

Contact:

NJCTS
50 Division Street, Suite 205
Somerville, NJ 08876

phone: 908.575.7350
e-mail: info@njcts.org

www.njcts.org

2008 YEAR IN REVIEW



Month by Month, Making Strides.

NJCTS Board of Directors

Tim Omaggio, *Board President*

Rebecca Spar, *Board Secretary*

Laurence Scot, *Board Treasurer*

Eliot Goldstein, *Board Attorney*

James Levitt, *Director*

Conrad Roncati, *Director*

Paul deCosta, *Director*

Cindy Yingling, *Director*

Faith W. Rice, *Executive Director*

A Walk Through Our Year



Dear Friends and Supporters of NJCTS,

Thank you so much for your part in helping the NJ Center for Tourette Syndrome and Associated Disorders mark another impressive year of providing service and support to thousands of families living with TS. Your commitment to our work is making a difference in the lives of the 1 in 200 New Jersey children affected by this disorder. But our mission is far from accomplished.

During 2008, NJCTS responded to a 42% increase in demand for our services. We are able to meet these demands without an increase in budget thanks to a simple management philosophy of collaborating and partnering to accomplish our goal. Thanks to our partnerships with Rutgers University, NJCTS is proud to offer the world's first Tourette Syndrome Sharing Repository - a resource for scientists worldwide to obtain cell and DNA samples to study the genetics of TS and work toward a cure. NJCTS and the Rutgers University Graduate School of Applied and Professional Psychology have partnered for nine years in the nation's only stand-alone, university-based TS clinic. The Rutgers TS Clinic is helping TS families grow stronger while arming a new cadre of clinical professionals to understand the challenges in diagnosing and properly treating TS.

Our outreach to educators remains strong and as of 2008, NJCTS has educated more than 50,000 New Jersey school professionals on how to identify a child with TS and make the learning environment conducive to their success. By offering free in-service presentations to all schools throughout the state, NJCTS is providing a service for educators and special needs children alike.

As in prior years, a 2008 goal was to enhance advocacy on behalf of children and families with Tourette Syndrome. This year we launched the "Wednesday is TS Day" awareness campaign that quickly gained support from the public and private sector. In June 2008 our campaign was endorsed on the floor of the US House of Representatives. NJCTS will continue to educate the public on this misunderstood neurological disorder in an effort to combat the stigma so often perpetuated in harsh media portrayals of individuals with TS.

These efforts combine to form a search mission of sorts. We know there are 28,000 New Jersey children who show signs of TS. We know there are thousands who remain undiagnosed, mislabeled and suffering without proper support and treatment. Many of these children are given unfair and inaccurate labels which can lead to poor self esteem and a lifetime of underachievement. NJCTS is doing so much so efficiently in its efforts to create awareness and provide education and support for TS and will continue to do so in 2009 and beyond. In these difficult times, more than ever, we need you to continue support for the work of NJCTS and for the families affected by Tourette Syndrome and its associated disorders.

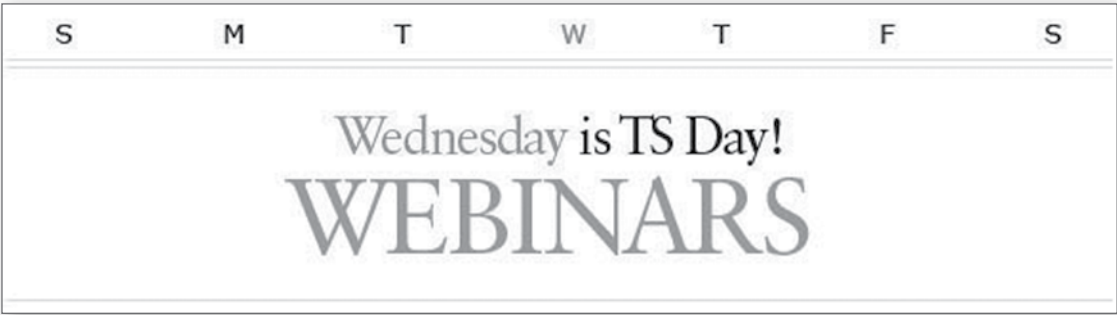
On behalf of the families we serve, I thank you.

Sincerely,

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

Faith W. Rice, *Executive Director*
New Jersey Center for Tourette Syndrome and Associated Disorders, Inc.

Introduction of the
Wednesday Webinar Series



On January 16, 2008 NJCTS launched the first in its Wednesday Webinar Series. The free presentations are open to anyone affected by TS including parents, teachers and health care providers.

“Using the web to conduct these online seminars is an important tool for us,” said Executive Director Faith Rice, “We’re now able to deliver support and education to the TS community with more timeliness and more efficiency.”

The first presentation, “A Nurse Talks About Tourette Syndrome” featured some of the problems parents and professionals encounter when diagnosing and providing treatments for TS. Susan Wightman-Hentz, RN, MSN, CPNP of the Children’s Hospital of Philadelphia discussed the challenges of treating TS with accompanying disorders and opened the discussion for other webinar participants to share their experiences and concerns.

Over the course of the year, NJCTS has welcomed webinar participants from across the country. In case you missed one, all presentations are archived on our website.



Here’s what participants had to say:

- “Extremely convenient and easy—LOVED IT!”
- “It was great to know I’m not alone!”
- “Both my children have Tourette’s. I’ve come away [from this webinar] feeling very optimistic about their condition.”
- “I thought the webinar far exceeded my expectations—I learned several new facets of Tourette that I can apply to some of my students and better work with the parents.”
- “I really appreciated the opportunity to ask a specific question of my own.”

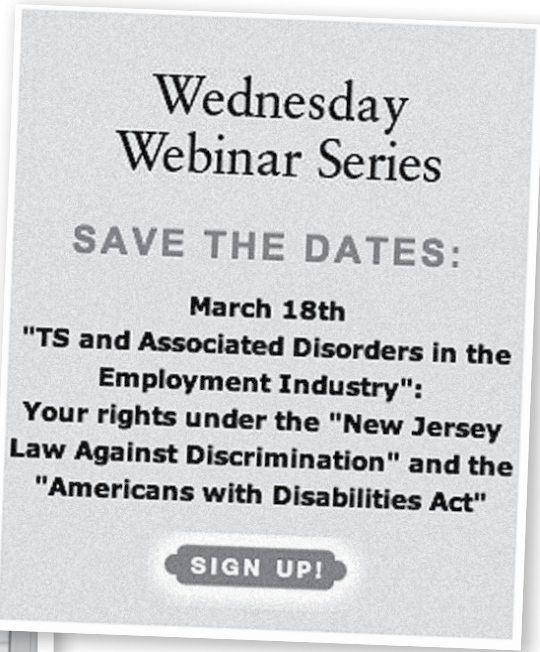


E-mail invitations ask participants to attend the webinars, which are then archived on our NJCTS website.

- In March, Dr. Jay Tischfield, Executive Director of the NJCTS Sharing Repository, shared insights into “Genetics and TS Research.” Through this webinar, participants had the opportunity to learn how they can become involved in this important research.
- A look at life “After the Diagnosis & Beyond the Tics: Tourette Syndrome in Childhood and Adolescence” was the focus of April’s webinar. Lawrence Brown, M.D. of the Children’s Hospital of Philadelphia highlighted effective strategies for helping kids and teens with TS, especially through their formative school years.
- In September, NJCTS conducted two in-service webinars for educators. These sessions were led by Ann Deutsch, MSN; Janine Howley, MA; and Cheryl Ludwig, MA, CCC-SLP. Our presenters stressed strategies that allow educators to create a place of learning that supports the social, emotional and intellectual development of all students.
- In October, Dr. Lori Rockmore, Clinical Director of the Tourette Syndrome Program at Rutgers University, led a discussion of “Mental Health Treatment for Individuals with TS: What’s Available and Can it Help”

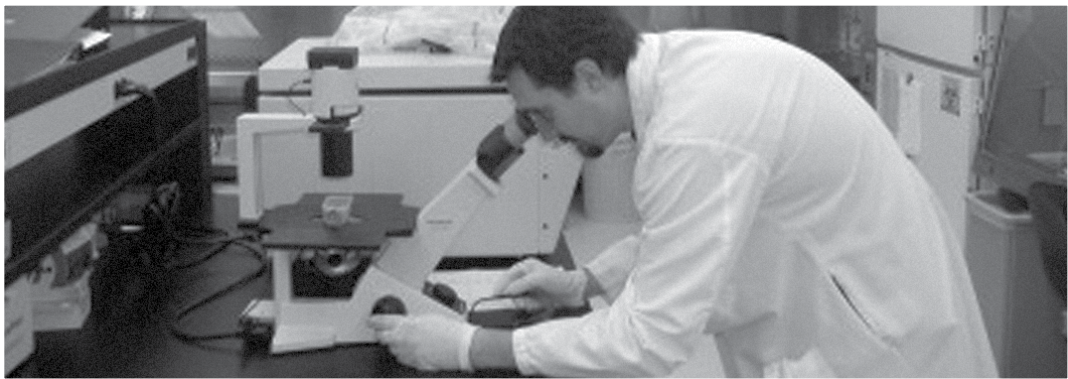
January by the numbers:

- **Most children with TS** also deal with at least one comorbid disorder
- **Wednesday Webinars** were introduced in 2008 to bring education and support to the New Jersey TS community of professionals and families across our state
- **800** individuals registered for a webinar in 2008



Our webinar series lets families participate in interactive presentations about TS and coping subjects right at their home computer

NJCTS Sharing Repository



Research into the genetics of TS and its associated disorders will lead to more effective therapies and treatments and possibly a cure.

The NJCTS Sharing Repository is the world's first source for access to DNA and cell lines for the sole purpose of studying Tourette Syndrome. Research has shown that TS has a genetic (inherited) component so to help scientists understand what causes this disorder, NJCTS partnered with Rutgers University to establish a place where qualified researchers from around the world can have access to genetic material from TS families.

June 2008 marked the one year anniversary of the repository's dedication and by all measures the program is a success. Research groups at Yale, Rutgers and Harvard Universities as well as representatives of the REIKEN Brain Science Institute in Japan have requested and received samples for use in their studies of TS. It is our hope that their research will one day lead to more comprehensive and effective therapies and a cure for TS.

The program is expanding beyond the boundaries of New Jersey- across the Delaware River. Dr. Lawrence Brown of the Children's Hospital of Philadelphia and the University of Pennsylvania has agreed to participate in screening study participants. DNA samples from these families will be included in the NJCTS repository.

Meet the team...



Jay A. Tischfield, Ph.D., FACMG
*Executive Director,
NJCTS Sharing Repository*

Dr. Tischfield is Executive Director of the NJCTS Sharing Repository and Director of the Human Genetics Institute of New Jersey. He is the recipient of active US National Institutes of Health awards in excess of \$70 million, much of which is to provide infrastructural support for sharing cell lines, DNA, clinical data and genotype data for studies on the genetics of "complex" diseases such as autism, schizophrenia, and bipolar disorder. To this end, he is Co-Director of the NIMH Center for Collaborative Genetic Studies on Mental Disorders and the NIDA Center for Genetic Studies, the NIDDK Genetics Repository and the NIAAA COGA Repository. He is American Board of Medical Genetics certified in two clinical subspecialties and is a Founding Fellow of the American College of Medical Genetics.

Dr. Tischfield is also currently MacMillan Professor and Chair of the Department of Genetics at Rutgers University and Professor of Psychiatry and Pediatrics at Robert Wood Johnson School of Medicine.



Gary Heiman, PhD
Director, NJCTS Sharing Repository

Dr. Heiman is the director of the NJCTS Sharing Repository. He is an epidemiologist, specializing in genetics of neuropsychiatric disorders. Dr. Heiman oversees the daily operating activities of the Repository. In addition to his work in Tourette Syndrome, he is also investigating the genetic relationship between epilepsy and depression.

Dr Heiman received his doctoral degree in epidemiology from Columbia University.



Robert King, M.D.
*Professor of Child Psychiatry,
Yale University*

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



Lawrence Brown, M.D.
*Associate Professor of Neurology and
Pediatrics, University of Pennsylvania*

Dr. Brown is a pediatric neurologist and co-director of the pediatric neuropsychiatry program at the Children's Hospital of Philadelphia.

In November the NJCTS Sharing Repository team published an article in *BMC Medical Genomics* describing the methods and sample description of the repository.



TS blood lines and DNA are processed, stored and distributed through the world's first TS Cell Sharing Repository



Dr. Tischfield and his work are profiled in Rutgers University's celebrated *Focus Magazine*

February by the numbers:

- In partnership with NJCTS, Rutgers University is home to the world's first Tourette Syndrome DNA sharing repository
- Rutgers also houses the world's largest collection of DNA for autism and schizophrenia
- In 2008, the NJCTS Sharing Repository provided DNA samples to researchers at Rutgers, Harvard and Yale Universities in the United States and to the REIKEN Brain Science Institute in Japan

In-Service Presenter Profiles

NJCTS provides in-service training and college workshops to educators, students and school administrators throughout the state. This program is arming teachers with the tools and skills they need to reach students with TS and is making New Jersey classrooms more supportive for children with all special needs.

Our team of in-service presenters is comprised of teachers, school nurses or other professionals with first-hand knowledge of TS. School in-service for faculty allows teachers to learn effective strategies for reaching students with TS and its associated conditions like obsessive-compulsive disorder, attention deficit disorder, depression and rage. In turn, this understanding creates a school environment where TS children are more likely to perform to full potential.

We also offer peer in-services where students learn about Tourette Syndrome and why it's important to foster a fair and inclusive environment. These sessions are designed to address bullying and end the stigma attached to this often misunderstood disorder.

To date, more than 50,000 NJ educators have been served by NJCTS.

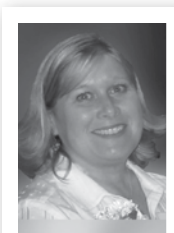
Meet our team:



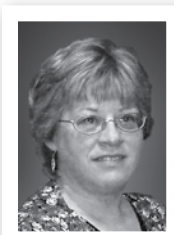
Ann Deutsch, MSN has over thirty years of nursing experience, fifteen of those years as a school nurse. She received her masters degree in nursing from Seton Hall University. She is currently a school nurse in an elementary school in Bergen county. Ann and her husband are parents of two adult children, one of whom has TS.



Gayle Forman, LCSW is a licensed clinical social worker. She has a family and marriage therapy practice with offices in Denville and Boonton. Ms. Forman has over 30 years experience working with TS children and families. Gayle has an adult son with Tourette Syndrome.



Janine Howley, MA has been a professional educator for over two decades. Her undergraduate and graduate degrees are in special education. She is presently a middle school teacher in Ocean County, NJ where she was selected "teacher of the year." She and her husband are the parents of an adult son with TS.



Cheryl Ludwig, MA, CCC-SLP is a nationally certified and licensed speech-language pathologist with 35 years experience working with children in public schools, private practice and as an adjunct professor at The College of New Jersey. She currently works as a speech pathologist in a county special services district. Cheryl and her husband are the parents of three children, all diagnosed with TS and associated disorders.



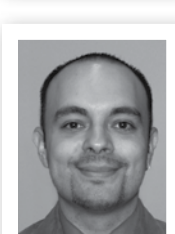
Carole Scheinholtz, MA is a retired elementary school teacher who taught in New York schools for over 33 years. Carole is resident of Monmouth County and has a grandson with Tourette Syndrome and associated co-morbid disorders.



Julie Swenson, M Ed, CSW is a certified special education teacher and a certified social worker with a master's degree in education. She taught special education and was a school administrator for 15 years and is currently an educational consultant to school districts, families and children. She and her husband are the parents of an adult son with TS.



Gail Walker lives in Gloucester County where she is a Basic Skills Improvement teacher. She is the mother of an adult son with Tourette Synrome and associated disorders.



Robert Zambrano, PsyD. received his Masters of Psychology and Doctorate of Clinical Psychology from the Graduate School of Applied and Professional Psychology at Rutgers University. He specializes in working with children and adults with Tourette Syndrome as well as OCD, depression, and other anxiety disorders.

March by the Numbers:

- **Over 50,000** NJ educators have received training from NJCTS to date
- **42** TS school in-service trainings for faculties and peers took place across New Jersey in 2008
- **16** NJ colleges have partnered with NJCTS to host educator workshops and presentations for students and community professionals

- **NJCTS provides credit-hours to educators who attend our workshops and in-service programs**
- **NJCTS works with the following colleges to make workshops and special presentations available to educators and students:**
 - Rutgers University
 - Kean University
 - New Jersey City University
 - Rowan University
 - Ramapo College
 - The Richard Stockton College of New Jersey
 - County College of Morris
 - Raritan Valley Community College
 - Bergen Community College
 - Passaic County Community College
 - Middlesex County College
 - Warren County Community College
 - Mercer County Community College
 - Ocean County College
 - Brookdale Community College
 - Sussex County Community College

Teachers and Students of the Year

In 2008 NJCTS honored three teachers as “Educator of the Year” and two high school students received “Student of the Year” scholarship awards.

The teachers were nominated by students and parents for their dedication to helping students with Tourette Syndrome. New Jersey Center for Tourette Syndrome gives its “Teacher of the Year” award to educators who go above and beyond their classroom duty to reach out to students with TS. NJCTS offers in-service training to teachers and recognizes those who apply strategy and compassion to create an exceptional learning environment for students with TS and associated neurological disorders.

NJCTS awards annual scholarships to college-bound high school seniors chosen for their academic performance, talents and life experiences dealing with Tourette Syndrome

April by the numbers:

- **Over 63,000** pieces of literature and newsletters were distributed to TS professionals and families in New Jersey in 2008 via email and hardcopy
- **146 children’s scholarships** have been awarded since 2001 to graduating New Jersey high school seniors diagnosed with TS who are continuing their education at a college or technical school



Classroom aide Lisa Quincey (left) and third-grade teacher Debbie Adams of Riverview Elementary School, Denville receive the 2008 NJCTS Educator of the Year Award from Michael (rear), Lisa (right) and Christopher Callahan. Mrs. Callahan said: “Ms. Adams took it upon herself to accept the challenge” of devising strategies to help Christopher in the classroom.



First grade teacher Carissa Campanella of Deane Porter Elementary School in Rumson poses with Bennett Stankovitz. Terry and Lawrence Stankovitz describe Ms. Campanella as a clever and positive teacher who exceeded their expectations in helping Bennett.



The Kornick Family thanks fifth-grade teacher Kerri McCaffrey for making the girls feel comfortable at Mountain View Middle School in Mendham. Mary Kornick said Ms. McCaffrey deserves the Educator of the Year Award because “she understands what daily struggles my kids face.”

TEACHER PROFILES



Debbie Adams is a third grade teacher at Riverview Elementary School in Denville. She was nominated by the Callahan family. Classroom aide **Lisa Quincey** was also recognized by NJCTS. Denise and Michael Callahan

credit Ms. Adams with taking special interest in their son and following through with special modifications to reach beyond the distractions of TS and its associated disorders. “She modified the structure of her classroom and her curriculum...She knew nothing of these afflictions and took it upon herself to accept the challenge... She is there for us from sun-up to sundown.”



Lisa Quincey



Carissa Campanella is a first grade teacher at Deane Porter Elementary School in Rumson. She was nominated by the Stankovitz family who described their son’s first grade teacher as a clever and proactive teacher who

employs a host of strategies to manage the nuances of TS. Here’s what Terry and Lawrence Stankovitz wrote: “Mrs. Campanella has exceeded our expectations. She spent hours of her personal time learning about TS and exploring strategies to help Bennett succeed.”



Kerri McCaffrey is a fifth grade teacher at Mountain View Middle School in Mendham. Nominated by the Kornick family, Ms. McCaffrey took strides to create a classroom environment where children with TS and all disorders can feel safe. That commitment extends beyond the classroom. Mary Kornick wrote: “She understands what daily struggles my kids face. She phoned me at lunchtime on their first day of middle school this year to let me know the girls were having a great day, just in case I was worried.”

STUDENT PROFILES



Erin Ludwig is a graduate of Ewing High School. Erin received a \$1000 scholarship and in 2008 graduated from

Rider University. Erin is currently working for the McCarter Theatre in Princeton.



Wesley Lanz is a graduate of Monmouth County Vocational School and Freehold Borough High School. Wesley received a

\$1000 scholarship and attended Universal Technical Institute to become a diesel mechanic.



Brian Wartel is a graduate of Moshe Aaron Yeshiva High School in South River. Brian has a talent for poetry and attended

Brandeis University in New York. Brian received a \$1000 award from NJCTS.



Christopher Ratshin of Toms River graduated from Monsignor Donovan High School and is attending Ursinus College in Pennsylvania. He was awarded a \$1,000 NJCTS scholarship in recognition of his accomplishments.



Austin Guerra of Randolph graduated from The Hudson School and is attending Parsons School of Design in New York. He won a \$500 NJCTS scholarship and recognition for his painting “Tourette on Canvas.”

Since 2001, 146 New Jersey students have been recognized through our scholarship program.

NJCTS Honored For Combating Mental Health Stigma



(Left to Right) Assistant Commissioner for the New Jersey Division of Mental Health Services Kevin Martone, Governor's Council on Mental Health Stigma Executive Director Celina Gray, New Jersey Association of Mental Health Agencies Executive Director Deb Wentz, a representative of the Bergen Community College mental health awareness program, Rev. John Harris Galilee Baptist Church, Faith Rice and Dr. Gary Heiman stand up against Mental Health Stigma at the 2008 Governor's Council on Mental Health Ambassador Awards Ceremony in Trenton.

In 2008, NJ Center for Tourette Syndrome received the first annual New Jersey Governor's Council on Mental Health Stigma Ambassador Award for health care.

The Ambassador Award recognizes organizations that have made significant contributions to reduce the stigma society attaches to mental health disorders. Celina Gray, executive director of the Governor's Council on Mental Health Stigma presented the award to NJCTS for its work in promoting "education, advocacy, research and creating new options for the treatment of Tourette Syndrome and associated disorders. NJCTS is empowering students and families across New Jersey to break down stigma."

"We believe empowering children and families to advocate for themselves will help demystify this disorder and foster an environment of greater understanding, tolerance and action on behalf of the mental health community at large," said NJCTS Executive Director Rice.

May by the numbers:

- **NJCTS was the first recipient** of the NJ Governor's Council on Mental Health Stigma Ambassador Award for Healthcare. NJCTS was recognized for "championing the effort to reduce mental health stigma."
- **187** people supported NJCTS by attending our Annual Recognition Dinner
- **Governor Corzine proclaimed** May 15–June 15 TS Awareness month in NJ
- **12 years in a row** a NJ Governor has proclaimed May 15–June 15 TS Awareness Month.

- May 15-June 15 was named "Tourette Syndrome Awareness Month" by a New Jersey governor for the past 12 years.
- NJCTS has taken a proactive approach to educating the public about Tourette Syndrome. Awareness campaigns are a priority and are aimed at parents, teachers and the public. In 2008, NJCTS introduced a bold grassroots effort asking everyone to set aside one day a week to devote to understanding Tourette Syndrome.
- Part of breaking the stigma of this disorder is helping the world understand what Tourette Syndrome is all about. Aside from educating teachers, NJCTS also conducts peer in-service programs designed to introduce school children to Tourette Syndrome and share invaluable lessons in tolerance and anti-bullying.

Through outreach, and advocacy, NJCTS grows awareness and fights the stigma associated with being different

Maybe he can't "just stop it!"

Maybe it's a neurological disorder

Maybe it's TS*

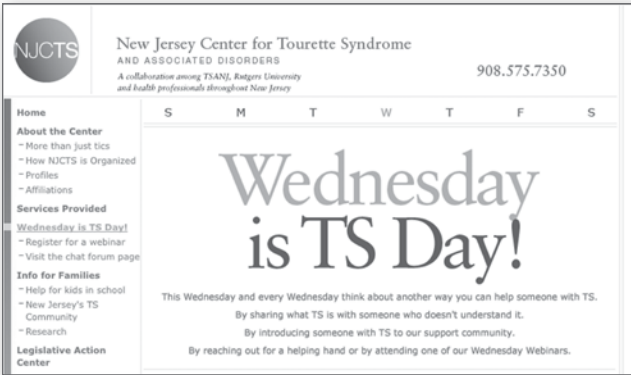
***Tourette Syndrome**
causes kids to have 'tics' – movements or sounds that they just can't help. But you can help them by contacting us...

New Jersey Center for Tourette Syndrome and Associated Disorders

908 575 7350 or njcts.org

Funded, in part, by New Jersey Department of Health and Senior Services

“Wednesday is TS Day” is Launched



Wednesdays are now known as “TS Day” for the 28,000 New Jersey children and families affected by Tourette Syndrome and associated disorders. *Wednesday is TS Day!* is a grassroots movement to raise awareness, create understanding and win support for programs to help individuals with TS.

The movement was launched by nine children with TS who took the stage, declaring a day of awareness and advocacy. NJCTS families, medical professionals and educators are encouraged to use each Wednesday to spread the word about Tourette Syndrome any way they can—whether it’s talking to a neighbor, hosting a bake sale for NJCTS, or an awareness-themed contest.

“The possibilities are limitless,” said NJCTS Executive Director Faith Rice. Tourette Syndrome is frequently misunderstood because of cruel and inaccurate media portrayals of the disorder. *Wednesday is TS Day!* is designed to face the stigma head-on, challenging the public to learn the facts about TS and associated neurological disorders like attention deficit disorder, obsessive compulsive disorder, anxiety and depression.

Another component of the *Wednesday is TS Day!* campaign is to alert parents, doctors and educators to the signs and symptoms of Tourette Syndrome. Right now, statistics show the average age of onset is seven years old. Unfortunately for many families, it may take years for proper TS diagnosis. New Jersey Center for Tourette Syndrome is a resource to guide families through the process and provides a continuum of support to the child with TS, parents, siblings, teachers and doctors.

JUNE HIGHLIGHTS

Wednesday is TS Day at the Ballpark
NJCTS volunteers rolled up their sleeves to spread awareness about Tourette Syndrome and the programs and services available to New Jersey families at five minor league baseball games throughout the state. The Newark Bears welcomed NJCTS in June where Faith Rice and TS dad Marc Brummer accepted a Wednesday is TS Day proclamation presented on behalf of Mayor Cory Booker.



Representatives from the city of Newark present a proclamation to “Wednesday is TS Day” volunteers and NJCTS families at Riverfront Stadium.

Wednesday is TS Day on the Boardwalk
NJCTS volunteers brought the advocacy campaign seaside in Wildwood. Passerby on the boardwalk were educated on Tourette Syndrome and the positive work of NJCTS.

Mayors from the following cities and municipalities have declared “Wednesday is TS Day”

- Newark
- Camden
- Somerville
- Trenton
- Wildwood

June by the numbers:

- **11,000 ballpark spectators** were exposed to our organization through the “Wednesday is TS Day” advocacy campaign
- **In our nation’s capital, NJ Congressman Albio Sires** introduced a resolution for a national “Wednesday is TS Day”
- **NJ mayors and legislators** came on board to join our “Wednesday is TS Day” campaign

Wednesday is TS Day in D.C.



NJ Congressman Albio Sires

What started as a grassroots effort to raise New Jersey’s awareness of Tourette Syndrome has become a national event. Congressman Albio Sires (NJ-13) is advocating on behalf of NJCTS to establish a national day of awareness for the 1 in 200 children exhibiting signs of Tourette Syndrome and its associated conditions including attention deficit and obsessive-compulsive disorders.

Congressman Sires introduced a resolution instituting a national TS Wednesday. Speaking to the House of Representatives, Rep. Sires said Tourette Syndrome is “a misunderstood disorder affecting an unknown number of people [because TS is] often misdiagnosed.” He continued by issuing a call for TS awareness and recognized the work of the New Jersey Center for Tourette Syndrome and Associated Disorders as “the first and only program of its kind in the nation and serves as the role model for others” across the country.



NJ State Senator Christopher Bateman (13)

This awareness effort in Washington echoes the advocacy by New Jersey State Senator Christopher “Kip” Bateman to designate “*Wednesday is TS Day!*” throughout the Garden State.

Here’s what Congressman Sires said:

Thank you, Madam Speaker. Today I rise to help raise awareness of Tourette Syndrome. This is a misunderstood disorder that affects an unknown number of Americans. The experts think that maybe 200,000 of us suffers from this neurological disorder, although no one really knows because it often goes undiagnosed.

That is why we need to increase awareness and applaud those who do that work on a daily basis. In my home state, the New Jersey Center for Tourette Syndrome and Associated Disorders provides an innovative, multi-disciplinary, multi-institutional approach to treatment for those New Jersey families with Tourette Syndrome. It is the first and only program of its kind in the nation and serves as a model for other centers. In concert with the State legislature, they declared every Wednesday in New Jersey as Tourette Syndrome Day to call attention to this disorder. In order to continue to bring awareness to this disorder, today I will introduce a resolution supporting the designation of a National Tourette Syndrome Day

July by the numbers:

- **28,000 NJ kids** show signs of Tourette Syndrome
- **In 2008 more than 50 family support group meetings** were held at hospitals to provide education and services to families in all 21 NJ counties



Cheryl Ludwig of Ewing and NJCTS Executive Director Faith W. Rice with Mayor Douglas Palmer of Trenton

NJCTS Family Support



Each spring, Camp Bernie offers a “Wonderful Weekend Away” for New Jersey’s TS kids and their families

Camp weekends are a tradition for NJCTS and 2008 was no exception. Families braved the high heat and humidity for what turned out to be another year of fun and camaraderie at YMCA Camp Bernie. The weekend, June 6-8 was a scorcher but that didn’t stop kids from doing what they do best: having fun.

NJCTS provides children with TS and its associated neurological disorders a camp experience for confidence building, family workshops and the opportunity to play without the stigma attached to this misunderstood condition.

The benefits of this type of environment have made a world of difference to the New Jersey children and families we serve; in just three days our program fosters a spirit of cooperation, understanding, self-esteem specially tailored to the needs of TS children and their families.

Now, thanks to a grant from Hoop-A-Paluzza, Inc., NJCTS is proud to present a second family retreat. In October 2009, NJCTS will host a South Jersey family weekend at Appel Farm in Elmer.

“We’re excited about this second offering,” said Faith Rice, “Not only will this be a more convenient opportunity for our South Jersey families, but it also gives us another occasion to gather our families for group support.”

When it comes to education, experience sharing and empowerment—NJCTS delivers.

Here’s what you had to say:

“Words can’t describe how nice it is to meet other people dealing with the same issues as myself.”

“My children love being with other kids with TS and OCD. It’s the one time out of the year where they feel like the ‘normal’ ones. For parents, it’s the one time we can be surrounded completely by people who honestly ‘get it’ and you don’t feel awkward or judged.”

“The sense of empowerment we all feel when we come away is priceless...my kids never want to leave.”

“It feels like a relief for us to attend Camp Bernie. My son waits all year for this opportunity to be himself and not stand out in a crowd. We relish the opportunity to have our experiences understood and our feelings validated.”

“Camp Bernie is like being able to take a breath of fresh air after a very long time.”

“Because of our camp experience, we have come out about TS and how it affects our family. On the first Wednesday after camp, we all (our three-year-old included) wore our TS T-shirts and hats to school and work. What a great opportunity to let others into our world.”

“Thank you for giving us the strength to embrace this part of our lives with courage and determination rather than fear or embarrassment.”

August by the numbers:

- **\$30,000 grant from Hoop-A-Paluzza, Inc.** will establish a second family retreat in 2009
- **621 kids and their families** have attended Camp Bernie since 2005

- Ghost Hunters star Dave Tango and his father Bruce spent some quality time with NJCTS families. Dave shared his experiences as a paranormal investigator and his struggles with TS.
- State Senator Leonard Lance (now Congressman Lance) came to Camp Bernie to speak to NJCTS families and share his support for funding this important organization.



NJ Congressman Leonard Lance



Dave Tango and his father Bruce spend quality time with NJCTS families at Camp Bernie.

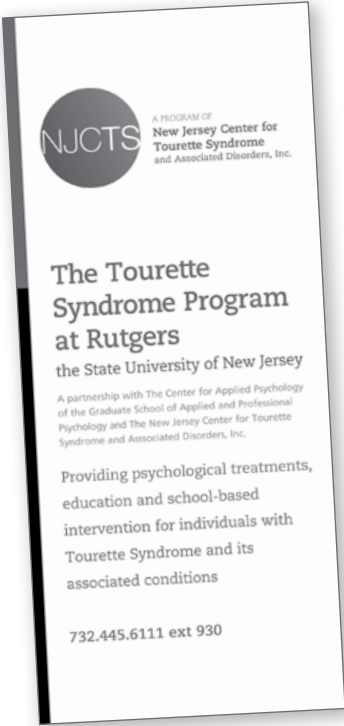


NJCTS Family Retreats are designed to help kids build self-esteem and meet peers with TS



Kids focus on fun—not tics, at Camp Bernie.

NJCTS Rutgers TS Clinic



Now in its ninth year, The Tourette Syndrome Program at Rutgers provides direct services for families and training for new professionals

Treatment methods include Cognitive Behavioral Therapy (CBT) and Habit Reversal Therapy to cope with TS, OCD, ADHD. ADD, anxiety and mood disorders. Clinicians work with families to develop behavioral intervention planning at home and at school. This holistic approach includes family therapy session and social skills groups.

These treatments are non-invasive and are used as an alternative in some cases to medication. CBT offers scientifically validated treatments for many of the challenges faced by individuals with TS. Habit Reversal Therapy is helping some children learn to better manage their tics. “The

The Tourette Syndrome Clinic at Rutgers University is in its ninth year and NJCTS is proud of this important collaboration with the Rutgers University Graduate School of Applied and Professional Psychology.

The TS Clinic at Rutgers is a university-based program where clinicians and clinical psychology doctoral students work under the supervision of a licensed psychologist. This collaboration between the Rutgers University Graduate School of Applied and Professional Psychology and NJCTS is used to assess, treat and support individuals and families who are living with TS.

At the clinic, individuals and families are given education information about TS and its associated disorders.

program is running very smoothly and we have been very pleased with the services we are offering and the outcomes we are seeing with our clients,” said Clinical Director Dr. Lori Rockmore. Right now there is a waiting list for services as more and more families are eager to take part in the program.

NJCTS aims to develop a new cadre of medical professionals to enter the field with a deeper understanding of Tourette Syndrome. This is the only program of its kind in the nation and more and more students are vying to participate. “With the successes we’ve had, many more doctoral students now want to work in the program as therapists and learn about treatment for TS and its associated disorders,” said Dr. Rockmore.

September by the numbers:

- **Rutgers TS Clinic**, a partnership between Rutgers University and NJCTS, is the only stand-alone, university based TS clinic in the nation
- **Rutgers University completed** its 9th year of partnership with NJCTS in 2008
- **\$120,000 Rutgers President’s Award** was received by GSAPP to recognize and expand the work of the Rutgers TS Clinic
- **3-hour lecture on TS** is a required part of training for all students enrolled at the Rutgers Graduate School of Applied and Professional Psychology

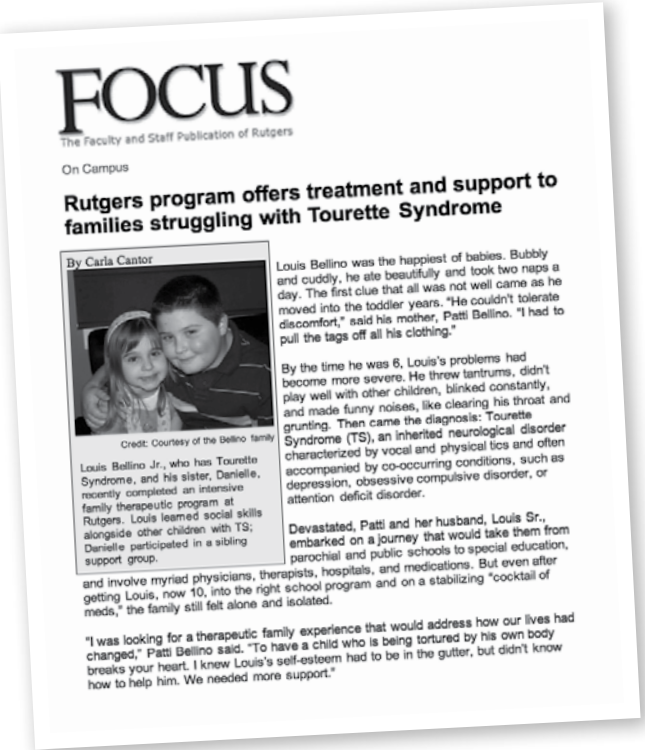
- In 2009, the social skills group program will expand to a satellite clinic at St. Clare’s Hospital in Denville.
- Dr. Rockmore is a psychologist with expertise in child development, impulse control disorders, parent training and social and emotional learning. She received her Doctor of Psychology degree in School-Clinical Child Psychology from Pace University and did her post doctoral training in Child and Adolescent Trauma at Mount Sinai School of Medicine.



Dr. Lori Rockmore is the clinical director of the program



Dr. Stanley Messer (L), Dean of the Graduate School of Applied and Professional Psychology and Dr. Lewis Gantwerk (R), Supervising Professor, were instrumental in building the Tourette Syndrome Program at Rutgers



The Center is featured in a recent issue of Rutgers University’s Focus Magazine

Coordinated Services

When a family is diagnosed with Tourette Syndrome, NJCTS provides a roadmap for services, support and clarity. Concerned parents are met with a checklist of things they'll need to navigate the challenges ahead. We're proud to offer this continuum of care through coordinated services and partnerships.

NJCTS has key partnerships in place to deliver support through first-of-its kind programs. Families receive referrals to agencies, doctors, psychological services and other experts in the area of TS, as well as direct support from NJCTS. In conjunction with Rutgers University, NJCTS has

established the world's first TS genetic sharing repository and America's only stand-alone student-clinician therapeutic TS clinic for children with TS, their siblings and parents.

October by the numbers:

- **NJCTS answered a 42% increase** in demand for family support in 2008
- **70% increase** in outreach to clinicians in 2008
- **51% increase** in outreach to educators in 2008



HELPLINE:
732-972-4459



NJCTS provides comprehensive services and support for families dealing with TS and its associated disorders. It's through our dedicated support group and helpline volunteers, and a loyal staff that we can accomplish so much.

NJCTS SERVICES

- **In-service and hospital and community training workshops** for mental health workers and other clinicians
- **Statewide in-service education**, liaison and training for educators, students and school administrators including college workshops
- **NJCTS Rutgers University Tourette Syndrome Partnership:** a practicum for doctoral students to study TS, work with TS families and develop programs specifically for TS families
- **NJCTS Sharing Repository:** makes cell and DNA samples available to qualified researchers worldwide to study the genetic causes of Tourette Syndrome
- **Coordinated services** for children and adults living with Tourette Syndrome
- **Advocacy** on behalf of people with TS and their families
- **Statewide newsletter** with information of interest to legislators, doctors, educators and TS families
- **www.njcts.org:** our comprehensive and helpful website
- **Wednesday Webinars:** monthly online seminars with topics of interest to the TS community
- **Family Retreat Weekends** (Camp Bernie, Hoopapaluza @ Appel Farm)
- **Annual children's scholarship award** given to a graduating NJ high school senior diagnosed with TS to further his/her education at a college or technical school
- **Annual educator of the year award** given to a NJ educator who has made a significant difference in the life of a child with TS
- **Annual healthcare provider of the year award** given to a NJ medical professional who has made a difference in the life of a child with TS

From TS to TV,
Dave Tango never forgets where he’s from.



Dave Tango and the cast of TV’s Ghost Hunters don “Wednesday is TS Day” hats

Sure he’s a Jersey guy. But that isn’t the only thing that brought him and his cast mates to Westfield. The cast of Sci Fi’s hit show Ghost Hunters came out to support the 28,000 New Jersey children with Tourette Syndrome (TS).



Dave Tango and Kris Williams take audience questions

They speak about the challenges they faced candidly in the hopes of comforting those who find themselves facing a new diagnosis.

Dave brought his Ghost Hunters cast mates Steve Gonsalves, Jason Haws, Grant Wilson and Kris Williams

Dave and his father, Bruce Tango, know what it’s like for children and families trying to cope with this often misunderstood neurological disorder. Dave was diagnosed in childhood and their journey prompted Bruce to organize and lead a recent fundraiser to benefit the NJ Center for Tourette

to Westfield to raise awareness of TS and the work of the New Jersey Center for Tourette Syndrome (NJCTS). NJCTS is grateful to Bruce, Dave and the entire Ghost Hunters cast. Despite a busy production schedule, Dave has gone out of his way to bring positive attention to Tourette Syndrome. “To have the support of such a high-profile group is outstanding,” said NJCTS Executive Director Faith Rice, “Dave’s story is so inspiring, and it means so much for kids with TS to have someone to look up to right here in New Jersey and know that they can go on to lead an exciting and successful life while managing TS.” Dave’s inspirational story is not lost on the children with TS who attended the event though they seem to prefer spending more time talking about his career as a paranormal investigator. “It just proves that life goes on beyond TS, and it’s good for the 1 in 200 New Jersey children with TS and their families to see someone with this disorder live a life not controlled by tics. It’s even better for the world to have to accept an understanding of TS that defies stereotypes,” said Rice. NJ Center for Tourette Syndrome & Associated Disorders leads the nation in services for TS families, medical professionals and educators.



Faith Rice with the members of Johnny Maestro and the Brooklyn Bridge

- **NJEA Convention:** Once again NJCTS was there to provide informative resources and materials to the thousands of educators in attendance. Visitors to our exhibit booth left with the understanding that 1 in every 200 New Jersey children manifests this misunderstood disorder and that teachers are on the front lines of helping to achieve diagnosis.
- **Tourette Syndrome Presentation:** NJCTS welcomed families to Virtua West Jersey hospital in Voorhees to take part in a special presentation by two renowned experts in TS. Pediatric neurologist Dr. Lawrence Brown, University of Pennsylvania associate professor of neurology and pediatrics and Children’s Hospital of Philadelphia, spoke about state-of-the-art treatments for TS. Geneticist Dr. Jay Tischfield, director of the NJ Center for Tourette Syndrome TS Sharing Repository at Rutgers University provided insights into TS genetic research. The demand for attendance far exceeded our expectations.
- **Family2Family:** NJCTS families joined together at South Jersey Regional Hospital in Vineland to meet others with TS. The event featured discussions lead by clinicians from the Rutgers TS clinic.

November by the numbers:

- **More than 49,000 attendees** were exposed to the work of NJCTS at the NJEA, ASHA, NJ School Nurses Association, National Association of Social Workers conventions and the American Academy of Pediatrics School Health and Hispanic Psychological conferences



Thousands of professionals visit the NJCTS booth, collect literature and attend break-out workshops at the NJEA and ASHA conventions in Atlantic City



Kids do hoops and have a great time to help raise awareness and support for TS and the work of NJCTS at an annual event hosted by the Hoop-a-Palooza Foundation.

NJCTS in their words...

The things we do are often best described by the people we serve.
Here is NJCTS, in their words:

Rutgers Genetic Study

“This study is so important and I cannot stress enough how thankful I am there are so many out there searching for answers, learning about the cause and finding out why so many are afflicted with TS.”

In-service Presentations

“Great to get insights from someone with firsthand experience with TS, not just professionally, but personally.”

“Informative, interesting, captivating and useful. Applicable strategies for all students especially special education and not only those with Tourette Syndrome.”

The presentation was extremely informative and very needed. It was excellent.”

Family Retreat at Camp Bernie

“A fabulous time where you feel accepted and understood. A safe place where kids with TS can be themselves and not have to spend all of their energy suppressing tics.”

“It felt good...sharing our mutual experiences and offering empathy and reassurance (with new families). Our son, in his third year, clearly feels like an alum- Camp Bernie is like his TS home away from home!”

“Camp Bernie was an outstanding experience for our family. As parents we really appreciated all of the interactions with other parents. We feel we have come away with a lot more knowledge about Tourette and how to cope with the more difficult aspects of the disorder. Our children had a blast! They are already begging to come back next year. How can you beat that?”

“What I always enjoy most is meeting with families who share our same concerns. No one really ‘gets it’ when you talk about what you go through with TS... except for these people. When you speak, it’s like you’re talking to someone who lives in your house and who has also ‘seen it all.’ I love the experience of meeting other families- just to know you’re not alone. That’s the biggest draw for our kids.”

“You are all so wonderful to provide such a great experience for these kids.”

“Thank you for giving us the strength to embrace this part of our lives with courage and determination rather than fear or embarrassment.”

“Because of our camp experience, we have come out about TS and how it affects our family. On the first Wednesday after camp, we all wore our TS shirts and hats to school and work. What a great opportunity to let others into our world!”

“[My son] learned how to convert sadness and fear to anger and excitement....he responded better to his sister because of this new strategy.”

DECEMBER HIGHLIGHTS

Scholarship Program

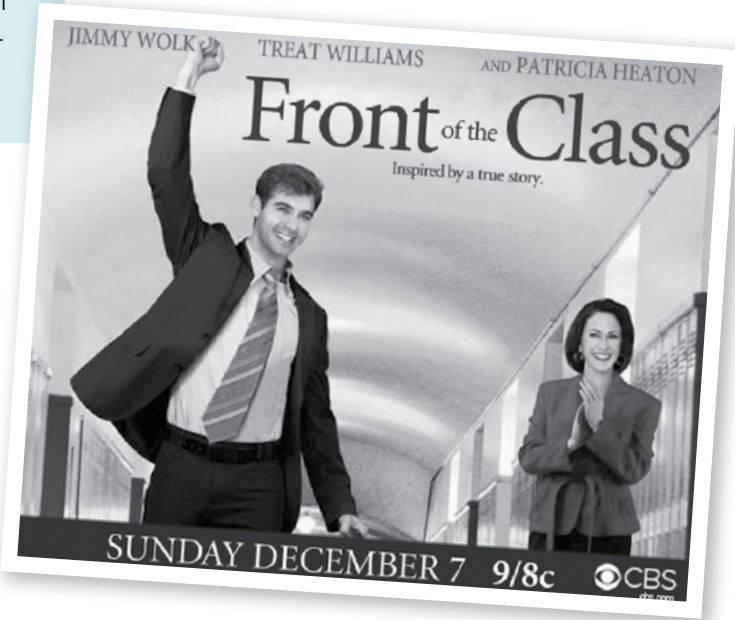
“You and your program made my life a little easier and I hope your program continues because it helped me and it will help many others.”

“It means a lot to me to be recognized by the organization. Continue helping other children like me that have Tourette. I will not forget you next year while attending Johns Hopkins University.”

December by the numbers:

- **11,880,000 viewers watched** Hallmark Hall of Fame’s “Front of the Class” – a positive depiction of Tourette Syndrome in the life of Brad Cohen—thank you, Brad!

These statements are just a small representation of the feedback we receive from parents, educators and health care providers. New Jersey Center for Tourette Syndrome is a lifeline to helping professionals and the families they serve understand TS. We are grateful for these words of encouragement, and as long as there are stories to tell we will share them. Our work at NJCTS isn’t finished until TS is no longer a reality.



By the numbers overview

January

- **Most children with TS** also deal with at least one comorbid disorder
- **Wednesday Webinars** were introduced in 2008 to bring education and support to the New Jersey TS community of professionals and families across our state
- **800** individuals registered for a webinar in 2008

February

- **In partnership with NJCTS, Rutgers University** is home to the world's first Tourette Syndrome DNA sharing repository
- **Rutgers also houses the world's largest collection** of DNA for autism and schizophrenia
- **In 2008, the NJCTS Sharing Repository provided DNA** samples to researchers at Rutgers, Harvard and Yale Universities in the United States and to the REIKEN Brain Science Institute in Japan

March

- **Over 50,000** NJ educators have received training from NJCTS to date
- **42** TS school in-service trainings for faculties and peers took place across New Jersey in 2008
- **16** NJ colleges have partnered with NJCTS to host educator workshops and presentations for students and community professionals

April

- **Over 63,000** pieces of literature and newsletters were distributed to TS professionals and families in New Jersey in 2008 via email and hardcopy
- **146 children's scholarships** have been awarded since 2001 to graduating New Jersey high school seniors diagnosed with TS who are continuing their education at a college or technical school

May

- **NJCTS was the first recipient** of the NJ Governor's Council on Mental Health Stigma Ambassador Award for Healthcare. NJCTS was recognized for "championing the effort to reduce mental health stigma."
- **187** people supported NJCTS by attending our Annual Recognition Dinner
- **Governor Corzine proclaimed** May 15 – June 15 TS Awareness month in NJ
- **12 years in a row** a NJ Governor has proclaimed May 15 through June 15 TS Awareness Month. A proclamation signed by Governor Corzine was presented to NJCTS in 2008.

June

- **11,000 ballpark spectators** were exposed to our organization through the "Wednesday is TS Day" advocacy campaign
- **In our nation's capital, NJ Congressman Albio Sires** introduced a resolution for a national "Wednesday is TS Day"
- **NJ mayors and legislators** are coming on board to join our "Wednesday is TS Day" campaign

July:

- **28,000 NJ kids** show signs of Tourette Syndrome
- **In 2008 more than 50 family support group meetings** were held at hospitals to provide education and services to families in all 21 NJ counties

August

- **\$30,000 grant from Hoop-A-Paluzza, Inc.** will establish a second family retreat in 2009
- **621 kids and their families** have attended Camp Bernie since 2005

September

- **Rutgers TS Clinic**, a partnership between Rutgers University and NJCTS, is the only stand-alone, university based TS clinic in the nation
- **Rutgers University completed** its 9th year of partnership with NJCTS in 2008
- **\$120,000 Rutgers President's Award** was received by GSAPP to recognize and expand the work of the Rutgers TS Clinic
- **3-hour lecture on TS** is now a required part of training for all students enrolled at the Rutgers Graduate School of Applied and Professional Psychology

October

- **NJCTS answered a 42% increase** in demand for family support in 2008
- **70% increase** in outreach to clinicians in 2008
- **51% increase** in outreach to educators in 2008

November

- **More than 49,000 attendees** were exposed to the work of NJCTS at the NJEA, ASHA, NJ School Nurses Association, National Association of Social Workers conventions and the American Academy of Pediatrics School Health and Hispanic Psychological conferences

December

- **11,880,000 viewers watched** Hallmark Hall of Fame's "Front of the Class" – a positive depiction of Tourette Syndrome in the life of Brad Cohen – thank you, Brad!