ENRICHING LIVES

NEW JERSEY CENTER FOR TOURETTE SYNDROME

2013 YEAR IN REVIEW

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

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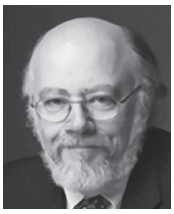

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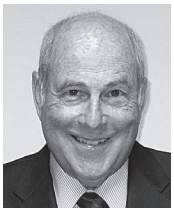

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Dear Friends and NJCTS Families,

We are approaching our tenth year as the nation's first Center of Excellence for Tourette Syndrome. Over the past decade we have set a new direction for TS research, created a generation of doctors with expertise in treating TS and provided tens of thousands of teachers across our state with strategies and tools for dealing with TS in the classroom. Each year through direct support, referrals, networking and advocacy training we have helped improve the daily lives of thousands of kids and families living with the devastating effects of Tourette Syndrome and associated disorders.

The time is right for you to get involved – be a donor, volunteer, funder, adviser – partner with NJCTS as we enter our tenth year of leading the nation with services and support for the TS community. If you're reading this, that means your life has been touched by Tourette Syndrome and you're close enough to join with us in making a difference for families dealing with TS today and for those yet to come. Please call me at 908.575.7350 to discuss where you can help. I very much look forward to your call.

Sincerely,

Faith W. Rice
Executive Director

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:

- Usually 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
- Misunderstood by the public and educators
- Underdiagnosed by medical professionals

Education Outreach

School In-Service Program

The NJCTS School In-Service Program provides valuable information about Tourette Syndrome and its associated disorders to education professionals and students in elementary and secondary schools across New Jersey. This direct outreach to those who interact with children and teens with TS grew in strength and enthusiasm in 2013.

In-service presentations, conducted by professional educators, psychologists or specially trained NJCTS Peer Advocates, aid in constructing a more positive, inclusive and successful classroom environment for students with TS and beyond.

Melissa Fowler, MA, MEd

Janine Howley, MA

Tracy Lederman, EdD

Cheryl Ludwig, MA, CCC-SLP

Richard Zakreski, PsyD

Robert Zambrano, PsyD

Julie Ryan, PsyD

Graham Hartke, PsyD

Meir Flancbaum, PsyD

Michelle Lubonski, MS Ed

Education Outreach

Youth Advocates Rally Students, Teachers and Legislators

In 2013, students in classrooms across New Jersey gained invaluable perspective about life with a neurological disorder from a group of talented NJCTS Youth Advocates. The presentations are designed to foster understanding, sensitivity and tolerance of Tourette Syndrome and its symptoms by describing the symptoms, causes and effects of the disorder. They also 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 an associated disorder such as OCD, ADHD, anxiety or depression themselves, though all have first-hand experience with one or most of them. Student-led in-service presentations are appropriate for all age groups and can be used in the school setting, for sports leagues, scout troops, camps or after-school programs.

AMANDA SILVERS

Amanda Silvers of East Brunswick talks to a psychology class at Spotswood High School about TS on behalf of NJCTS

NJCTS Youth Advocates have something special in common; they're not afraid to take tough questions. When Amanda Silvers reached out to Spotswood Public Schools to offer a peer in-service presentation, she was quickly scheduled to speak to three high school psychology classes. Impressed with her poise, honesty and message; Amanda was invited to stay the day and speak to all six classes with a total of 138 students and faculty. As always, it was time well spent. After Amanda gave a primer about Tourette – the definition of vocal and motor tics, when children are often diagnosed, who is affected by TS, etc. – she fielded an array of questions typical of many peer in-service programs:

"When did you and your family start noticing that you had symptoms?"

"Are there any medications for TS?"

"Does your Tourette ever go away?"

"Do you have a lot of friends who support you no matter what?"

"How have your teachers been about it?"

"Does it affect relationships?"

"Can you swim?"

"Does anyone ever ask you what's wrong with you?"

2013 YOUTH ADVOCATE PRESENTERS

Emily Fleischman	Tommy Licato	Sarah Baldwin
Amanda Silvers	Katie Delaney	Anna Baldwin
Grace Hawruk	Tess Kowalski	
Dylan Teator	Sarah Ethridge	

SCHOOLS PARTICIPATING IN THE YOUTH ADVOCATE PROGRAM

MADISON MIDDLE SCHOOL	Madison
MEMORIAL MIDDLE SCHOOL	Fair Lawn
EAST BRUNSWICK HIGH SCHOOL	East Brunswick
ORANGE AVENUE MIDDLE SCHOOL	Cranford
SPOTSWOOD HIGH SCHOOL	Spotswood
MILLSTONE RIVER SCHOOL	Plainsboro
HAWTHORNE HIGH SCHOOL	Hawthorne
WARREN MIDDLE SCHOOL	Warren
CLEARVIEW REGIONAL MIDDLE SCHOOL	Mullica Hill

Dare to Dream Conference

Middlesex County College
Mercer County College
Montclair University

Education Outreach

Faculty & Peer In-Service

2013 PARTICIPATING SCHOOLS

PRINCETON FRIENDS SCHOOL	Princeton
QUEEN CITY ACADEMY CHARTER	Plainfield
MARY S. SHOEMAKER SCHOOL	Woodstown
PARK MIDDLE SCHOOL	Scotch Plains
WASHINGTON STREET SCHOOL	Toms River
HIGHLAND ACADEMY	Galloway
WARREN MIDDLE SCHOOL	Warren
CLARA BARTON SCHOOL	Bordentown
OUR LADY OF MOUNT CARMEL	Boonton
TEANECK COMMUNITY CHARTER SCHOOL	Teaneck
CLEARY ELEMENTARY SCHOOL	Buena
WHITMAN ELEMENTARY	Turnersville
WASHINGTON ELEMENTARY	Turnersville
UPPER FREEHOLD REGIONAL HIGH SCHOOL	Allentown
MILLSTONE RIVER SCHOOL	Plainsboro
SOUTH PLAINFIELD HIGH SCHOOL	South Plainfield
CONOVER ROAD PRIMARY SCHOOL	Colts Neck
MOUNT PLEASANT ELEMENTARY	Livingston

Tess Kowalski presents a peer inservice to students at Millstone River School in Plainsboro on behalf of her sister, Paige

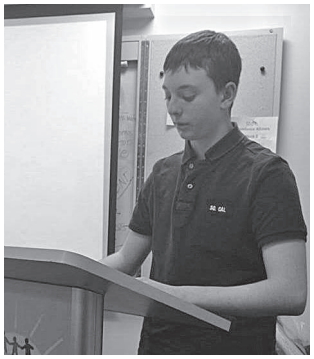
Over the years, NJCTS has reached over 60,000 New Jersey educators. In 2013 we continued our longstanding tradition of serving as a resource at the annual NJEA convention in Atlantic City

Sisters Sarah and Anna Baldwin teach peers about life with TS and the importance of accepting our differences as strengths

Education Outreach

The complexities that accompany TS and its associated conditions present a unique set of challenges to the medical and education communities. Doctors, nurses, psychologists and teachers who work with children with TS need accurate information and practical strategies. NJCTS is committed to educating professionals through a variety of outreach methods. In 2013, NJCTS delivered a full roster of workshops and lectures to thousands of New Jersey medical and education students through college and hospital lectures; and tens of thousands of teachers and administrators through professional development conferences. After the success of our 2012 Dare to Dream conference, NJCTS was invited by the New Jersey Department of Education to participate in two student leadership conferences to prepare high school students with disabilities for college and career readiness. Our reputation for delivering timely and functional information speaks for itself; and is one of the ways NJCTS is paving the way for the TS community.

TOMMY LICATO



Youth Advocate Tommy Licato describes his life with TS to doctors and medical students at Bristol Myers Squibb Children's Hospital. By participating in Patient-Centered Medical Education, Tommy is helping a new generation of doctors to see patients with greater compassion.

2013 NJCTS PRESENTATIONS THROUGHOUT NEW JERSEY

SOMERSET COUNTY LIBRARY	Bridgewater
MERCER COUNTY EDUCATION CONFERENCE	Trenton
CHILDREN'S SPECIALIZED HOSPITAL	Mountainside
BERGEN COMMUNITY COLLEGE	Paramus
PASSAIC COUNTY COMMUNITY COLLEGE	Paterson
NJEA CONVENTION & WORKSHOP	Atlantic City
RUTGERS UNIVERSITY	Piscataway
OVERLOOK MEDICAL CENTER	Summit
NJ DEPARTMENT OF EDUCATION YOUTH TRANSITION CONFERENCE	Edison
NJ STATE TRANSITION COMMITTEE	Trenton
SUMMER INCLUSION CONFERENCE	Ewing
AAP SCHOOL HEALTH CONFERENCE	Somerset
SCHOOL NURSES CONVENTION	Somerset
COUNCIL FOR EXCEPTIONAL CHILDREN	Ramapo

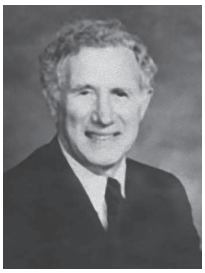
Red Flags Workshop in Bridgewater

The three-hour workshop, which was geared primarily toward early childhood and elementary educators, discussed 10 possible "red flags" – markers we look for that generally indicate a learning disability or learning difference in a student – that educators and parents might look for in a child with Tourette Syndrome, ADHD, OCD and/or other associated neurological disorders. Red flags include immaturity, trouble with transitions and following directions, sensory issues and impulse control.

Here is a sampling of feedback our inservice and college workshop programs receive on a regular basis:

- *"This was one of the best workshops I have ever attended. Thank you for sharing your knowledge and stories."*
- *"It was an excellent presentation. She provided a wealth of information in only an hour."*
- *"A lot of my misconceptions were cleared up. It has helped me to understand how my student feels and how to recognize a tic."*

Education Outreach



2013 Scholarship Dedicated to the Memory of NJCTS Adviser

Since 2001, the NJCTS Children's Scholarship Award has been presented to more than 200 outstanding high school seniors in the state of New Jersey who have excelled in their schools, communities and lives – representing themselves as excellent advocates for Tourette. The 2013 Scholarship was dedicated to the memory of Dr. Nathan Weiss, President Emeritus of Kean University, who was a longtime friend and trusted adviser to NJCTS.

FIRST PLACE WINNER

AMANDA SILVERS

East Brunswick

Amanda's winning essay was titled "Taking Control" and while at East Brunswick High school she was a member of the National Honor Society and Tourette Syndrome Peer and Patient Educator, and has been part of East Brunswick's student athletic training and girls soccer teams, the United Synagogue youth group and Fast Break Basketball. She also has tutored other students, taken piano lessons and engaged in various forms of youth council community service.

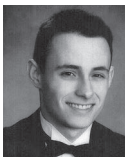
SECOND PLACE WINNER

ELIANA ROTH

Cherry Hill

Eliana's winning essay was titled "True Medicine" and during her years at Cherry Hill High School West she was a member of the National Latin Honor Society, the National Honor Society and has been part of ballet, weight training teams and synchronized figure skating teams – including the Skyliners Team USA and Junior World Team. Her exploits have been featured on the "Today Show," and she has competed in prestigious events such as the French Cup.

HONORABLE MENTION WINNERS



Evan Bisirri
Marlton

Ellen Carpinelli
Summit

Jordan Chervin
Manalapan

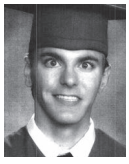
Jayne DeRogatis
Basking Ridge

Emily Fleischman
Fort Lee

Lauren Francis
Iselin

Conor Hilliard
Pennington

Brandon Moszkowicz
Collingswood



Robert O'Hearn, Jr.
Marlton

Anthony Rodolico
Totowa

Paul Rothlauf
Ringwood

Connor Travis
Berlin

Benjamin Weinfield
East Brunswick

Education Outreach

NJCTS Educators of the Year Give Encouragement and Confidence

Since 2001, NJCTS has recognized outstanding educators who have made a difference in the lives of students with TS. The 2013 nominations were so compelling, NJCTS broke with tradition to select three outstanding winners.

ELIZABETH VIOLA

Elizabeth Viola, a fourth-grade teacher at Parsons Elementary School in East Brunswick, made a friend for life in her student, Ally Abad. Even though Ally is on her way to high school, Miss Viola is still involved in her accomplishments by attending her recent talent show and emailing Ally's mother for updates on her progress in school.

"I don't know what I would have done if I didn't have her on our side," Ally's mother Susan said of Viola, who regularly kept a set of color-coded index cards – white for things that worked well when teaching Ally, red for things that didn't pan out.

"[Fourth grade] was an extremely difficult year [for Ally], and Miss Viola worked hard to be the best teacher she could be to my daughter, letting nothing get in the way of providing Ally with a stress-free, caring learning environment," she said.

Elizabeth Viola, left, receives her NJCTS Educator of the Year Award from former student Ally Abad. The two keep in touch as Viola has continued to support and check up on Everett since she was in her fourth grade class.

KEVIN HAJDUK

School principals have a lot on their plate, but Kevin Hajudk makes time for his students. When developing an anti-bullying assembly at South Plainfield Middle School, Hajduk asked 13-year-old Tommy Licato for his input and if he'd like to speak. For a young man eager to spread the word about Tourette Syndrome and advocate on behalf of those with special needs who are stigmatized, this was a chance to change lives.

"Kids, even upperclassmen, came up to me after school and congratulated me on the assembly," said Licato, an active NJCTS Youth Advocate who regularly speaks to students, teachers, parents and health-care professionals about TS. "It was wonderful. He said I was a natural and that I should look into being an advocate for Tourette. That meant the world to me."

Hajduk also was highly supportive of Licato's idea for "Dare To Be Different" a day in which students could demonstrate – through clothing and other means – what they loved about themselves that made them different.

"He is a fine role model for all the youth of South Plainfield," said Licato's mother, Karen, "All educators should be as caring and involved in the lives of our youth. I truly believe that Tommy would not be as comfortable speaking out and being an advocate without this principal being so involved and encouraging him."

South Plainfield Middle School Principal Kevin Hajduk, right, receives his NJCTS Educator of the Year Award from Karen and Tommy Licato.

LOREN MACTAGGART

The time teachers invest in their students never returns empty. Loren MacTaggart, a math teacher at Summit High School, went out of her way to make sure Ellen Carpinelli was learning in an environment where she would thrive.

Margaret Brody, Ellen's mother, said MacTaggart regularly worked with Ellen before school to make sure she was on top of what was learned in class. This was a way to help with Ellen's nonverbal learning disorder, according to Brody. The NJCTS Children's Scholarship winner credits MacTaggart because she "made her want to go to math class each day," and checked in on her during free periods just to see how she was doing with her schoolwork and life in general.

"Mrs. MacTaggart is a woman who is honestly a genius. She helped someone who had never been able to understand math do well in a challenging course," said Ellen, who regularly received tutoring at home, before school and after school from MacTaggart to help her prepare not only for everyday class, but also for the PSAT and SAT. "I can't say enough about the difference she has made in my life. She deserves this award for making such a difference in the life of a person with Tourette Syndrome and in the lives of so many other students."

Medical Outreach

Yale University Lauds NJCTS Patient-Centered Medical Education Program

When the nearly 120 Yale School of Medicine faculty and students in child psychiatry, psychology, social work and pediatrics crammed into the Cohen Auditorium, they knew the Patient-Centered Medical Education (PCME) presentation delivered by the team from the New Jersey Center for Tourette Syndrome & Associated Disorders (NJCTS) would provide insight into their areas of expertise and study.

They were aware that a rare opportunity to hear directly from adolescents, young adults and parents about the perspectives, stresses and needs of living with TS and its associated neurological conditions was in front of them and could help them better diagnose and treat conditions such as TS, which affects 1 in 100 kids and adults.

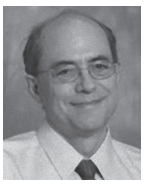
What they didn't expect was the kind of program that, in their own words, can serve as an educational model for instructing physicians and family practice residents specializing in just about every type of medical condition across the nation.

But that's what they got when NJCTS Peer Advocates Grace Hawruk, 17, Tommy Licato,14, and Tess Kowalski, 14, teamed up with Dr. Stuart Green of Overlook Medical Center in Summit, NJCTS Education Outreach Coordinator Melissa Fowler and Tess' father, Tim Kowalski, to – in the words of Dr. Andres Martin, Editor of the Journal of the American Academy of Child Psychiatry, "put a human face on the problem."

"The kids were really terrific," added Dr. Martin, who along with Yale Child Study Center Professor of Child Psychiatry Dr. Robert King, introduced the PCME panel. "It made all the difference hearing from the kids and parents themselves, rather than just referring to charts and numbers. It was a real reminder to us all of why we are here and doing what we're doing."

Dr. Jim Leckman

Professor of Pediatrics and Psychiatry, Yale Child Study Center



"It was a wonderful opportunity for me to see in action the things I try and do myself," said Dr. Leckman, who has worked with individuals affected by Tourette Syndrome for more than 30 years. "To make this happen around the country and around the world is exactly what needs to be done. It will only make things better for all of us."

The next generation of doctors and the country's most influential medical professionals were impressed by the NJCTS Youth Advocate PCME model.

Heidi Grantz

Clinical Director, Yale Child Study Center's TS/OCD Clinic

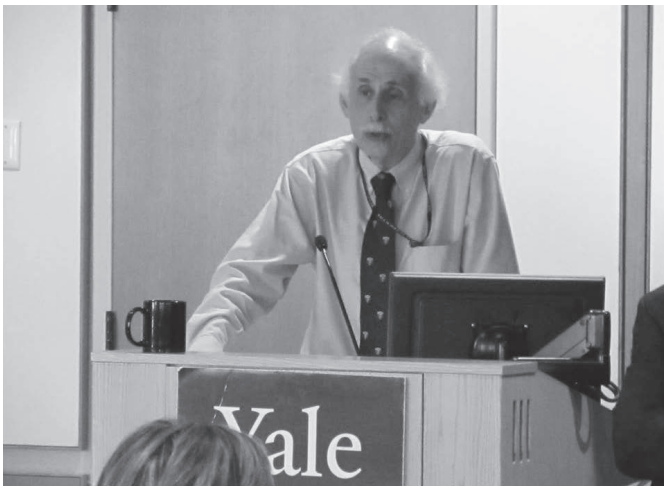
"This presentation is something we would love to be able to implement here, where we can have our patients learn to become advocates," Grantz said. "What was most impressive about what they had to say was how they find TS has defined their lives in really positive ways, ways that have provided them with confidence to move forward in life."

Youth Advocate Grace Hawruk shares her experiences navigating adolescence with TS

Youth Advocate Tess Kowalski

Medical Outreach

NJCTS was invited to present "Tourette Syndrome Youth Advocates: A Patient-Centered Education Model in Action" to medical students at Yale University.



Dr. Robert King, Medical Director of the Yale TS/OCD Clinic provides insight into the complexities of this neurological disorder.

NJCTS Education Outreach Coordinator Melissa Fowler, MA, MEd, offered insight into the connections at home and school - adding another dimension of understanding for the medical students and instructors in the audience.

Dr. Stuart Green of Overlook Medical Center explains how he worked with NJCTS to develop the patient-centered model for TS which includes teens and parents to help clinicians gain a greater understanding of the struggles and joys that are part of life with Tourette.

Dr. Lawrence Vitulano

Associate Clinical Professor, Yale Child Study Center's TS/OCD Clinic

"I have been working in the field for 28 years, and this truly was one of the more impressive presentations I've heard," Dr. Vitulano said. "The kids weren't merely primed to tell us what they should be telling us. Their stories were personal and will have a profound effect on me as I continue to study self-esteem as one of the collateral problems of having Tourette Syndrome."

Youth Advocate Tess Kowalski and her father, Tim, discuss family life with TS and its associated conditions.

Medical Outreach

Since its inception in 2010, the Patient-Centered Medical Education program has been presented by NJCTS at more than 15 hospitals in New Jersey. Allowing young people and their families to share TS from their perspective serves as an invaluable tool for resident physicians and other healthcare professionals.

Each PCME presentation is led by a medical professional with expertise in diagnosing and treating TS and is designed with the following learning objectives in mind:

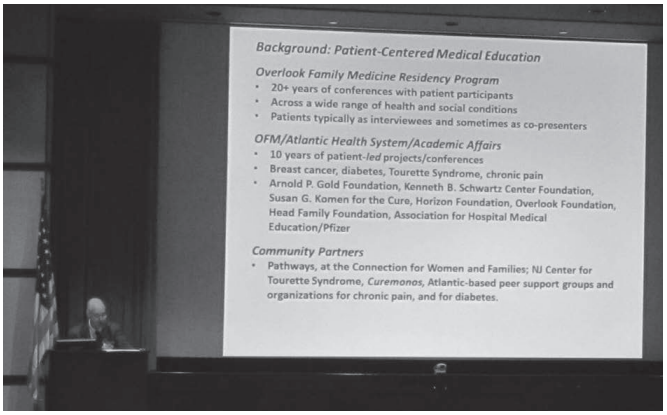
- Identifying and differentiating between the signs and symptoms of patients with varying tic disorders
- Describing and identifying the most common associated conditions in individuals with TS
- Giving the latest advances and comprehensive approaches in treatment for individuals with tic disorder
- Presenting a patient-centered perspective of life with TS

PCME GRAND ROUNDS PARTICIPANTS IN 2013

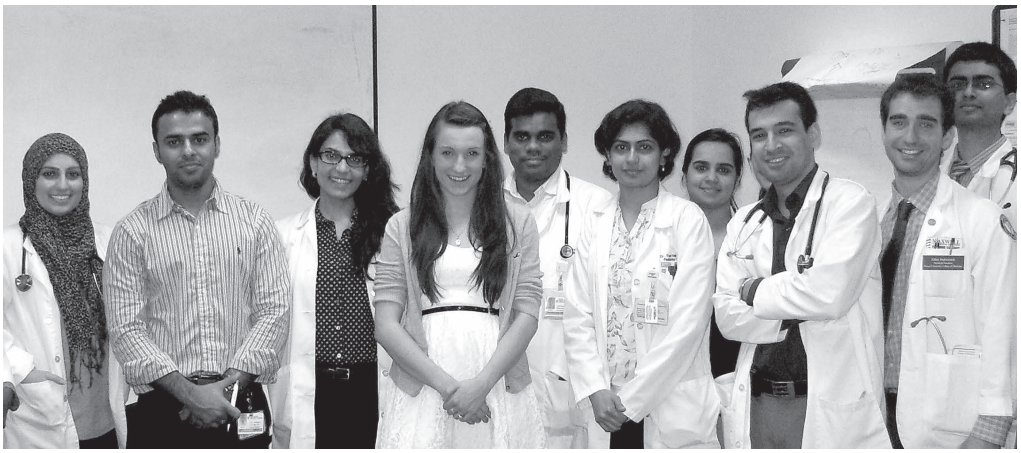
ROBERT WOOD JOHNSON UNIVERSITY HOSPITAL	New Brunswick, NJ
ST. PETER'S HOSPITAL	New Brunswick, NJ
UNIVERSITY OF MEDICINE AND DENTISTRY	Newark, NJ
YALE UNIVERSITY	New Haven, CT
CHILDREN'S SPECIALIZED HOSPITAL	Mountainside, NJ

"The attendees gained valuable insight into Tourette Syndrome, and came away with a dramatically expanded perspective on the difficulties patients and their families face"

~ Dr. Bill Bernstein of The Children's Hospital at Saint Peter's University Hospital



NJCTS conducts trainings, workshops and grand rounds presentations with the latest in TS research and treatment to practicing clinicians across the state



NJCTS Youth Advocate Grace Hawruck meets with clinicians and medical students following a PCME presentation at St. Peter's hospital in New Brunswick.

"I learned a whole new perspective of the condition, which cannot be described in written words in the books that we spend years reading."

~ Dr. Shobhit Jain, chief pediatric resident at Goryeb Children's Hospital

Medical Outreach

Preparing a New Generation of Healthcare Professionals to Meet the Needs of Individuals with TS

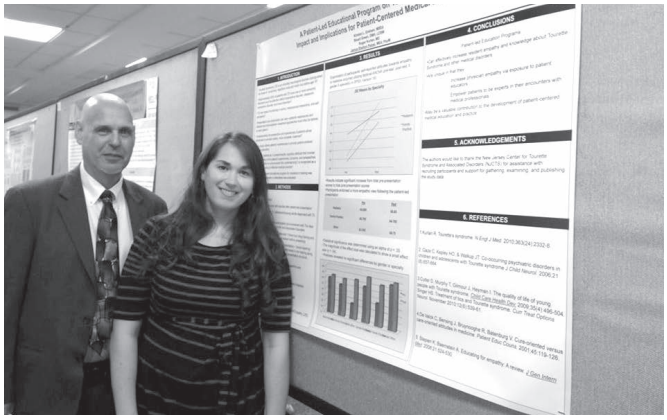
What makes NJCTS unique is its collaborations and partnerships with leading universities and experts in neurology, psychology and education. By drawing upon these resources, NJCTS is a world leader in training and information for medical professionals. In 2013, NJCTS and the Rutgers University School of Applied and Professional Psychology presented Habit Reversal Training Exposure and Response Prevention Therapy for Tourette Syndrome and Obsessive Compulsive Disorder, an intensive clinical workshop for psychologists.

Over the course of the day-long program, leaders from the TS Clinic at Rutgers provided updated information about Tourette Syndrome and approaches to treatment using the latest research. Participants learned how to apply Habit Reversal Therapy to patients with tic disorders and additional methods to augment treatment for even greater success.

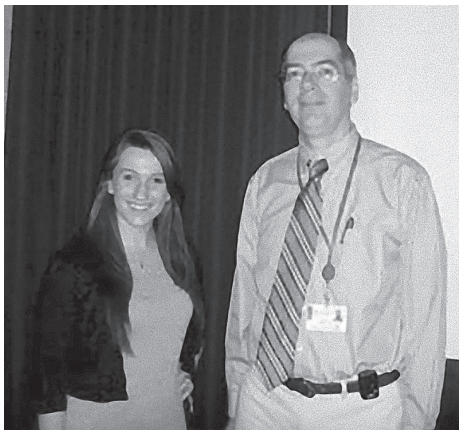
To address the needs of individuals with obsessive-compulsive disorder, workshop participants were shown key treatment components of Exposure and Response Prevention Therapy (ERP) in which a person with OCD is therapeutically guided to confront and conquer the intrusive thoughts or fears that interfere with their daily life.

This cutting-edge training session was delivered by Lori Rockmore, Psy.D, Clinical Director of the Tourette Syndrome Program at Rutgers; Meir Flancbaum, Psy.D, Post-Doctoral Fellow at Behavior Therapy Associated in Somerset and Assistant Research Director of the TS Clinic at Rutgers; and Shawn Ewbank, Psy.D, senior psychologist at the Manhattan Center for Cognitive Behavioral Therapy and assistant clinical director of the TS Clinic at Rutgers.

In 2013, NJCTS Medical Outreach programs delivered in-person training to over 300 physicians.



Dr. Stuart Green and NJCTS's Kirsten Graham present the latest collaborative research and patient-centered training at Morristown Memorial Hosptial's prestigious yearly research conference



Grace Hawruk and Dr. Tolga Taneli deliver a grand rounds presentation at UMDNJ where he is director of the Division of Child and Adolescent Psychiatry.

NJCTS maintains a Physician Referral List (PRL)is a direct link for families and professionals to access more than 200 medical professionals who have expertise in treating TS and associated disorders (ADHD, OCD, anxiety, depression, etc.) The list is compiled from interviews with clinicians and recommendations from our families and other clinicians. The PRL 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 these areas. The medical professionals on the PRL include:

- Neurologists
- Psychiatrists
- Psychologists
- Social workers
- Developmental pediatricians

Family Support

Kids and Families Find "Freedom to Be Themselves" at 9th Annual Family Retreat Weekend

Having a place where kids with TS can gather and enjoy fun without the feeling of being different is so important to NJCTS. It's why we all look forward to the annual Family Retreat Weekend at Camp Bernie. In addition to the Friday night campfire and Saturday night Talent Show, campers also enjoyed candid information sessions.

Kids were given the chance to talk and ask questions to teen mentors in a special panel discussion setting. The questions were honest, sincere and gave great encouragement to younger kids who wanted to know what life holds in store for them. (The consensus: TS doesn't have to hold you back from teenage fun!) Parents gathered for a special, all-access question and answer session with Dr. Tolga Taneli.

A place to gather for fun, support and practical life skills – a proud accomplishment for NJCTS. NJCTS has welcomed more than 2,000 children, parents and siblings since the first Family Retreat Weekend.

From left, Gayle Forman, LCSW, Assemblyman Eric Peterson, Dr. Lisa Cox and NJCTS Executive Director Faith W. Rice following the "Family Dynamics" workshop. Assemblyman Peterson (R-23) attended the workshop while touring the 9th annual Family Retreat Weekend

We couldn't make the weekend a success without a team of outstanding volunteers:

Marilyn LaMarca
Liz LaMarca
Kim Rice
Mike Rice
Matt Sullivan
Steven Lindenbaum
Al Stark
Amanda Silvers
Lily Deng

And featured speakers:

Tolga Taneli (MD)
Gayle Forman (LCSW)
Lisa Cox (PhD, LCSW, MSW)

Thank you to our sponsors:

The Brad Cohen Tourette Foundation
The HAPI Foundation
ShopRite of Hunterdon
Wegmans of Bridgewater
Costco

Yes, it's fun to stay at the Y-M-C-A Camp Bernie for our Family Retreat Weekend!

It's more than just a climb – the ropes course at the Family Retreat Weekend is about facing your fears, building confidence and encouraging others. The challenges were led by volunteers from the TS Clinic at Rutgers.

"We love the whole weekend; from the reassurance that other families are going through what you're going through, to the great advice and new paths that you seek as a result of the interactions, to the positive social experience for my children. The whole weekend is soul affirming."

Family Support

Teen mentors tackled the younger kids questions about growing up with TS at a special panel discussion moderated by Dr. Lisa Cox

Barbershop quartet Gimmie Cool Water treated campers to a medley of favorites. Alan Hardy, Mark Van Bruggen, Richard Nurse and NJCTS volunteer Matt Sullivan dazzled with their harmonies.

Graduate Students from the NJCTS TS Clinic at Rutgers University's School of Applied and Professional Psychology who conducted work-shops for our campers:

Caroline Axelrod

William Benson

Alycia Davis

Logan Durland

Caroline Haim

Members of the Rutgers University Cell and DNA Repository who set up a convenient one-stop mini-clinic where families interested in participating in the TS Genetics Repository could enroll:

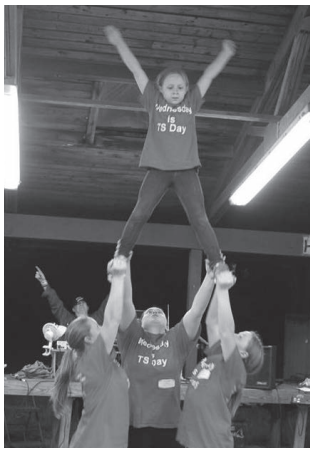
Donna Tischfield
(BSN, RNC-NICU)

Jay Tischfield
(PhD, FFACMG)

Nawei Sun (PhD)

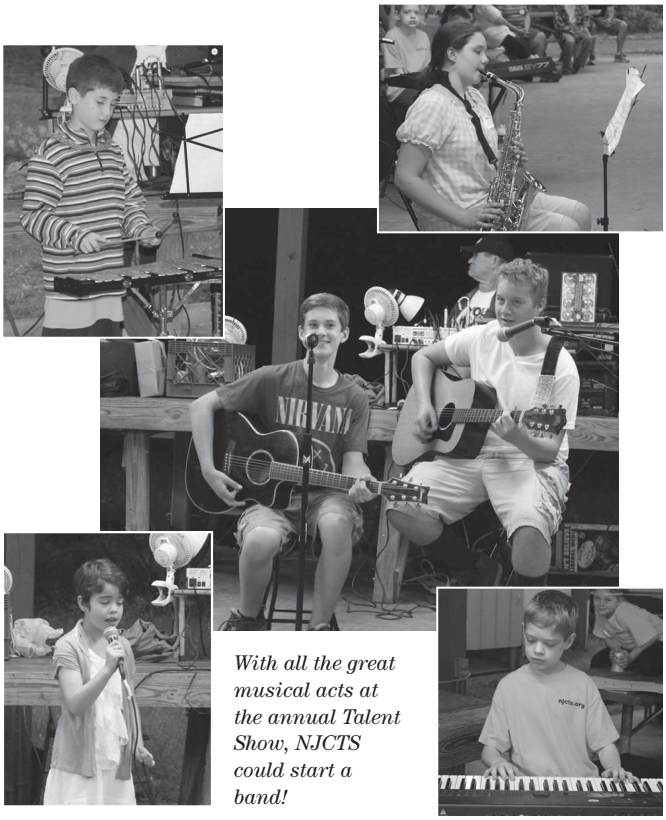
Cara Nassello (PhD)

Hera Potamianou



The Silenzio family takes the Talent Show to new heights

Sisters Adrianna and Isabella Lopez perfect their souvenirs by adding just the right touches of paint. Crafts like rock painting are a hit among kids of all ages at the Retreat.



With all the great musical acts at the annual Talent Show, NJCTS could start a band!

"This weekend is the most important time of the year for us. It is critical that my children and I get to be around others experiencing similar things surrounding their TS."

Family Support

☛ **In 2013, the NJCTS Wednesday Webinars welcomed 783 live attendees. Over the course of the year, thousands of prior presentations were downloaded from the Webinar Archive at NJCTS.org.**

Wednesday Webinar Series is Changing Lives Around the World

While NJCTS offers a variety of school inservice programs, workshops and conferences; the need for accurate and practical information about TS and its associated conditions extends far beyond New Jersey. The Wednesday Webinar series brings world-class seminars electronically to families, medical professionals and educators. Celebrating its 5th year in 2013, hundreds of parents and professionals worldwide attended presentations delivered by NJCTS' cadre of experts in neurology, psychiatry, psychology, education and law. Now a recognized and trusted source, NJCTS welcomes participants from almost all 50 states and several countries including Canada, the Virgin Islands, the United Kingdom and Guatemala to name a few.

Attendees have the opportunity to ask questions during the live presentation and are invited to access a web-based chat room where they can post additional questions to the topic-presenter. Credits are offered to qualified professionals. All presentations are archived on NJCTS.org for continued viewing.

Stephanie Goodman, CNC

Food Choices: How Do They Affect Our Performances

Ms. Goodman explores much of today's information and misinformation about nutrition – including signs of food allergies or sensitivities. The presentation also features practical ideas on changes to our diets to improve our health and nutritional intake.

Steven E. Tobias, PsyD

A Systematic Approach to Parenting

Dr. Tobias offers insight on how to parent our children systematically rather than emotionally. He suggests that what works for one child may not work for another; and how getting the results we want often means taking a different approach.

Graham Hartke, PsyD

iSocialSkills: Strategies to Help Students, Parents, and Educators

Dr. Hartke discusses the impact technology has had on communication, learning, attention, and socialization in today's society. He then gave us strategies to help students, parents, and educators reduce risks, cope with challenges, and utilize technology in pro-social ways.

Cyber Safety Guide for Parents and Educators

Dr. Graham Hartke presents strategies for preventing and responding to cyberbullying and risky online behaviors in children and adolescents.

Mark Mintz, MD

Medication Management for Tics and Tourette Syndrome

Dr. Mark Mintz explains the biological rationale for using medications for tics and TS, and the various types of drugs that have shown to be beneficial; and the risks and benefits of such therapies. This presentation is for professionals and families dealing with Tourette and associated disorders such as OCD, ADHD, anxiety, depression and mood disorders.

Robert Zambrano

Dealing With School Refusal

Dr. Robert Zambrano discusses some of the underlying anxieties that cause school refusal and gave appropriate interventions. He also covers a collaborative approach between parent, student and school.

Shawn Ewbank, PsyD

The NJCTS Tourette Syndrome Program at Rutgers University: A Model Resource for the TS Community

Dr. Ewbank, clinic director, explains how the NJCTS Tourette Syndrome (TS) Clinic works and the services it provides from counseling to research to training of doctoral students. This presentation also features an in-depth look at the treatments offered at the clinic such as cognitive-behavioral therapy, Exposure and Response Prevention (ERP), and Comprehensive Behavioral Intervention Therapy (CBIT/HRT).

Michael Osit, EdD

Holiday Stress: Coping Strategies for Parents and Kids

Dr. Michael Osit discusses helping parents identify signs of stress in themselves and their children; causes of stress, and ways to prevent and manage holiday-related stress.

Family Support

Support Groups Re-launch in 2013 as Parent Connection

For over a decade, NJCTS and the Tourette Syndrome Association of New Jersey (TSANJ) have partnered with hospitals throughout the state to offer parents a place to gather for support on a regular basis. In 2013 the support group program re-launched as the Parent Connection program. "We changed the name of the support groups to Parent Connection to highlight that parents can go to meet other parents going through similar issues," said NJCTS Family Outreach Coordinator Leanne Loewenthal, MSW, "Parents often tell us they feel alone in all of this and the Parent Connection meetings reduce that isolation." The following is a list of regional "connection points" where parents can engage in face-to-face discussion, encouragement, friendship and networking with other TS families:

Atlantic/Ocean: Richard Stockton College
Burlington/Camden: Virtua-Marlton
Middlesex/Union: JFK Medical Center
Somerset/Hunterdon: Somerset Medical Center
Morris/Sussex: St. Clare's-Denville

NJCTS Answers the Call – 1,987 times in 2013

The phone rings and it's often a parent looking to find a doctor specializing in TS; an educator trying to help a student; a social worker looking to make the right connections for a client- NJCTS offers family support in many different ways. We know that 1 in 100 people show signs of TS- so it's no surprise that our phone is always ringing- with 1,987 calls for help in 2013. Here's what we're doing:

- A mother from Union County called because her 9-year-old with TS and ADHD needed a referral for psychiatrists and psychologists who have experience treating Tourette. The current pediatrician prescribed medication for the child's ADHD that caused the tics to worsen. In addition, the woman was looking for advice on working with her school to ensure the proper special education program for her child. NJCTS was able to provide a list of mental health professionals in her area who specialize in TS and ADHD and literature on accommodations in school and links to webinars on this topic.

- A doctor from Children's Specialized Hospital referred a parent from Somerset County to NJCTS for mental health referrals and advice on how to put together a 504 plan for her child's success in the classroom. NJCTS was able to connect this parent with a list of mental health professionals in her area as well as articles guiding her through the process of working with her child's school to address special education needs.

- A social worker who attended an NJCTS school in-service directed a mother to call regarding her 9-year-old son with a humming tic and trouble focusing. NJCTS provided the mother with a list of neurologists and other physicians who specialize in tics and to help with strategies for dealing with lack of attention and began the process of setting up a peer advocate presentation for the whole school.

- A mother from Middlesex County with an 11-year-old daughter called NJCTS in search of treatments for tics that do not involve medicine. She was given information about Habit Reversal Therapy.

- A 15-year-old diagnosed with TS in an Essex County hospital. He was brought to the hospital by police after expressing suicidal thoughts online. The young man has blinking and throat-clearing tics which were initially diagnosed as allergies by his pediatrician. His mother reached out to NJCTS for more information on TS and a roadmap of what to do next. She was assisted with finding a doctor who could treat her son and was referred to the Rutgers TS Clinic.

- A Middlesex County father called for help with his 19-year-old son with TS and OCD. His son would like to continue his education and get a job- but his fear of germs is making his life difficult. This father is looking for local doctors so that his son, who can only drive short distances, can get treatment on his own. He was given a list of local TS experts.

- A mother from Gloucester County called in search of a doctor specializing in TS so that her son, a high school senior, could be properly assessed for a Tourette diagnosis and help with his tics. She was referred to the appropriate clinicians and invited to the next Burlington/Camden Parent Connection meeting.

- A mother from Nashville, TN called because her 7-year-old son was recently diagnosed with TS. She said she felt very alone and had many questions about the diagnosis, treatment and how to handle TS with his school. Although we were unable to find doctors in her area, NJCTS did connect her with several families in New Jersey who were happy to exchange e-mails, a link to webinars and articles on TS diagnosis, treatment, family support and school accommodations.

NJCTS VOLUNTEER NETWORK
We couldn't continue to provide world class outreach for the Tourette Syndrome community without our network of volunteers who helped us accomplish the following in 2013:

EVENT VOLUNTEERS
- Family Retreat Weekend at Camp Bernie
- NJ Walks for TS at Mendham and Ramapo
- NJCTS Parent Connection facilitators
- Annual New Jersey Education Association (NJEA) Convention in Atlantic City

OFFICE VOLUNTEERS
- Contacting medical professionals on our Physicians Referral List (PRL) to update our records
- Mailings
- Flyer distribution
- Grant writing
- Fundraising
- Seeking corporate sponsorship opportunities
- Graphic design

PRESENTATION OPPORTUNITIES
- Teens for the Youth Advocate Program
- Families for the Patient-Centered Medical Education Program

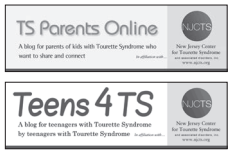
Family Support

Social Media & Blogs

Part of NJCTS' commitment to providing critical support and information to families means putting it in the most approachable terms in a variety of different platforms. People with TS and those who love them made important and poignant connections through NJCTS' social media channels – NJCTS.org, Facebook and Twitter. Our parent and teen blogs continued to grow in 2013 as well. With ever-increasing numbers of page hits, followers and likes; here's a look at what our community is creating:

Blogs:

TSParentsOnline www.njcts.org/tsparents
Teens4TS www.njcts.org/teens4ts



TSParentsOnline and Teens4TS are online communities for parents and teenagers affected by Tourette Syndrome from all over the world. These pages regularly feature touching stories, new ideas, personal experiences, and a glimpse into the hopes and dreams of people who are looking for others to identify with what they are going through. In 2013, the blogs received over 52,000 hits on more than 550 posts from across America and several countries worldwide. Teens4TS is a comfortable atmosphere where adolescents can share their thoughts and creative expressions (like poetry and music) on topics ranging from relationships, bullying and managing tics. TSParentsOnline allows concerned mothers and fathers to share strategies, frustrations and encourage one another.

NJCTS.org www.njcts.org

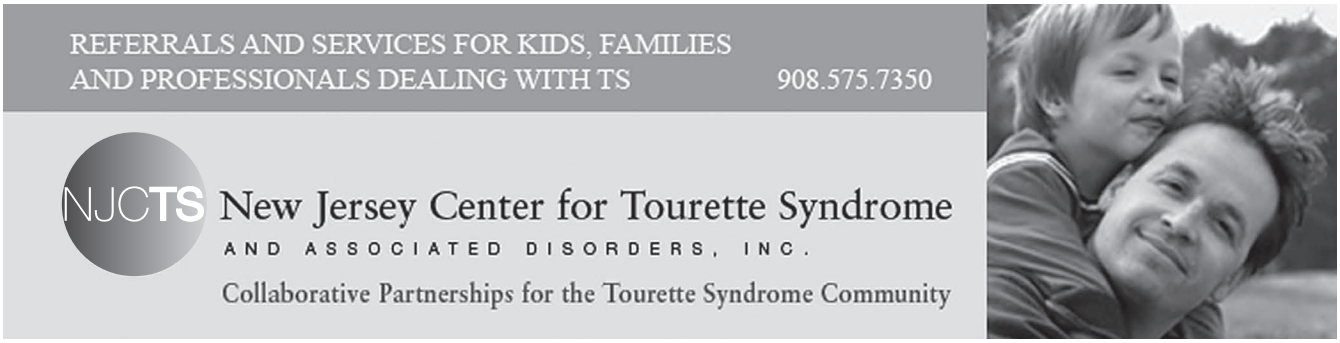
NJCTS's website offers resources for families including assistance for kids in school, scholarships and awards; as well as a host of information for educational and medical professionals. A complete list of support groups, links to TS resources and a history of our organization are just a few of the other features of the site which receives as many as 130,000 hits per month. Visitors can view archived presentations and sign up for upcoming events like seminars, Wednesday Webinars, advocacy events and more.

Facebook www.facebook.com/TouretteSyndrome

NJCTS provides a beacon of support and information for people living with TS around the world through social media outreach and Facebook has caught the attention of thousands in 2013. As the number of views, likes and comments continues to grow, each visitor is reminded of the services and community offered by NJCTS.

Twitter http://twitter.com/NJCTS

NJCTS relies on Twitter to call attention to issues of interest to the TS community at home and around the globe- ranging from local event reminders to breaking news of interest to families and professionals with interest in TS and its associated conditions. By the end of 2013, NJCTS reached over 3800 followers- 327 more than the previous year alone!



www.NJCTS.org

Awareness & Advocacy

Record Crowd Beats High Wind and Low Temperatures to Walk for TS in Mendham

When NJCTS launched the NJ Walks for TS program in 2010, it had the vision of the New Jersey Tourette community assembling en masse to promote awareness and advocacy for a neurological disorder that remains misdiagnosed and misunderstood by the general public, education and medical professionals.

That mission is not yet fully accomplished, but it is a lot closer to becoming a reality after the 4th annual NJ Walks for TS at Mendham on November 23 drew the program's largest crowd and greatest fundraising effort to date.

Despite bone-chilling temperatures and brisk winds, more than 400 runners, walkers, volunteers, legislators and members of the general public from more than half of New Jersey's 21 counties descended upon Borough Park and donned bright orange and green TS awareness T-shirts to support not only NJCTS, but their family, friends, co-workers and the many others affected by Tourette Syndrome.

The NJ Walks for TS at Mendham fundraising site remained open through December 2 and received additional donations that helped surpass the goal of raising $50,000 to fund the organization's landmark School In-Service Program, which seeks to educate students and teachers at schools in every corner of New Jersey about TS, anti-bullying initiatives and self-advocacy.

One of the School In-Service Program's presenters, Howell resident Tracy Lederman, Ed.D., is so enthusiastic about the program's success and what it has done to help her 12-year-old son that her family rented a big yellow school bus to ferry 40 of her relatives and friends to Mendham for the event. Lederman's son and his cousins ran the entire route and were among the first to cross the finish line.

"We were so excited to get off that bus and participate in the walk," said Lederman, "The School In-Service Program is one of the most important aspects of what NJCTS does. Every school in this state needs to realize the importance of this educational tool and how it can benefit their students, teachers and parents."

Honorary Committee members Assemblyman Anthony Bucco, Congressman Rodney Frelinghuysen, NJCTS Executive Director Faith W. Rice and Youth Advocate Tess Kowalski prepare to hit the trail

Denise Heimowitz gathered 19 friends and family for "Team Becca", one of our largest. 16-year-old Alec Wolf rallied 24 walkers for his team "Alec's World" and Greg Miskell brought 14 members for "Team E"

The Honorary Committe for the 2013 walk included: soccer superstar Tim Howard, WFAN's Craig Carton, Dr. Jay Tischfield, State Senator Christopher "Kip" Bateman (R-16), Dr. Robert King of the Yale Child Study Center TS/OCD Clinic, State Senator Michael Doherty (R-23), Dr. Stuart Green of Overlook Medical Center, State Senator Anthony Bucco (R-25), Rebecca Spar, Esq. education rights attorney for Cole Shotz of Hackensack, State Senator Loretta Weinberg (D-37), Assemblyman Troy Singleton (D-7), Congressman Leonard Lance (R-7), Assemblyman Jack Ciattarelli (R-16), Congressman Rush Holt (D-12), Assemblywoman Donna Simon (R-16), Congressman Rodney Frelinghuysen (R-11), State Senator Stephen Sweeney (D-3), Assemblyman Anthony Bucco (R-25), State Senator Diane Allen (R-7), Assemblywoman Holly Schipisi (R-39), and State Senator Richard Codey (D-27).

WALK SPONSORS:

Asurion
DCH Acura
Overlook Medical Center
Saker Shop Rite
Whole Foods
Investors Bank
Twin City Pharmacy

Running a 5K, or 3.2 miles, is hard work for most of us...but these ladies look great as they cross the finish line on Park Street in Mendham

"What an achievement – pulling off planning, organizing and facilitating any event is a challenge and gratifying. But to do one that has so much meaning to you and your family is a great feeling. Thank you for raising more awareness of TS in the community and the world."

~ The O'Neill Family (Team James)

NJ Walks For TS at Ramapo College Welcomes 150

When AnnaKatharine Miehe first started planning the NJ Walks for TS at Ramapo College as the senior project for her Communication Arts major, she knew a lot of time, effort and patience would have to go into the process. What she didn't foresee was how big of a success the event would turn out to be.

More than 150 walkers and 200 people total turned out to be a part of the event on a beautiful sunny Sunday afternoon on April 14. Bright neon green NJ Walks For TS T-shirts dotted Ramapo's pristine campus, with the walkers beginning and ending the nearly 3-mile trek at the college's historic Arch. Every walker arrived and departed with a smile on their face and more knowledge about Tourette Syndrome in their minds, much to the delight of Miehe.

"After all the hard work that went into planning NJ Walks for TS at Ramapo College, I am so pleased with the turnout and the amount of money that was raised," said Miehe, whose fundraising efforts helped bring in more than $8,000 to benefit the statewide education outreach and peer advocacy programs of NJCTS. "I truly believe Tourette Syndrome awareness has increased on campus, and people are more familiar with the disorder. It is an honor to be able to contribute and give back to people who have always been an inspiration to me. NJCTS' programs have proven to be incredibly beneficial for the TS community, and it is imperative to support their efforts."

The walk attendees were a balanced mix of Ramapo College students, many of whom have connections to the campus' rich Greek Life, and members of the New Jersey TS community. NJCTS and its membership were strongly represented as well, as the NJ Walks For TS program branched beyond its Mendham roots for the first time since its inception in 2010.

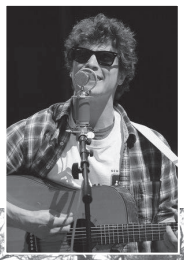
The NJ Walks For TS program aims to foster self-advocacy among members of the Tourette community and create awareness of this misunderstood neurological disorder among the general public. This was a day to celebrate these accomplishments.

The NJ Walks For TS at Ramapo College Honorary Committee included included U.S. Congressmen Albio Sires (D-NJ8), Leonard Lance (R-NJ7), Rush Holt (D-NJ12) and Scott Garrett (R-NJ5), New Jersey State Senator Gerald Cardinale (R-39) and Assemblywoman Holly Schepisi (R-39).

One of the most notable memories from the walk was the solidarity shown by those from the Tourette community, and it didn't go unnoticed by one Ramapo College who wished to be cited only as Cortney, " I was struck by the number of people who attended and participated, and the enthusiasm they showed. Most were there for a specific person affected by TS – a brother, a daughter, a sister, a son – or to walk for themselves. It was impressive."

NJ Walks for TS takes over Ramapo College

AnnaKatharine Miehe leads participants in the NJ Walks for TS at Ramapo College, which she helped plan and execute for her Communication Arts major Senior Project.



North Jersey rock band The Lappes entertained the crowd

When people Walk for TS, they're walking for someone they love. This family is wearing a special little girl close to their hearts.

Gathering for a good cause and good cheer- the crowd encourages walkers crossing the finish line

Awareness & Advocacy

TS Awareness Month 2013

Tourette Syndrome Awareness Month, as proclaimed annually in the Garden State by the Office of the Governor of New Jersey, takes place from May 15 through June 15th. NJCTS marked the month with several member and partner-initiated events:

- A walkathon to benefit NJCTS was conducted by Josh Klapper of Scotch Plains at Terrill Road Middle School
- NJCTS represented the TS community by delivering an awareness presentation at South Brunswick Middle School's "Celebrating Uniqueness Day"
- The Northern Burlington Chapter of DECA (Distributive Education Clubs of America) conducted a civic consciousness project in support of research to help fight TS during the week of May 13-17 at all schools in the Northern Burlington County Regional School District. The district- which serves Chesterfield, Mansfield, North Hanover and Springfield Townships- raised $630 to benefit NJCTS programs and services.
- NJCTS partnered with the Statewide Parent Advocacy Network (SPAN) to present an information session on parental rights regarding their children's education under the Individuals with Disabilities Education Act- offering practical advice in navigating the special education process.

Advocate Honored By Legislator

New Jersey Assemblywoman Holly Schepisi (R- 39) joined NJCTS Executive Director Faith Rice at the NJ Walks for TS in Ramapo to present River Dell High School senior Emily Fleischman with the NJCTS Youth Advocate of the Year Award for her exemplary work on behalf of the organization. Fleischman also volunteered in setting up the event and walked the course with her mother, Florence.

"I want to thank NJCTS for honoring me with this prestigious award. I am flattered and thrilled beyond words," she said. "The support for TS is amazing and appreciated."

Assemblywoman Holly Schepisi (R-39) presents Emily Fleischman with the 2012 Youth Advocate of the Year award along with Faith Rice at the NJ Walks for TS at Ramapo College

The Terrill Middle School Builder's Club raised $3,500 for NJCTS during a special TS Month walk-a-thon

Research

Rutgers Partnership Program GSAPP

The TS Clinic furthers the mission of NJCTS in the areas of TS treatment and research. The Clinic's approach is to focus not only on the child living with TS but his/her family as well. Families who come to the Clinic become part of a community, overcoming the isolation that accompanies the stigma of TS. The Clinic collaborates with NJCTS to perform peer and faculty inservice trainings, parent groups and skills groups for children. The Clinic staff participates in a retreat for families with TS. Five doctoral students are trained each year and there are waiting lists of students and families to participate in this unique practicum, which won the Rutgers President's Award in 2007. This program is the only one of its kind in the nation

Rutgers Partnership Program NJCTS Cell & DNA Sharing Repository

In 2007, though a partnership with the Rutgers University Department of Genetics, NJCTS established the Tourette Syndrome Cell & DNA Sharing Repository, a sharing resource of clinical and genetic data which can be accessed by qualified researchers from throughout the world.

The ultimate goal of this study is to identify genetic factors that play a role in causing TS and related disorders such as OCD and ADHD. NJCTS established this model program, which in 2011 was accepted into the National Institutes of Mental Health. As part of this federal program, the NJCTS Sharing Repository at Rutgers serves as the flagship collection site among 26 collection sites around the world. This is the first program to make uniformly-catalogued TS genetic material available to researchers. The tools, samples and documentation created at the NJCTS Sharing Repository at Rutgers are giving researchers never-before-seen access to understanding the DNA of TS.

"The major stumbling block to doing research on Tourette Syndrome has been a lack of DNA samples," according to Dr. Jay A. Tischfield, Director of the Human Genetics Institute at Rutgers University and a researcher for more than 40 years. "You can't just do research on samples from five or 10 people. You need hundreds if not thousands of samples."

In 2013, NJCTS conducted a series of information and recruitment sessions where families gathered to learn more about the project, meet with researchers and participate in the study through interviews and blood samples.

The TS Clinic team at Rutgers Graduate School of Applied and Professional Psychology is led by Dr. Shawn Ewbank (right)

Dr. Jay Tischfield welcomes members of New Jersey's 16th legislative district on a tour of the Cell and DNA Repository at Rutgers University.

Research

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

Assemblywoman Donna Simon (R-16), Assemblyman Jack Ciattarelli (R-16) and State Senator Christopher "Kip" Bateman (R-16), all NJCTS supporters, learn about the groundbreaking research taking place at Rutgers that is shaping the future of TS treatment

Rep. Albio Sires (D-8) discusses research techniques with Dr. Jay Tischfield

Legislative Outreach

Collaborative Academic Research Efforts for Tourette Syndrome Act of 2013

Congressman Albio Sires (D-NJ8) has introduced bill H.R. 146, which 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. A primary purpose of this legislation is to establish regional centers of excellence across the country to conduct research into the cause, diagnosis, early detection, prevention, control and treatment of Tourette Syndrome and associated disorders such as Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder, anxiety and depression. A companion bill, S. 637, also has been introduced in the Senate by Senator Robert Menendez (D-NJ). Throughout the year, support for the bills poured in from across New Jersey, and throughout the U.S.

New Jersey's 12th District
Considering that 1 in every 100 people in the United States have Tourette, it is only fair that we receive a share of legislative support.

New Jersey's 12th district
Unfortunately, there are too many children and families across the US that do not have access to resources that help them deal with TS; this results in impaired learning, poor self-esteem and great psychological stress to those affected with Tourette. Funding the expansion, intensification, and coordination of programs and activities of the National Institutes of Health with respect to Tourette syndrome outlined in this legislation will ensure that those suffering from this neurological disorder will have access to resources that will improve their lives.

New York's 22nd District
Significant progress has been made in understanding Tourette in the last decade, but we still know far less about this disorder than other neuropsychiatric disorders in childhood (for example, autism or ADHD).

New Jersey's 4th District
Please support this bill- we desperately need the research for not just the current generation but future ones as well.

New Jersey's 6th District
Both of my children have to live with this disorder every day of their young lives and they want a cure.

Connecticut's 2nd District
I hear from parents every day who are confused and looking for answers and there are no solid answers that I can give them. I talk to younger people who are feeling like they are the only person in the world like them and I can't tell them how many people in our country are just like them because the numbers frequently cited make no sense. We need more research on this condition.

New Jersey's 7th District
My son has Tourette's and we come across new issues all the time in learning how to deal with this disease... he is an object of ridicule. If more folks knew more about TS maybe it would go a lot smoother for TS kids in school. Teachers and students could be more accepting. We need more alternative medicines, natural remedies, more resources and thus FUNDING. Please support this bill for further research..

New York's 11th District
As an occupational therapist, I work with many patients who suffer from TS. I feel the support from this legislation will have a tremendous impact on those who suffer from the syndrome.

New Jersey's 7th District
The longer it takes to diagnose, the more the suffering. [TS] can be a physically exhausting, mentally all-consuming condition as one works hard to keep it somewhat manageable, and it's socially ostracizing. Takes a huge toll on the body, mind, and loved ones. Please help.

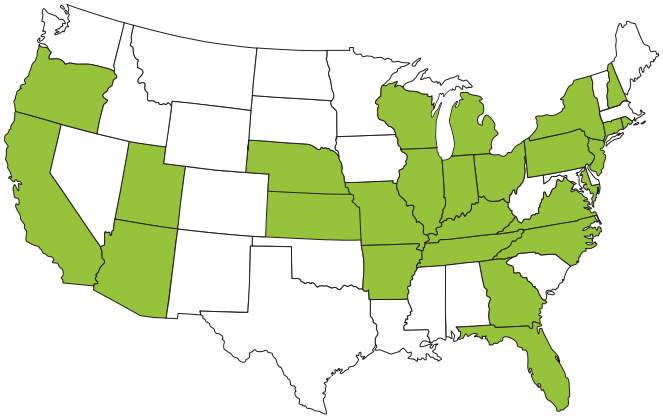
Kansas's 4th District
There are days [my 12-year-old son] will have to miss school because of his tics or his other disorders and he cannot do many things like other children can. PLEASE help our children and adults who have TS. It hurts my heart to watch my son in agony pain because of his tics get severe and no medication works...please help.

Rhode Island's 1st District
Tourette Syndrome has had a profound affect on my child's life. We need to make a concerted effort to find better treatments and ideally a cure. There is also a huge lack of awareness that needs to be addressed. Collaboration in these matters can only help.

Legislative Outreach

New Jersey's 11th District
I am both public school educator and the parent of a now young adult with TS. When my son was diagnosed with TS, I had to fight very hard for TS awareness in his school. Autism is constantly at the forefront of educators minds; however, the reality is that MANY of our students have TS and its associated disorders. This bill must pass.

Arkansas's 2nd District
I am across the country from anyplace that offers help and services for people with TS. I have severe Tourette and it cripples me, I spend most my time in a wheelchair unable to see or speak. If there were more places that could help I could take part in my family again, maybe even get a job



Voters affected by TS voiced their support for federal legislation in 2013 from every corner of the United States

Congressman Leonard Lance and NJCTS Host Roundtable Discussion

Congressman Leonard Lance (R-NJ7) long has been a supporter of NJCTS and New Jersey's TS community. He has co-sponsored fellow Congressman Albio Sires' (D-NJ8) Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act. He partnered with NJCTS to host his second roundtable discussion on April 19th at the Mountainside Public Library, meeting with families from in and around District 7 who have first-hand experience dealing with Tourette Syndrome and its associated neurological disorders. Each of the families in attendance thanked Congressman Lance for touting the CARE for TS Act, but Congressman Lance was quick to shift the plaudits elsewhere.

"The New Jersey Center for Tourette Syndrome should be given credit for taking the lead in this, Faith and Congressman Sires in particular," Congressman Lance said, referring initially to NJCTS Executive Director Faith W. Rice. "It is very helpful and educational to meet with you, and I admire the courage of all of you – particularly the young people. It's always good to put a face to a cause." The three youth in attendance – Josh Klapper, Thomas Burke and Cory Singer – all had an opportunity to paint a picture for Congressman Lance of what it is like to live with Tourette or personally experience its effects in the life of a friend of family member.

"Students and teachers usually have no idea what TS is. We need to give more education about TS and what it is, especially to the teachers, said Singer who attended the roundtable with his mother, Jill Pavel. "Teachers say, 'Whenever you have the tics, leave the classroom.' That's wrong. And awareness is the key to fixing it. People with TS should never be ashamed of who they are." Congressman Lance implored the boys, their mothers and the rest of the TS community to do their part in getting the word out there about Tourette, saying: "A greater awareness of issues like this is of interest and need to the larger community. What can you do? Writing op-ed pieces to the newspaper is a good idea. They can help educate the public better on these issues. The most persuasive arguments come from a parent advocate or a young person who is an advocate themselves." Also in attendance at the roundtable was Borough of Mountainside Councilman Glenn Mortimer.

From left, Susan and Josh Klapper of Scotch Plains, Jill Pavel and Cory Singer of South Plainfield, Congressman Leonard Lance (R-7), Anne and Thomas Burke of Summit and NJCTS Executive Director Faith Rice meet at Mountainside Library to discuss the importance of TS legislation.

NJCTS Executive Director Faith W. Rice meets Mountanside Councilman Glenn Mortimer and Congressman Leonard Lance

Year in Pictures

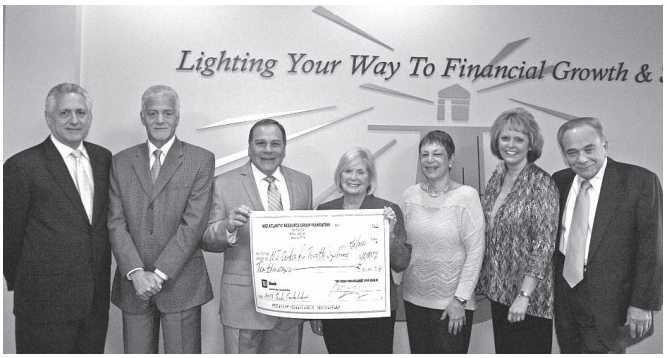
In June, NJCTS Family Outreach Coordinator Marty Butterfield (left) was honored by the New Jersey Association of Mental Health and Addiction Agencies (NJAMHAA) with the Outstanding Behavioral Healthcare Supporter Award at its annual Courage & Compassion Awards reception. She is pictured with State Senator Loretta Weinberg (D-36), Faith Rice and NJAMHAA Executive Director Debra Wentz

NJCTS Board Member Conrad Roncati, Boomer Esiason, Faith and Kim Rice strike a quick pose at Craig Carton's Strike Out Tourette celebrity bowl-a-thon at Chelsea Piers

Vice President and Marketing Manager for the Clinton branch of Investors Bank, Victor Rivera, left, hands an Investors Bank Foundation grant check for $2,500 to NJCTS Finance Director Santina Reichenbach. The grant will be used to help fund NJCTS' School In-Service Program

TS families in South Jersey gathered in Mantua Township for a Family Fun Night of games, food and support

Walking for a good cause takes the chill off a cold November morning and warms the hearts of this team at the 4th annual NJ Walks for TS at Mendham



From left, MARG Charitable Foundation Trustees Alan Salowe and Larry Buccheri, MARG President Scott Salinas, NJCTS Executive Director Faith W. Rice, MARG Vice President Judi Popick, MARG Vice President/Secretary Linda Blum and MARG Executive Director Art Hodes during the April 6 MARG Gala Dinner Fundraiser, at which NJCTS was presented with a $10,000 check

Year in Pictures

On his way to becoming the next Iron Chef, Josh Klapper chose NJCTS to be the beneficiary of a fundraising service project. He set up Josh's Pop-Up Restaurant and sold tasty meals to raise money and awareness for TS

Casey Warcola, 11, of Boy Scout Troop 1 in Mendham, raised $70 in donations to the New Jersey Center for Tourette Syndrome & Associated Disorders from selling TS awareness bracelets as a troop project.

The staff of NJCTS visits Rutgers Graduate School of Applied and Professional Psychology

A heartfelt song to entertain walkers during the Builders Club fundraiser for NJCTS

Dr. Lisa Cox and Al Stark share a laugh at the 9th annual Family Retreat Weekend

So many NJCTS families wear their heart on the sleeves to show support, raise awareness and help new families facing a TS diagnosis

Anna and Liz share a hug in South Jersey

New Jersey Center for Tourette Syndrome
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Collaborative Partnerships for the Tourette Syndrome Community

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