

TOUCHING LIVES A YEAR OF ACCOMPLISHMENT



NJCTS New Jersey Center for Tourette Syndrome
AND ASSOCIATED DISORDERS, INC.
Collaborative Partnerships for the Tourette Syndrome Community

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AND ASSOCIATED DISORDERS, INC.
Collaborative Partnerships for the Tourette Syndrome Community

Dear Friends and Supporters of NJCTS,



I'm proud to live in New Jersey. With the help of our state legislators and Rutgers University, NJCTS has established the country's only Center of Excellence for Tourette Syndrome. It's an accomplishment that's touching the lives of thousands in the Garden State, and beyond.

For those of you who may not already know, NJCTS is an outgrowth of the Tourette Syndrome Association of New Jersey (TSANJ). In 2004, with support from the NJ Department of Health and Human Services – TSANJ helped create a better way to deliver programs and links to NJ families and individuals with TS. The idea for a Center of Excellence, offering a range of coordinated services was born. Today, NJCTS – the first and only program of its kind in the nation – has grown into an exciting model that puts New Jersey at the forefront of addressing the need for more effective treatment options, support and professional assistance for those with TS and their families.

New Jersey's investment in Tourette Syndrome is paying off through direct savings to taxpayers. Here's what the Center of Excellence is doing today:

RESEARCH: Through the world's first Tourette Syndrome cell and DNA Sharing Repository at Rutgers University, researchers around the world are drawing from this collection of rare genetic samples. This project is bringing bioresearch interest to the Garden State and the opportunity for additional federal funding to Rutgers.

EDUCATION: The nation's only stand-alone student-clinician TS clinic is preparing a new cadre of doctors to be experts on this misunderstood disorder. Through direct, onsite training for health professionals and educators, NJCTS is equipping these important professionals to better accommodate the children and families they serve.

FAMILY SUPPORT: One in 100 individuals here in New Jersey is coping with the symptoms of Tourette Syndrome. The impact of this disorder goes far beyond the individual to include parents, siblings, grandparents, schools and employers. Through a support helpline, monthly webinars, news updates and support groups, NJCTS is making New Jersey an accepting place for the Tourette Syndrome community.

ADVOCACY: Providing a voice for those with this misunderstood disorder is at the heart of the NJCTS mission. New Jersey is the only state in the nation with a Governor's Council on Mental Health Stigma. In 2008, NJCTS received the Council's 1st Annual Ambassador Award in Healthcare.

Accomplishments on this scale, in such a short period of time, are only possible through key collaborations. Rutgers University has been a critical partner in establishing this Center of Excellence. It began with a vision and the continued support of many important lawmakers. We're grateful to the state legislature and New Jersey Congressional delegation for their support and commitment to this progressive campaign. With such strong collaborations and partnerships, the work of the Center is just beginning. Programs and services will continue to expand as new needs are identified. As you'll see in this review, new programs are added to NJCTS all the time. The Center is growing and expanding, soon to include a second office on the campus of Rutgers University.

Thank you for your part in bringing excellence to this elusive and cruel disorder. I'm finding the climate in New Jersey to be quite warm for the Tourette Syndrome community.

Sincerely,

A handwritten signature in black ink, appearing to read 'Faith W. Rice'. The signature is fluid and cursive, written over a white background.

Faith W. Rice
Executive Director

“THROUGH ITS PARTNERSHIP WITH RUTGERS UNIVERSITY, NJCTS HAS DEVELOPED A WORLD-CLASS RESEARCH BASE FOR SCIENTISTS AND PRACTICAL TRAINING FOR MEDICAL PROFESSIONALS IN RECOGNIZING AND TREATING TOURETTE SYNDROME.”

N

JCTS is working hard to advance the study of Tourette Syndrome and its associated disorders.

Tourette Syndrome is a neurological disorder characterized by involuntary muscle and vocal movements known as tics. Several co-occurring conditions such as obsessive-compulsive and attention deficit hyperactivity disorders, depression, rage, anxiety and learning disabilities are common. As many as 1 in 100 children show symptoms of

TS, and right now there is no cure. Through its partnership with Rutgers University, NJCTS has developed a world-class research base for scientists, and practical training for medical professionals in recognizing and treating Tourette Syndrome.

In 2009, four researchers associated with the Center and Rutgers University were invited to present their projects at the 5th International

Tourette Syndrome Symposium in New York City. To join the ranks of leading scientists studying TS is quite an honor and a statement on the power of innovative partnerships. The Symposium, sponsored by the national Tourette Syndrome Association, was designed to create a networking opportunity for basic and clinical scientists to focus on new treatments.

NJCTS was cited in June 2010 issues of the *New England Journal of Medicine* for contributing to Dr. Matthew State's discovery of a genetic mutation that offers new clues about the cause of TS. Garden State families rolled up their sleeves and donated blood samples to the TS Repository at Rutgers University. Genetic material from NJCTS families is included in groundbreaking research.

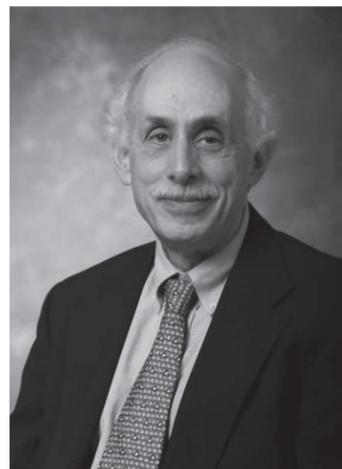


Researchers are using samples from the NJCTS Sharing Repository to understand causes and treatments for Tourette Syndrome and its associated disorders.

Dr. Jay Tischfield is Executive Director of the NJCTS Sharing Repository and Director of the Human Genetics Institute of New Jersey. Through the Repository, scientists from across the globe are able to study the genetic causes of Tourette Syndrome.

RESEARCH

Families participating in the genetics study at Rutgers – led by Dr. Jay Tischfield, Dr. Gary Heiman and Dr. Robert King – are creating a base of DNA from which researchers are able to study TS. The Tourette Syndrome Sharing Repository is a resource for the scientific community and samples have been drawn upon from researchers from Harvard, Yale and the RIKEN Brain Institute in Japan among others. This collection is a resource for the scientific community on a global scale. It's the world's first DNA sharing repository focused solely on the study of the causes and treatments of TS.



Dr. Robert King of Yale University's Child Study Center works with NJCTS to screen families for the TS Sharing Repository program.

PROJECTS BY NJCTS AFFILIATED RESEARCHERS INCLUDE:

- New Jersey Center for Tourette Syndrome Sharing Repository: Methods and Sample Description
– Gary A. Heiman, Ph.D.
- An Overview of the Tourette Syndrome Program at Rutgers University
– Rachel Merson, B.A.
- Two-week Intensive Behavior Therapy for Tics: A Case Study
– Meir Flanbaum, Psy.M
- Older Adults Adaptation to Stigma and Tourette Syndrome
– Lisa Cox, Ph.D., MSW, LCSW



Dr. Gary A. Heiman is director of the NJCTS Sharing Repository overseeing daily operating activities. He and nurse JoAnne O'Brien interview families and draw samples for inclusion in the Repository.



Collected samples are cryogenically sealed in a facility at the Rutgers Life Science Institute.



Neurologist Abba Cargan, Dr. Shalonda Kelly, Dr. Lori Rockmore and Dr. Brian Chu prepare to speak about Tourette Syndrome at a Rutgers training session.

53,190 PROFESSIONALS WERE
EXPOSED TO NJCTS AND ITS
COORDINATED FAMILY SERVICES
AT CONVENTIONS STATEWIDE



Tourette Syndrome awareness is important to members of the Hunterdon County School Nurses Association and County Health Director John Beckley.



Denise Marsala-Williams and husband Larry Williams coordinated a golf outing to benefit NJCTS. The event was a big success, and through their efforts, participants learned about Tourette Syndrome and the "Wednesday is TS Day" campaign.

NJCTS is taking Tourette Syndrome awareness to new heights. Over the past two years, more lawmakers have joined forces to issue proclamations of support to the NJ Tourette Syndrome community. In 2009, State Senators Christopher "Kip" Bateman and Jeff Van Drew passed a resolution on behalf of the entire State Senate commending the work of the "Wednesday is TS Day" campaign.

A group of NJCTS families from across the state gathered in the statehouse on the day the SR77 was passed and recognized by Senate President Richard Codey. NJCTS Youth Spokesman Dean Roncati led a group of kids with TS to personally thank Senator Bateman and Senator Codey for their support. "It takes courage to live

with Tourette. It also takes courage to be an outspoken supporter," said Roncati. "The kids of New Jersey cannot speak for themselves and rely on [lawmakers] for help."

The youth TS movement gained even more strength in 2010 when NJCTS was approached by Emily Carrara. Emily, a high school junior,

wanted to create a walk as a show of support for her cousin who has TS. That effort grew to become "Mendham Walks for TS." The 5K walk and family fun run drew a crowd of more than 300 people and raised more than \$25,000 for NJCTS.



NJCTS Youth Spokesman Dean Roncati (center) presents Senator Christopher "Kip" Bateman (center) with token of thanks and a "Wednesday is TS Day" hat moments before the State Senate passed a resolution supporting the work of NJCTS. Dean and his family are joined by the Lang, Kowalski and Brzycki families in the statehouse.

AWARENESS

Also in 2010, NJCTS Executive Director Faith Rice was named a Russ Berrie Award winner for Making A Difference for her work on behalf of the Tourette Syndrome community. It's an honor two decades in the making. After years of struggling to get an accurate diagnosis for her son, the retired IBM executive set her mind on creating an organization to provide a roadmap of services and referrals for children and families facing a Tourette Syndrome diagnosis. Today, NJCTS is gaining national attention for delivering first-of-its kind programs and services to families with TS, educators and health professionals.

The NJ Tourette Syndrome community received quite a boost of attention when soccer superstar Tim Howard chose to represent NJCTS in the Pepsi Refresh Project. Tim was joined by two other Team USA members representing their respective charities, and fans were asked to visit the Pepsi Refresh Project website and vote for their favorite player/charity. Thanks to your help and the votes of thousands nationwide, Tim won the contest and NJCTS received the \$50,000 prize!



Alex Weiner and his family brought positive attention to Tourette Syndrome during his Bar Mitzvah. In lieu of presents, Alex asked friends and family to make donations to NJCTS.



Members of the New Jersey Association on Higher Education and Disability (NJAHEAD) declare "Wednesday is TS Day!" (Seated) Ramona Kopacz [Ramapo College], Loretta Cramer [Ocean County College], David Nast [County College of Morris] (Standing) Jennifer Aitkens [New Jersey City University], Rosellen Moller [Ocean County College], Teri Yamiolkowski [The College of New Jersey], Meredith Vicente [Cumberland County College].



Somerville Mayor Brian Gallagher signs "Wednesday is TS Day" proclamation as a show of support to the TS community.



Soccer superstar Tim Howard, at the height of World Cup fever, chose to represent NJCTS in the Pepsi Refresh Project. The soccer player with the most votes won \$50,000 for their respective charity. Thanks to your help, he won...and so did NJCTS!



Jay Geyer, a college student with TS, presents The College of New Jersey President R. Barbara Gitenstein with a "Wednesday is TS Day" hat in support of TS awareness. He's joined by TCNJ's Disability Support Coordinator Teri Yamiolkowski (left) and NJCTS Executive Director Faith Rice.

AWARENESS



Cousins Brendon McCarthy and Emily Carrara welcome a crowd of 300 participants to the first "Mendham Walks for TS" 5K. A member of their family has TS, which prompted Emily to recruit Brendon and reach out to NJCTS and create an event to raise TS awareness.

Joya Weil of Mendham leads participants through a warm up before gathering at the starting line.



The first annual "Mendham Walks for TS" brought a crowd of more than 300 and raised \$25,000. Most importantly, it brings together people who are touched by TS. It's a gathering and a celebration in the spirit of advocacy.



Each fall, Bruce Tango hosts a fundraiser on behalf of NJCTS. Bruce is the father of Dave Tango of TV's *Ghost Hunters*. Bruce always puts together a great lineup of entertainers. In 2009, the cast of *Ghost Hunters* and *Ghost Hunters Academy* joined Dave and Bruce in Westfield.

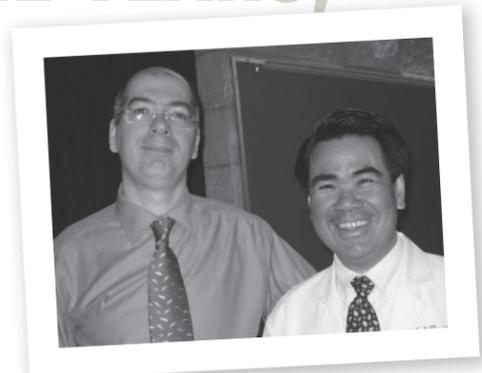


A group of participants gathers after the race.



The Roncati Family at the finish line.

MORE THAN 4,000 PARTICIPANTS REGISTERED FOR NJCTS SCHOOL IN-SERVICE PRESENTATIONS, WORKSHOPS AND WEBINARS IN 2009 ALONE. OVER THE YEARS, NJCTS HAS PROVIDED TRAINING TO MORE THAN 60,000 EDUCATORS.



Dr. Tolga Taneli and Dr. Elmer David take a break from an NJCTS grand rounds presentation at UMDNJ-Newark in February.

“Bravo! We thoroughly enjoyed the presentation on TS. The class was SO engaged and insightful. Everyone came away with a wonderful understanding of what TS is and how [our student with TS] is a hero to all!” – VILLAGE SCHOOL, HOLMDEL

Equipping teachers and child study teams with techniques and strategies improves performance for children with Tourette Syndrome and other neurological disorders, and it is vital to the mission of what we do.

To date, the NJ Center for Tourette Syndrome has provided direct training to more than 60,000 New Jersey educators. The Center provides professional development to teachers, school nurses, social workers, guidance counselors aides and administrators at no cost to ensure that current and future students with TS and other disorders thrive in a tolerant, understanding and supportive environment and have the opportunity to fulfill their role in society.

A small investment in NJCTS relieves the taxpayer burden by tens of millions of dollars. NJCTS in-school trainings hold the potential to save millions of dollars by educating school staff to understand and accommodate the needs of children with TS – keeping them in the traditional classroom and out of costly special needs schools.

The following is a quote from one of the many messages received from the families of children with TS:

“When my son was in the seventh grade, he was unable to attend school and he had to stay home because he was disturbing the other students. The school he was going to suggested we take him out of school and put him in a school for special children. With the help of [NJCTS] we were able to get a tutor for my son and the

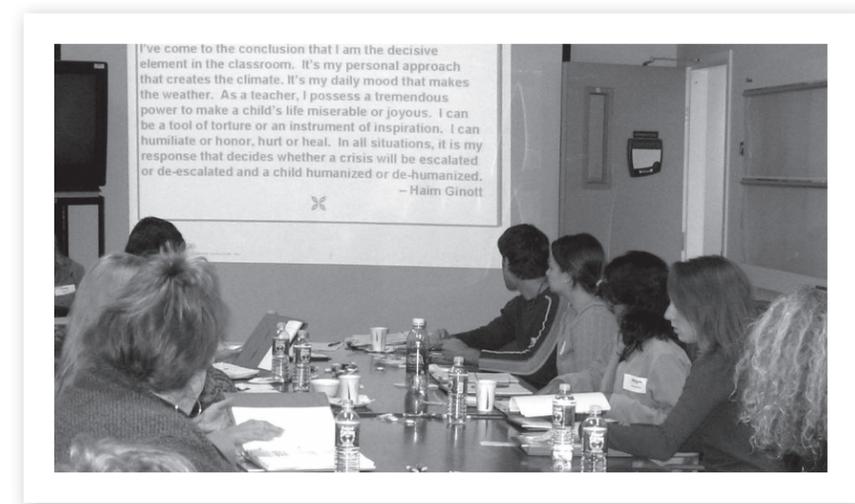
proper treatment. My son is now graduating this year from high school and will be attending Penn State. If it weren't for [NJCTS] he would never have made it. I thank NJCTS for my son's success.”

– P.E. RIDGEWOOD, NJ

New Jersey leads the nation in direct outreach to educators. Better understanding and effective strategies encourages TS students to stay in class and fulfill their potential. To date, NJCTS has awarded 146 privately funded scholarships to college-bound high school seniors with Tourette Syndrome, reinforcing the message that students with TS should face no limits to their success.

IN-SERVICE PROGRAM FOR TEACHERS: This course is designed to teach educators about TS and its associated conditions such as ADHD and OCD, anxiety, depression, difficulties in fine/visual motor skills, sensory defensiveness, auditory processing and other learning disabilities. Instruction and testing accommodations are discussed including classification, intervention and modification for behavior management.

PEER IN-SERVICE PROGRAM FOR STUDENTS: Children receive training and character education in how to treat all individuals with respect. Special emphasis is placed on anti-bullying tactics.



All NJCTS in-service presenters, workshop leaders and support group facilitators undergo specialized training in Tourette Syndrome and related issues.

EDUCATION

COLLEGE WORKSHOPS: The Center partners with 16 colleges and universities throughout New Jersey to provide professional development training for educators focusing on advanced strategies for accommodation.

LECTURES AT NJ COLLEGES: NJCTS presenters are invited to guest lecture on Tourette Syndrome and special education to graduate-level students enrolled in some of New Jersey's most respected teaching, psychology and social work programs. In 2010, Cheryl Ludwig delivered a keynote address at the NJ Division of Early Childhood Annual Conference at Kean University and Janine Howley presented direct training to teachers and paraprofessionals through the East Orange Early Intervention Head Start Program.

WEDNESDAY WEBINAR SERIES: NJCTS brings cutting-edge information and strategies for dealing with Tourette Syndrome and its associated disorders directly to parents and professionals. Best of all, these sessions are broad-

cast and viewers are able to participate from the convenience of their home or office. Presenters take questions after each session and address additional questions on the NJCTS Webinar Discussion Board on NJCTS.org. All presentations are archived on our website and can be viewed at any time, at no cost.

But, education doesn't end with teachers and students; NJCTS takes every opportunity to educate doctors, nurses, psychologists, social workers and other professionals as well. NJCTS is committed to developing a cadre of well-qualified professionals with the ability to understand and assist children with TS.

GRAND ROUNDS: NJCTS presents up-to-the-minute information on TS diagnosis, treatment and research to residents and community professionals through partner hospitals statewide. By reaching clinicians in residency, we hope to broaden the network of doctors who have interest and expertise in TS.

SPECIALIZED TRAININGS: In 2010, NJCTS presented to the Overlook Medical Center Training Conference, the New Jersey Department of Health Special Child Health supervisors, and two day-long presentations to hospital mental health workers through UMDNJ's University Behavioral Healthcare program. In 2010, NJCTS partnered with Dr. Stuart Green (founder of New Jersey's Anti-Bullying Coalition) for the first Patient-Centered physician training on TS. A family with TS shares their experience to a group of resident physicians with the goal of developing clinician empathy and understanding to improve outcomes.

CONFERENCES: Outreach to targeted professionals is of utmost importance. That's why NJCTS presents to annual conventions for state teachers, social workers, psychologists, and pediatricians.

"I learned about something I thought I knew about. The class gave me the whole picture it filled in gaps I may have had about what TS is."

– BERGEN COMMUNITY COLLEGE WORKSHOP ATTENDEE



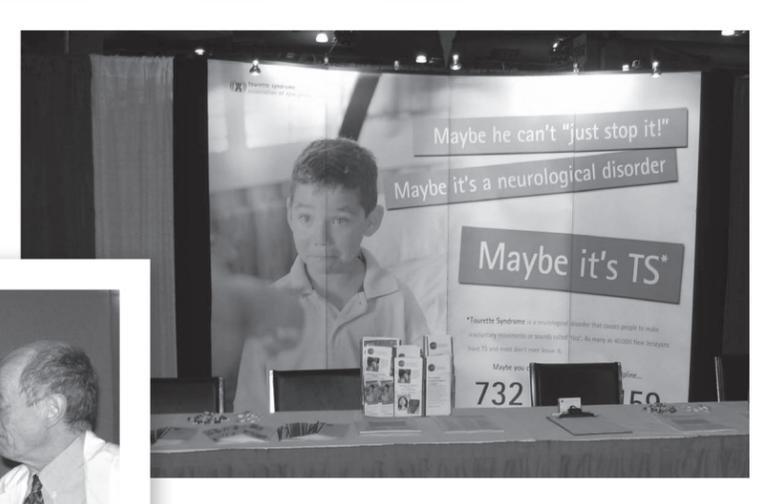
NJCTS presents grand rounds trainings to medical and mental health professionals at hospitals throughout the state.



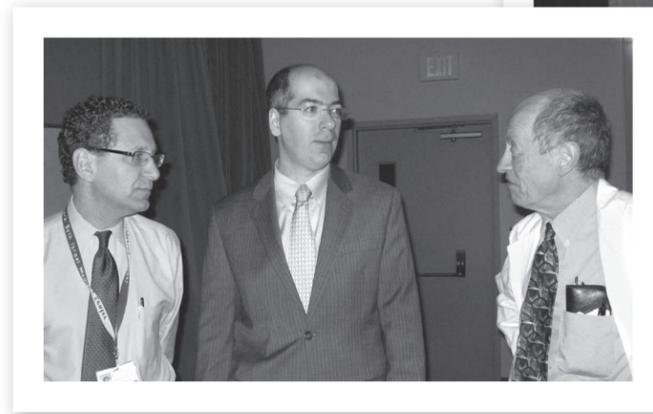
Dr. Abba Cargan lecturing to doctoral students at the Graduate School of Applied and Professional Psychology at Rutgers University in April.



NJCTS provides professional development at no cost to educators and health care professionals throughout New Jersey.



NJCTS has a presence at the region's most important professional outreach conventions. Educating professionals is an important priority.



Dr. Joshua Rosenblatt (left) and Dr. Jules Titelbaum (right), pictured here with Dr. Tolga Taneli, are both pediatric experts who attended our grand rounds presentation at Newark Beth Israel in March.



(Left to right) 2009 NJCTS Scholarship winners Syed Muzzamil and Benjamin Miller, and 2010 winners John Wiczorek and Matthew Mueller, are exemplary students, demonstrating leadership in the classroom and in volunteer pursuits despite having TS.

FAMILIES ATTEND THE NJCTS FAMILY RETREAT WEEKEND AT CAMP BERNIE



NJCTS Family Retreat Weekends empower children with TS and their siblings to understand the ups and downs of living with this neurological disorder. Our goal is to promote stronger families.

“We met families who can relate to what we are going through. There was instant understanding and fellowship. We were able to share our stories freely without being judged. It was helpful to know that we are not alone.” – C.P.

Now, families of children with TS have two “camps” to choose from. In 2010, NJCTS expanded its popular family retreat weekend to reach South Jersey through Appel Farm in Elmer. With the cut of a ribbon, an inaugural quilt and a special performance of a TS advocacy play, dozens of children and families gathered on a crisp October weekend to launch the South Jersey family retreat program. “Our camp in North Jersey has been such a success that we couldn’t wait to expand the program to reach our families in South Jersey,” said NJCTS Executive Director Faith Rice, “We expect this opportunity to double the amount of families who get to experience this special blend of fun, advocacy and arts.”

From the moment a parent suspects their child has Tourette Syndrome, NJCTS is ready to help. We provide a roadmap of services for families on the path of dealing with the ever changing challenges of TS. Through NJCTS.org, Helpline and Wednesday Webinars, NJCTS is available to provide resources 24 hours/7 days a week for individuals and families.

Being able to help parents and children understand what to expect and, more importantly, where to go for help is the reason why NJCTS exists. Executive Director Faith W. Rice knows the struggle firsthand.

“My son was trying to cope with Tourette Syndrome for years and years before it was finally- accurately-diagnosed,” said Rice, “And once it was, the doctor said there was nothing we could do. How do you say that to people?” Years later, NJCTS provides referrals to physicians specializing in Tourette Syndrome, support groups at hospitals throughout the state, a volunteer-run Helpline and education programs that tackle the issues most important to families dealing with Tourette Syndrome.



Pam and Brandon Adams take teamwork to a new level while perfecting their cupcake icing technique – a sweet activity at the South Jersey retreat.



NJCTS Executive Director Faith Rice (left) is a 2010 Russ Berrie Award recipient and is recognized for her work in founding NJCTS.

FAMILY SUPPORT



Support group volunteers show the “W sign” for “Wednesday is TS Day” in the NJCTS office. (Clockwise from center) Kara Biondo, Lauren Lindenbaum, Brad Israelsky, Roberta Israelsky, Linda Magyar and Marion Sterpe.



NJCTS members Jack and Patty Lang support TS awareness at the Statehouse in Trenton.



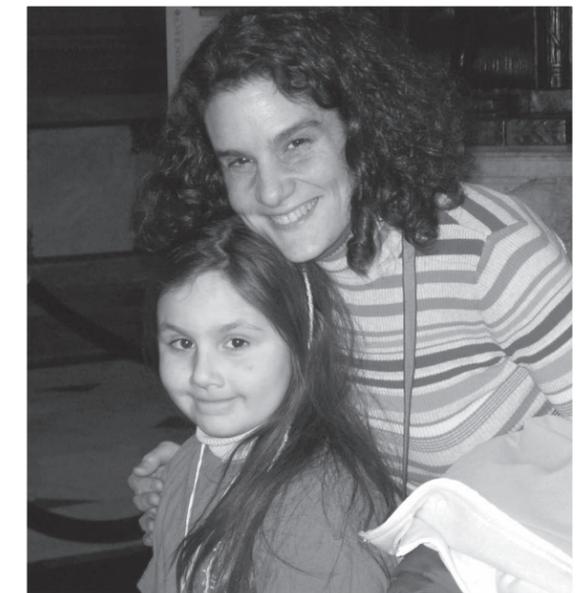
Emilio and Antonio Guzman show off the inaugural family retreat weekend at Appel Farm quilt. Each child contributed a square commemorating their favorite highlights.



Sydney Kroeter shows off her pretty pumpkin, one of many arts and crafts taking place at this highly interactive retreat.

“My son saw that there are other kids, not just himself, dealing with Tourette Syndrome. It was interesting how children talked openly about their experiences in schools and how the general public had difficulty understanding and dealing with their individual problems.”

– G.H.



Leslie Kowalski and daughter Tess share a smile at an NJCTS advocacy event.

IN 2009, THE WHEELS OF AN NJCTS YOUTH ADVOCACY ACADEMY WERE SET IN MOTION TO TRAIN INDIVIDUALS WITH DISABILITIES TO SUCCEED ON THE PLAYING FIELD OF LIFE.



Through something as simple as a T-shirt, NJCTS encourages everyone to wear their advocacy on their sleeve.

With a disability, each day brings opportunity for challenges and chances to self-advocate. NJCTS is training young adults to emerge as leaders in the fight against TS stigma. In 2009, the Young Adult Advocacy Program launched with two workshops geared to individuals ages 14-21. Through instruction, role playing and interactive breakout groups participants are given skills to advance their interest in advocacy.

NJCTS also offers peer mentoring during Family Retreat Weekends. Dean Roncati of Haworth has attended Camp Bernie since 2005, but in 2009 he was there for more than just fun. “I’m here to talk about how to deal with the pressures of life with TS,” Roncati said.

As if being a teenager isn’t hard enough, adolescents with Tourette Syndrome have to cope with being different.

“A lot of kids here [at camp] ask me, ‘How do I tell my friends I have TS?’ and I tell them to be honest. You just say, ‘You may notice I do this and act this way, it’s because I have Tourette Syndrome,’” Roncati advised, “But make sure you do your research first so you know how to explain what you have.”

His advice to anyone feeling unaccepted is to “tell an adult, make other people know what you’re going through.”

Roncati’s mentorship extended to children and adults alike. While there are plenty of parents, educators and health professionals on hand, kids and teens take comfort in knowing they’re not alone and can trust the advice of someone who has recently been through the stage they’re currently in.

“I’m just trying to help kids with their problems with friends, or worries

about side effects of medications,” said Roncati, who encourages all kids with TS to be their own advocates.

The Youth Adult Advocacy program is growing and plans are in the works to launch a Youth Advocacy Academy at Rutgers University in 2012.



“The Guys” Thomas Bryant, Aaron and David Brummer at an advocacy meeting at Rutgers University.

ADVOCACY



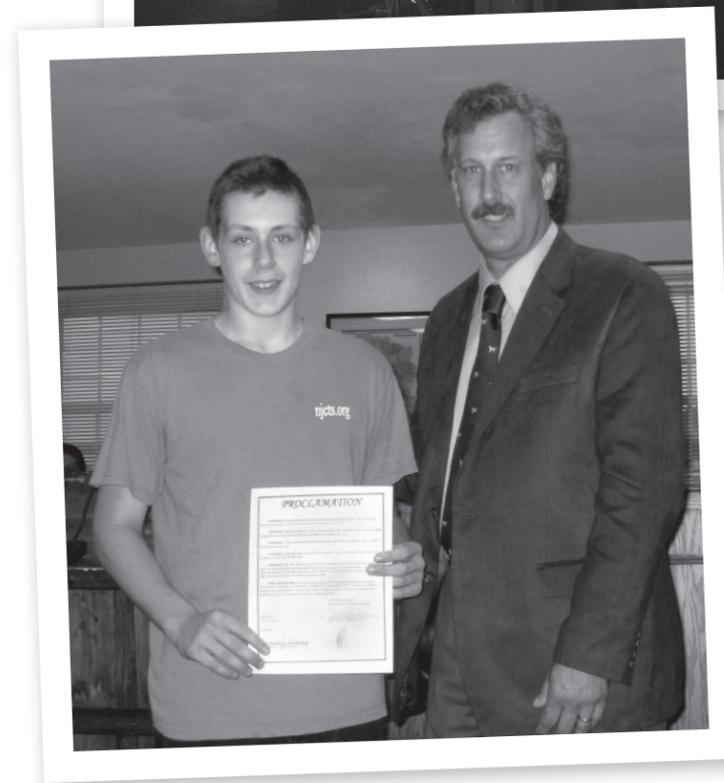
State Senator Michael Doherty visits the Family Retreat Weekend at Camp Bernie to show support for New Jersey families with TS. He's joined by Marc Brummer.



NJCTS Teen Spokesman Dean Roncati and State Senator Christopher "Kip" Bateman



NJCTS Board Member Conrad Roncati, State Senator Richard Codey, Dean Roncati, Mia Roncati and Laurie Roncati. Senator Codey is a longtime supporter of Tourette Syndrome awareness.



Drew Friedrich of Pequannock asked Mayor Joe Jorgensen to issue a proclamation on behalf of "Wednesday is TS Day." Mayor Jorgensen issued the measure of support in Drew's honor.

“Thank you so much for these [doctor referrals]. You don’t know how happy I am to find your organization and the resources you offer. We deeply thank you.” – B.K.

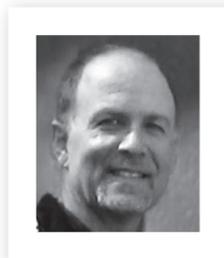
NJCTS RESPONDS TO THOUSANDS OF CALLS FROM FAMILIES AND PROFESSIONALS EACH YEAR.

*As you can see, NJCTS continues to grow and innovate despite economic challenges. Our mission is to deliver services to individuals and families with Tourette Syndrome—and until that need doesn’t exist, we will continue to offer support employing efficiencies through partnerships and collaborative efforts across the state. If you haven’t been a part of NJCTS, join us as we move forward. We’re grateful for the ongoing support of our friends, families and foundation sponsors. **Together, we’re making a difference!***

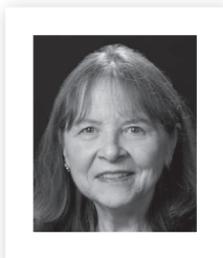
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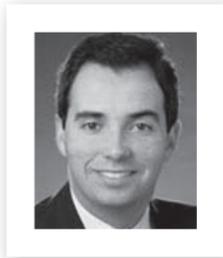
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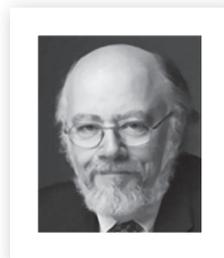


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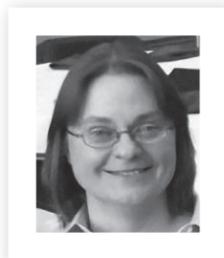


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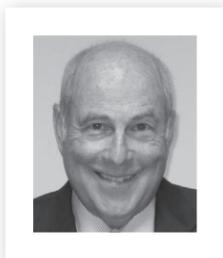
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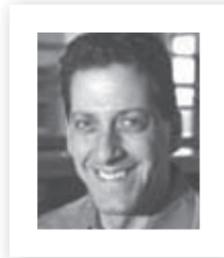
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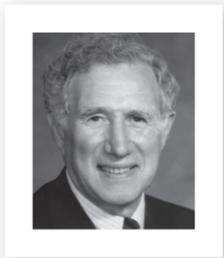
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