS Awareness Month Proclamation.*

# Awareness & Advocacy



*From left, Terrill Road School fifth-grade teacher Connie Dovi is all smiles after two of her students, Jannine Huby and Josh Klapper, developed a Tourette Syndrome service learning project with NJCTS Youth Advocate Tess Kowalski.*



*Congressman Leonard Lance meets with NJCTS member families during a roundtable discussion at the Somerville Public Library.*

## THANK YOU!

NJCTS would like to thank all organizations, families and individuals for their generous donations and gifts throughout the year to support the NJCTS mission of providing quality programs and services for the Tourette Syndrome community. There are many ways to continue that support in 2013, including:

- Giving by phone, mail or the website via PayPal
- In honor of a loved one
- To recognize a special occasion
- Family-initiated fundraising events
- Gifts to support a specific program
- Monthly donations through workplace giving
- Corporate matching gifts
- Planned giving options

For more information about our programs and giving opportunities, please call 908-575-7350 or visit <http://www.njcts.org/donations.php>.

## NJCTS RECEIVES FUNDS FROM YANKEES GOLF OUTING

On May 15, 2012, the New York Yankees held their second annual New Era Pinstripe Bowl Charity Golf Tournament, which took place at Forsgate Country Club in Monroe, N.J. NJCTS was one of several nonprofit organizations to benefit from the more than \$100,000 raised from the tournament, and getting NJCTS on the docket to receive donations from the event was honorary board member and WFAN Sports Radio talk-show host Craig Carton. The event was attended by a notable cast of dignitaries from the sports world, including former New York Giants football stars Carl Banks, Mark Bavaro, Howard Cross, Luke Petitgout and Amani Toomer; former Yankees greats David Cone, Lee Mazzilli, Joe Pepitone, Mickey Rivers and Roy White; and Rutgers University football coach Kyle Flood and former quarterback Mike Teel.

“We are honored that the Yankees and all of the sports stars who attended this important event once again have recognized Tourette Syndrome as a disorder worthy of advocacy and awareness, and are grateful for their continued support,” NJCTS Executive Director Faith W. Rice said. “We also want to thank Craig Carton for his continued support of our organization and the 1 in 100 children and families affected by TS.”

# Research

## Tour of Cell and DNA Sharing Repository draws national interest

To celebrate the fifth anniversary of the NJCTS Cell and DNA Sharing Repository at Rutgers University, and to showcase the program's prominence as part of the National Institute of Mental Health, the Center hosted a tour of the facility in October 2012. Reporters, photographers and Rutgers University staff walked through the RUCDR Infinite Biologics laboratories, storage and processing rooms and clinical service areas of the sprawling Human Genetics Institute of New Jersey complex, which is overseen by Dr. Jay A. Tischfield and Dr. Gary Heiman.

According to NJBIZ Magazine, the repository "has grown in size and reputation, and has become a beacon of light in the Tourette Syndrome community." Dr. Heiman, a geneticist in charge of the day-to-day operations of the facility, said families across the country affected by TS are eager to help by sending in blood samples laden with their DNA. The repository is the only one of its kind in the world and receives samples from 26 collection sites around the world. Those samples are processed and stored at RUCDR until requested by researchers.

Stories and pictures from NJCTS' tour of the Cell and DNA Sharing Repository at Rutgers University were published in a host of national publications, including:

NJBIZ Magazine	NJTODAY	Binghamton Press of New York
Courier News	Lafayette Advertiser of Louisiana	Asheville Citizen-Times of North Carolina
Home News Tribune	Appleton Post Crescent of Wisconsin	Great Falls Tribune of Montana
MyCentralJersey.com	Bucyrus Telegraph Forum of Ohio	The Coloradoan
Morristown Daily Record	Chillicothe Gazette of Ohio	DelawareOnline.com
Asbury Park Press		
Courier Post		
Patch.com		



The Human Genetics Institute of New Jersey and the NJCTS Cell and DNA Sharing Repository are part of the sprawling Life Sciences complex on Rutgers University's Busch Campus



This laboratory at the Human Genetics Institute of New Jersey at Rutgers University helps process research material for the NJCTS Cell and DNA Sharing Repository



Dr. Jay A. Tischfield explains how a sampling machine is used at one of the NJCTS Cell and DNA Sharing Repository's laboratories at Rutgers University

# Research

## Genetic research at Rutgers University

Through a partnership with the Rutgers University Department of Genetics, NJCTS has established a sharing resource of clinical and genetic data which can be accessed by researchers around the world, including the 26 collection sites shown below. That resource, which has been in place since 2007, became the National Institute of Mental Health

Sharing Repository in September 2011. The ultimate goal of this study, which is led at Rutgers University by Dr. Jay A. Tischfield, Director of the Human Genetics Institute, is to identify genetic factors that play a role in causing TS and related disorders such as OCD and ADHD.



## NJCTS Sharing Repository collaborators collect samples at these sites around the world

### USA

- CT** Yale University School of Medicine
- IA** University of Iowa
- IN** Indiana University School of Medicine
- MO** Washington University in St Louis
- NJ** Rutgers, The State University of New Jersey
- NY** New York University and Nathan S. Kline Institute
- NY** Columbia University
- OH** Cincinnati Children's Hospital Medical Center
- PA** Children's Hospital of Philadelphia
- WA** Seattle Children's Hospital

### EUROPE

- Denmark** University of Copenhagen
- Germany** University Hospital, Dresden
- Germany** University Hospital of Ulm
- Germany** Hamburg University-Eppendorf
- Netherlands** University Medical Center, Groningen
- Netherlands** Yulius voor Geestelijke Gezondheid, Rotterdam
- Spain** Virgen del Rocío University Hospital, Sevilla
- Spain** Hospital Clinic Barcelona
- UK** Great Ormond Street Hospital For Children
- UK** Guy and St Thomas, London

### KOREA

- Anyang** Hallym University Sacred Heart Hospital
- Goyang** Kwandong University MyongJi Hospital
- Goyang** Ilsan Hospital (National Health Insurance Co.)
- Seoul** Korea Institute for Children's Social Development (KICSD)
- Seoul** Yonsei University Severance Hospital
- Seoul** Seoul Metropolitan Eunpyeong Hospital





New Jersey Center for Tourette Syndrome

AND ASSOCIATED DISORDERS, INC.

Collaborative Partnerships for the Tourette Syndrome Community

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