

NJCTS NJ Center for Tourette Syndrome AND ASSOCIATED DISORDERS, INC.

Collaborative Partnerships for the Tourette Syndrome Community

## **THE NATION'S FIRST CENTER OF EXCELLENCE** FOR TOURETTE SYNDROME

### 2016 Year in Review

50 Division Street, Suite 205 Somerville, NJ 08876 908-575-7350 www.njcts.org Email: info@njcts.org

### NJCTS MISSION STATEMENT

NJ 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 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.



Dear Families and Friends,

If you have Tourette Syndrome you are lucky to live in New Jersey! Established in 2004 as the nation's first Center of Excellence for Tourette Syndrome, NJCTS provides support for kids and

families; outreach and training for the education and medical communities; support for collaborative research into better treatments; patient advocacy and a continuum of youth development services. Since 2004 we have reached more than 700,000 people through our core programs.

As you look through our 2016 Year in Review I think you'll be impressed by our programs and reach but what really matters is what we can do for you and your family. Give us a call. Whether it's help finding a doctor, the need to connect with another family, psychological services, or support for peer or faculty trainings in your child's school, we are here just as we have been for tens of thousands of families over the years. We urge you to become part of our community and benefit from all that is in place to support your needs. I look forward to hearing from you.

Warm wishes,

Faith W. Rice Executive Director

### Contents

- 2 Research
- **4** Youth Development
- 6 Webinars
- 7 Education Outreach
- **10** Medical Outreach

- **11** Community Outreach
- **12** Family Support
- 14 Awareness & Advocacy
- **21** Impact by the Numbers
- 23 We Are NJCTS

### What is Tourette Syndrome?

Tourette Syndrome (TS) is an inherited neurobiological disorder characterized by the childhood onset of uncontrollable vocal and physical tics. It is estimated that 1 in 100 individuals 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 10 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 Hyperactivity Disorder, Obsessive Compulsive Disorder, learning disabilities, panic attacks, depression, generalized anxiety disorder, sleep disorders
- Misunderstood by the public and educators
- Underdiagnosed by medical professionals

### RESEARCH

### The World's First Cell & DNA Sharing Repository for Tourette Syndrome

NJCTS, Rutgers University, and participating families have forever changed the direction for Tourette Syndrome research.

NJCTS, in partnership with Rutgers University's RUCDR Infinite Biologics, established the NJCTS Cell & DNA Sharing Repository in 2007 as a resource of clinical and genetic data for Tourette Syndrome. A collaboration with Yale University and other partners helped to develop a set of uniform methods and collection tools. After four successful years into the pilot, the National Institute of Mental Health recognized the repository as a federal asset and funded its expansion. Through the establishment of the Tourette International Collaborative Genetics (TIC Genetics) study, the repository now includes more than 25 collection sites around the world. NJCTS-affiliated experts are bringing the latest information to New Jersey families through Tourette Syndrome workshops led by Dr. Gary Heiman, Director of TIC Genetics. In 2016, Dr. Robert King, professor of child psychiatry at the Yale University Medical School and medical director of the TS/OCD Clinic at the Yale University Child Study Center, traveled to New Jersey monthly to conduct screening interviews and information sessions for individuals and families interested in participating in the TS study.

Every day, scientists are working to find a cure for TS. This work would not be possible without the continued support of families participating in the study through interviews and tissue samples.

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

#### USA

#### **CA** University of California San Francisco

- **CT** Yale University School of Medicine
- IA University of Iowa
- NJ Rutgers, The State University of New Jersey
- NY Icahn School of Medicine at Mount Sinai
- NY Nathan S. Kline Institute for Psychiatric Research
- **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 of Lübeck
Germany	University Hospital Carl Gustav
	Carus Dresden
Germany	University Hospital of Ulm
Germany	University of Hannover
Netherlands	de Bascule, Academic Center for
	Child and Adolescent Psychiatry
Netherlands	University Medical Center,
	Groningen
Netherlands	Yulius Child and Adolescent
	Psychiatry, Rotterdam
Spain	Virgen del Rocío University
	Hospital, Sevilla
Spain	Hospital Clinic Barcelona
UK	Great Ormond Street Hospital
	For Children, London
UK	Evelina Children's Hospital,
12	London

#### **KOREA**

Goyang	Kwandong University MyongJi
	Hospital
Goyang	llsan Hospital (National Health
	Insurance Co.)
Seoul	Korea Institute for Children's Social
	Development (KICSD)
Seoul	Yonsei University Severance Hospital

### RESEARCH

### TS Clinic and Practicum at Rutgers University Graduate School of Applied and Professional Psychology

Created in 2000, the NJCTS Tourette Syndrome Clinic and Practicum at Rutgers University continues to further our mission in the areas of family support, treatment, and research. The Clinic's approach is to focus not only on the child living with TS but also his/her family. Families who come to the Clinic become part of a community, overcoming the isolation that accompanies the stigma of TS. The Clinic works with NJCTS to perform peer and faculty in-service trainings, parent groups and skills groups for children, and the clinic staff participates in NJCTS Family Retreat Weekends.

The NJCTS Tourette Syndrome Clinic and Practicum provides a unique, hands-on learning experience for advanced graduate students striving to increase awareness of TS in the professional community. The students are the future practitioners for individuals with TS, a specialized area of psychological care that has alarmingly few specialists nationwide. Their consistent ability to provide relief and assistance to families in need has built the reputation of the Practicum, allowing it to become the premier place for the behavioral treatment of TS-related issues.

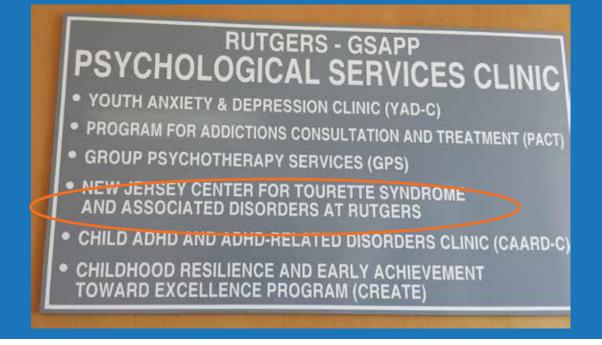
This is the only such program in the nation providing a university-based, stand-alone teaching practicum and psychological clinic. The TS Clinic represents accessible, affordable care for individuals from New Jersey and surrounding areas. Since its inception, the Clinic has treated more than 1,200 patients and families with TS in New Jersey as well as from

the surrounding New York and Pennsylvania area and has trained more than 50 new psychologists who are now in practice across the country.

The clinic offers evaluation and treatment services according to a sliding scale based on family income, with session fees as low as \$5 when need is demonstrated. A central tenet the mission is that individuals will not be turned away from needed psychological services due to inability to pay standard fees. GSAPP therapists are all clinical and school psychology doctoral students.

#### The NJCTS Tourette Syndrome Practicum and Clinic provides:

- · Individual, family, and group therapy
- · Cognitive-behavioral therapy
- Habit reversal therapy
- · Social skills development sessions
- · Referrals to physicians and testing services
- Services available on a sliding scale



### **YOUTH DEVELOPMENT** Offering a Continuum of Services for Youth at all Stages of Life

As many as 1 in 100 individuals show some signs of Tourette Syndrome. Through Youth Development and related programs, NJCTS strives to address the stigma and isolation that can be experienced by kids living with TS by building a safe community for children and their families.

The NJCTS Youth Development Program identifies, recruits, trains, and supports children of all ages with TS. The program provides support, leadership, networking, education, and advocacy services to families. From the moment they first make contact with our organization, they are immediately supported through information and referral, access to webinars, and connections to other TS families. For our youngest children we provide support through a variety of activities including:

- NJ Walks for TS: Families can participate in events by walking, fundraising, and volunteering. The program was created by kids, for kids in collaboration with NJCTS and supports the NJCTS Education Outreach program.
- Family Retreat Weekend: Families can attend our annual weekend away where they meet others with TS, learn more about their diagnosis, share stories, attend workshops, engage with peer mentors, and just have fun.
- In-Service presentations: Presentations are offered statewide in elementary and secondary schools to educate school professionals and help them promote a more successful classroom environment for children with TS and associated disorders.
- **Peer presentations:** Presentations geared toward students in schools help to build empathy, tolerance, and acceptance as well as provide an anti-bullying message.



Ranging in age from 12 to 18, 14 new NJCTS Youth Advocates were trained at the North Jersey training session, bringing the total to 31 Youth Advocates trained in 2016.

As children get older, we engage them in activities that help them learn to advocate for themselves and give back to the community. Training opportunities prepare youth above the age of 12 to meet the challenges of adolescence and adulthood by achieving their full potential. At this stage, children have the ability to be involved in experiences that help them recognize their own strengths and create change within schools, medical facilities, and their own communities.

Youth above the age of 12 can participate in many leadership activities and NJCTS strives to stay connected with our constituents well beyond the teenage years. We provide a variety of activities for teens and young adults including:

- Youth Advocate presentations: This program trains teens to lead presentations about TS and associated disorders to students, medical professionals, and community groups.
  - As peer educators: In 2016, Youth Advocates presented to nearly 5,000 students and teachers at schools throughout the state.
  - As patient educators: Youth Advocates work with our doctors to provide presentations at hospitals throughout the region to educate doctors and medical staff about the unique needs of patients living with TS and associated disorders.
- NJCTS Tim Howard Leadership Academy: The Academy is a four-day intensive program for teens living with TS. The program focuses on empowerment, self-leadership, building advocacy skills, and resilience.
- Scholarships: Since 2004, NJCTS has awarded more than 200 scholarships to graduating New Jersey high school seniors who have been diagnosed with TS and will be attending a college, university, or trade school in the fall following their graduation from high school.
- Young Adult Mentoring Opportunities: NJCTS identifies young adults to serve as peer mentors at various events throughout the year. Mentors have the opportunity to engage with younger kids and newly diagnosed families at the Family Retreat Weekend, Leadership Academy, Youth Advocate trainings, and at community outreach events.
- **Community Presenters:** Young adults can train to become presenters, educating community organizations throughout the state of NJ about TS and associated disorders.

## YOUTH DEVELOPMENT

### The Third Annual NJCTS Tim Howard Leadership Academy Participants Gained New Skills for Life

The NJCTS Tim Howard Leadership Academy empowered a new set of leaders in the Class of 2016. Each of the participants took part in an intensive four-day training promoting self-empowerment, selfleadership, and resilience—all important skills to succeed while living with Tourette Syndrome.

Created in 2014 in partnership with U.S. Men's Soccer goalkeeper and TS advocate Tim Howard, the Academy is the only leadership program for teens diagnosed with TS in the nation.

The 3rd annual Academy took place at Rutgers University from August 4-8 and emphasized the biological, psychological, and social components surrounding a TS diagnosis. Leading TS experts from area Universities including Rutgers, Yale, and the University of Pennsylvania led presentations and workshops throughout the program. Participants had the opportunity to learn from the neurologists, geneticists, psychologists, and social workers and were able to ask their most burning questions about their diagnoses.

"We want them to leave as experts, ready to face a public who is misinformed about TS," said Leadership Academy Director Melissa Fowler. "They have a unique opportunity to learn more about their diagnosis from our expert presenters."

Each of the participants—who hailed from New Jersey, New York, Pennsylvania, Maine, Tennessee, North Carolina, California and Ontario, Canada—contributed thoughtful questions and were eager to share life-skills tips with one another. They were assigned to teams led by coaches—successful young adults who also live with TS. "It means so much to teens to engage with coaches and presenters who are the ideal role models," said NJCTS Executive Director Faith W. Rice. "Learning from others who are living successful lives with a TS diagnosis is invaluable."

The Class of 2016 contributed to "The Teenage Guide to Living with Tourette Syndrome" which has been published as an ebook on standwiththegreats.org.

Throughout the course of the Academy, participants spoke of resilience and leadership and defined personal goals for themselves. With the lessons and skills they gained, this class will step up to be the voice of awareness in their own communities.

#### 2016 Leadership Academy Presenters:

Angelo N. Alago, Psy.M., *Rutgers University* Lawrence W. Brown, MD, *Children's Hospital of Philadelphia* Joseph Buonadonna, Psy.D., *School Psychologist* Lisa Cox, Ph.D., MSW, *Stockton University* Susan Furrer, Psy.D., *Rutgers University, GSAPP* Lesley Geyer, MA, *Pediatric Therapeutic Services* Stuart Green, DMH, LCSW, MA, *NJ Coalition for Bullying Awareness and Prevention* Robert A. King, MD, *Yale Child Study Center* Anna Rubenstein, *Tourette Syndrome Advocate* Michael Rubenstein, MD, *University of Pennsylvania* Matt Singer, DC, *Integrative Holistic Center* Jay Tischfield, Ph.D., *Rutgers University Department of Genetics* Rob Zambrano, Psy.D., *Stress and Anxiety Services of New Jersey* 



## WEDNESDAY WEBINARS

### Since 2008, the NJCTS Educational Webinar Series Explores the Details of Living Well and Learning with TS and Associated Disorders

The need has never been greater for practical and accurate information about TS and associated disorders for families, educators, and healthcare professionals. In an effort to bridge that knowledge gap, NJCTS provides valuable education for the benefit of all through the Wednesday Webinar series. Since 2008, more than 30,000 parents and professionals have attended webinars delivered by NJCTS experts in neurology, psychiatry, psychology, education, and law. As a recognized and trusted source, NJCTS welcomes participants from across the country and around the world. What makes Wednesday Webinars so powerful is that attendees have the opportunity to ask questions during the live presentation. This allows families who do not have regular access to professionals with experience in TS the chance to connect with an expert. Credits are offered to qualified professionals, making this an important learning tool for educators as well. All presentations are archived at NJCTS.org for continued viewing.

### Wednesday Webinar presentations in 2016 included:

### Assistive Technology: Five Tools to Support Students

Brian S. Friedlander, Ph.D. College of St. Elizabeth

**Behavior Management** Joseph Buonadonna, Psy.D. *School Psychologist* 

### Mindfulness and Self-Compassion: How Grounding in the Present Can Help Enrich the Future

Janice Autera, Psy.D. NJCTS Tourette Syndrome Clinic at Rutgers University

### Play Therapy: What is it and How Can it Help My Child?

Colleen Daly Martinez, Ph.D., LCSW, RPT-S Rutgers University, School of Social Work

### Charter Schools—Understanding Your Child's Rights

Rebecca K. Spar, Esq. Cole Schotz P.C.

#### What is Dyslexia and What Can We Do About It? Michelle Humm, Ph.D. *Center for Neurological and Neurodevelopmental Health*

**Transitioning from High School to College** Andrew J. Lee. Psy.D. *Director of Monmouth University's Counseling and Psychological Services* 

#### What to Say and How to Say It — How Best to Explain to Your Child and the Family About a Diagnosed Mental Health Condition Lori Rockmore, Psy.D. Specialized Psychological Services

Private Schools — Understanding Your Child's Rights Rebecca K. Spar, Esq. *Cole Schotz P.C.* 

**Disclosure: How and What to Tell the Rest of Your World** Rob Zambrano, Psy.D. *Stress and Anxiety Services of New Jersey* 

# EDNESDAY WEBINARS

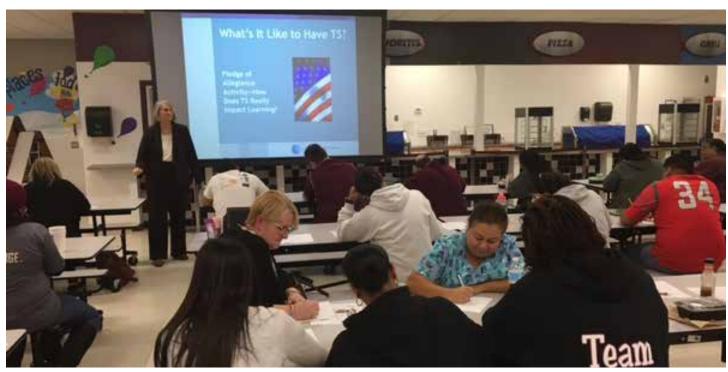
## **EDUCATION OUTREACH**

### **Faculty In-service Program**

The NJCTS School In-service Program provides tools and strategies for educators, guidance counselors, child study teams, administrators, school nurses, and support staff for assisting students with TS and associated disorders in elementary and secondary schools across New Jersey.

These presentations inform and enlighten professionals about Tourette Syndrome and co-occurring disorders such as OCD, ADHD, learning disabilities, depression, anxiety and the impact they can have on a child's school performance. The workshops also provide educators with specific classroom strategies and accommodations that can have a positive impact on a student's academic success. NJCTS in-service presenters are teachers, school nurses, psychologists, or other professionals with education or medical backgrounds and have first-hand knowledge of TS. The presentations promote more positive, inclusive, and successful classroom environments for all students.

. . . . . . . . . . . . . . . .



Dr. Lisa Cox guides teachers and staff through an exercise which demonstrates what it feels like to have TS during a faculty-in service presentation.

### Faculty In-service Participating Schools in 2016 included:

Bergen County Technical School, Paramus Bleshman School, Paramus Branchburg Central Middle School, Branchburg Bunker Hill Middle School, Sewell Essex County School Nurses Association, South Orange Hamilton Primary School, Bridgewater Holy Cross School, Rumson Joseph Kushner Hebrew Academy, Livingston Medford Lakes School District, Medford Lakes Mt. Horeb School, Warren Mt. Pleasant Middle School, Livingston Navesink Elementary, Middletown North Hunterdon High School, Annandale Park Ridge High School, Park Ridge Passaic County Supervisors of Child Study, Bloomingdale Peter Cooper Elementary School, Ringwood Temple Emanuel, Cherry Hill Tuscan Elementary School, Maplewood Union County School Nurses' Association, Clark Valley View School, Watchung Voorhees High School, Glen Gardner Walter T. Bergen School, Glen Gardner Walter T. Bergen School, Bloomingdale Warren Township Schools, Warren West Deptford Middle School, West Deptford West Milford High School, West Milford

#### **Presenters:**

Diana Antinoro-Burke, Psy.D. Meir Flancbaum, Psy.D. Nicole Janiec, NCSP Gina Maria Jones, M.Ed Tracy Lederman, Ed.D. Michelle Lubonski, M.Ed Cheryl Ludwig, MA, CCC-SLP Michelle Miller, Psy.D. Maddie Pucciarello, MPH Lori Rockmore, Psy.D. Rob Zambrano, Psy.D.

## **EDUCATION OUTREACH**

### Youth Advocates Spread TS Education, Awareness, and Anti-Bullying Message to all Corners of the State

Classrooms and organizations across New Jersey gain invaluable perspective about life with Tourette Syndrome from NJCTS Youth Advocates. The Youth Advocate program provides teens and young adults—who are 13- to 18-year-olds and either have a diagnosis of TS or live with a family member with TS—with opportunities for training in leadership and advocacy.

Since the program began, NJCTS Youth Advocates have conducted more than 300 presentations to

audiences as large as 800 students, raising awareness, standing up to bullying, and increasing understanding of this often-misunderstood disorder. In 2016, Youth Advocates led 26 workshops, reaching thousands across the state.

As part of the NJCTS continuum of services for youth, the Youth Advocate program trains a new generation of leaders who educate others about the neurological disorder and gain an in-depth understanding of TS and associated disorders.



NJCTS Youth Advocate Dan Ortner educates nearly 200 seventh grade students and school faculty at Gateway Regional High School in Woodbury Heights, NJ. For a child struggling with how to explain Tourette Syndrome to his or her teachers and student peers, NJCTS Youth Advocate presentations are making it a little easier, every day, in all corners of New Jersey.

### Youth Advocate Presentations were conducted at the following institutions:

Bells Elementary School, Turnersville Bradley Gardens School, Bridgewater Clearview Middle School, Mullica Hill Crossroads South and Crossroads North Middle Schools, South Brunswick Deal School, Deal Fairmont School, Hackensack Gateway Regional High School, Woodbury Heights Hamilton Primary School, Basking Ridge Hilldale Elementary, Pine Brook Hillside Intermediate School, Bridgewater Howard Brunner School, Scotch Plains Joseph Kushner Hebrew Academy, Livingston Mercer County Community College, West Windsor Middlesex Community College, Woodbridge Morris County School of Technology, Denville Oakview Elementary School, Woodbury Pascack Valley High School, Woodbury Pascack Valley High School, Montville Robert R. Lazar Middle School, Montville Rosa International School, Cherry Hill Rowan University, Glassboro South Plainfield High School, South Plainfield Stockton University, Galloway Temple Emanuel, Cherry Hill Temple Emanu-El, Westfield William J. McGinn Elementary, Scotch Plains William Patterson University, Wayne

### Youth Advocates who led presentations in 2016:

Anna Baldwin Eric Baldwin Sarah Baldwin Mary Kate Donahue Rachel Flynn Jacob Gerbman Wyatt Gray Mike Hayden Hallie Hoffman Cami Jimenez Paige Kowalski Tess Kowalski Tommy Licato Dan Ortner

### Youth Advocates who were trained in 2016:

Tara Barr Anna Blair **Kyla Butler** Noah Feldstein **Rachel Flynn** Jacob Gerbman Wyatt Gray **Charles Griebell Christopher Hand** Cami Jimenez **Dominic Jordan** Paige Kowalski **Ethan Lederman** Sarah Lichtblau **Benjamin Mars Cameron Mehlman Dan Ortner Anthony Palmeri** Sam Regen Jordan Rullo **Trevor Salvior** Anna Claire Sems Brennan Skirzenski Jenna Smith

## **EDUCATION OUTREACH**

### **2016 Youth Scholarship Winners**

Since 2001, the NJCTS Youth Scholarship Award has been given to more than 200 outstanding high school seniors in New Jersey who have excelled in their schools and communities. In 2016, 12 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing outstanding advocates for Tourette Syndrome.

### **FIRST PLACE WINNER**



### **SEAN KENNEDY**

Turnersville Kennedy's award essay was titled "Thank you, Tourette's." He is a member of the Math Club, Spanish Club, Interact Club, and Spirit Club and played for St. Augustine Prep's Rugby and Lacrosse teams.

### SECOND PLACE WINNERS



### **MADELYN ONESTI**

Woodstown Onesti's award essay was titled "Resilience Through Adversity." She is a petty officer third class in the US Naval Sea Cadet Corps and serves as a volunteer firefighter with the Harrisonville Volunteer Fire Company.



#### **JORDAN TANTUICO** Union

Tantuico's award essay was titled "A Journey with Tourette Syndrome." He is a member of the Chess Club, Future Business Leaders of America, and National Honor Society. In his spare time he enjoys playing the piano, snowboarding, reading, and coding.

### **HONORABLE MENTION WINNERS**



Noelle Gizzi West Caldwell





**Eric Rushinski Burlington Township** 



**Curtis J. Knorr** Hackettstown



**Meghan Schiereck** Delran



Sebastian Lijo Branchburg

Michael Schluter

Fair Haven



**Zachary Muniz** Long Valley



Kyle Ossowski Lawrenceville



**Nicholas Frantz** 

### **MEDICAL OUTREACH** Educating the Medical Community about Tourette Syndrome and Associated Disorders

NJCTS works with hospitals throughout New Jersey to present Grand Rounds and Patient-Centered Medical Education (PCME) workshop trainings for doctors, nurses, and other healthcare providers.

Grand Rounds are presented by Tourette Syndrome experts and a teenager or young adult to groups of between 50 and 100 physicians and many of these sessions are also open to community professionals.

PCME sessions are presented to residents in pediatrics, neurology, and family practice by a teenager or young adult with Tourette Syndrome, along with their parents. The presenters describe their experience with

TS at school, at home, and in the community, and focus on initial diagnosis, quality of life, and encounters with physicians and the healthcare system. The goal of this medical education program is to help physicians enhance their understanding of the perspectives, stresses, and needs of patients with neurological disorders and their families and to improve interpersonal and communication skills in patient encounters.

In 2016, NJCTS reached nearly 1,000 medical professionals through Grand Rounds and PCME trainings at hospitals throughout the state and through regular distribution of the latest TS-related research articles.



Harvey Bennett, MD, Atlantic Health, led a Grand Rounds with Patient-Centered Medical Education presentation with NJCTS Youth Advocate Tess Kowalski at Hunterdon Medical Center. Tim Kowalski provided a parent's perspective to the doctors and medical staff in attendance.



### **COMMUNITY OUTREACH** Informing the Community about Tourette Syndrome and Associated Disorders

NJCTS offers Community trainings designed to support professionals in community-based organizations across New Jersey, providing information about Tourette Syndrome and its associated disorders.

In 2016, NJCTS continued to emphasize an expanded focus to underserved communities, developing relationships with a wide range of local organizations who can, in turn, reach families in need.

This outreach has provided NJCTS with the opportunity to collaborate with representatives of Care Management Organizations, Family Support Organizations, Family Success Centers, child welfare, schools, hospitals, mental health organizations, and a wide range of county-based social and human service agencies. The goal of such partnerships is to connect families in need with the support and services available through NJCTS and its partners.



Volunteers Karen Licato and Susan Everett represented NJCTS at the New Jersey Chapter of the American Academy of Pediatrics' School Health Conference.

### **Community Presentation Participating Organizations in 2016 included:**

- Bergen County Disability Services, Hackensack CarePlus, Fair Lawn Circle of Care, Woodland Park Crisis Mobile Children's System of Care, Robbinsville Family Partners of Sussex and Morris, Newton Hudson County School Nurses Association, Bayonne Millburn High School National Association of Social Workers New Jersey Conference, Atlantic City New Jersey Academy of Pediatrics School Health Conference, Somerset New Jersey Association of School Psychologists, Monroe
- New Jersey Association of School Social Workers, Iselin
- New Jersey Center for Inclusive Education Summer Inclusion Conference, Montclair
  New Jersey Council for Exceptional Children Spring Conference, Mahwah
  New Jersey Department of Health Special Child Health Services, Trenton
  New Jersey Directors of Disability Services, Toms River
  New Jersey Education Association Annual Convention, Atlantic City
  New Jersey Speech-Language-Hearing Association Annual Convention, Long Branch
  Perform Care, Hamilton
- School Nurses Conference, Iselin Temple Emanuel Mental Health Expo, <u>Cherry Hill</u>
- The Arc of New Jersey

Township of Washington Public Library, Washington

### Presenters:

Barbara Chabner, Psy.D. Penny Dragonetti Graham Hartke, Psy.D. Nicole Janiec, NCSP Gina Maria Jones, M.Ed Tracy Lederman, Ed.D. Leanne Loewenthal, MSW Cheryl Ludwig, MA, CCC-SLP Maddie Pucciarello, MPH

### Volunteers:

Carolyn Baldwin Amanda Cicchino Susan Everett Karen Licato Fred Storer

### FAMILY SUPPORT Family Retreat Weekend—Welcome to the Community!

Families from all across New Jersey who are affected by Tourette Syndrome and associated disorders joined in a fun-filled weekend at YMCA Camp Bernie in Port Murray, NJ, June 10-12. For the 12th year, NJCTS Family Retreat Weekend provided children and their families with the opportunity to meet others with TS, learn more about their diagnosis, and engage with peer mentors in a fun, safe, and supportive environment.

Families had many opportunities to bond and share stories while participating in Camp Bernie's activities, including swimming, basketball, wall climbing, archery, arts & crafts, and so much more. Kids let loose to really be themselves during the Friday night campfire and let their abilities shine during the Saturday night Talent Show. Kids and parents also participated in the educational portion of the weekend, attending powerful workshops and discussion groups.

"Every time we meet a new TS family at Family Retreat Weekend, we learn something new and always find comfort and hope," said one parent. "Our connection with the TS community is a strong one. These families know what we go through and understand our struggles and triumphs."

NJCTS is also connecting young people around the world who shared their challenges of living with TS. This year at Family Retreat Weekend, campers had the unique opportunity to connect with a group of young advocates in Istanbul, Turkey. Bekir Artukoglu, who organizes the group in Turkey, joined us at Camp Bernie and helped translate so that kids could share stories about school experiences, family and social issues. This was the start of the Global GreaTS—a virtual support system for young people living with TS.

NJCTS Family Retreat Weekend is an essential event for families affected by Tourette Syndrome to learn more about the diagnosis and, most importantly, to know that they are not alone and that support and services are available at every level.



Families had the opportunity to learn from Dr. Jay Tischfield and Dr. Gary Heiman about the Tic Genetics study.









Campers connected with a group of young TS advocates in Istanbul, Turkey.





The Saturday night Talent Show is always the highlight of the weekend.

## **FAMILY SUPPORT**

### Jeff Vitek Memorial Fund for Youth Development

In the fall of 2015, Susan and Patrick Vitek established the Jeff Vitek Memorial Fund for Youth Development at NJCTS in honor of the cherished son they loved and lost.

Jeff struggled with Tourette Syndrome throughout his school years and the Viteks sought to get him the support and services he needed.

Jeff was extremely creative, inventive, successful, and had an outstanding sense of humor. A passionate supporter of children and helping kids feel better about themselves, Sue and Pat know that Jeff would have been a wonderful mentor had he been given the opportunity.

"When you lose a child you want to do something meaningful, giving other kids the help that Jeff didn't have was the best thing we could think of," the Viteks recalled. "All of the things NJCTS is doing are the things that we missed, our son missed, and that we feel passionate about. We are grateful that NJCTS will help others in Jeff's name."

The Jeff Vitek Memorial Fund for Youth Development will ensure the continuation and growth of essential training and empowerment programs for youth, transforming them from patients to self-advocates and helping to pave their way to productive, resilient lives.

Sue and Pat encourage others to support the NJCTS Youth Development programs and ask you to consider making a donation in honor of or in

### **Physicians Referral Network**

NJCTS maintains a Physician Referral Network comprised of more than 200 medical professionals who have expertise in treating Tourette Syndrome and associated disorders. The list is compiled from interviews with clinicians and recommendations from our members as well as other clinicians. It is a direct link for families to medical professionals across the region with expertise in TS, ADHD, OCD, anxiety, and depression.

The Physician Referral Network is a critical aspect of the work at NJCTS, and it is reviewed and revised to provide the best, most up-to-date information on clinicians with understanding of TS and its co-occurring disorders. memory of someone you love to help sustain the fund.

To make a contribution to the Jeff Vitek Memorial Fund for Youth Development, visit our website at www.njcts.org or call 908-575-7350.

#### Supporters:

The Rice Family — "In loving memory of Ellen and Ted Warner" The Concepcion Family — "In honor of our son, Christian" Edwin W. Whitehead Edward and Linda Finn Ruth Ely William and Mary Ann Silber James and Diane Wright — "In memory of Jeff Vitek and in honor of Sue and Pat Vitek" Jennifer Perkins — "In memory of Jeff Vitek and in honor of Sue and Pat Vitek" Richard and Janice Newport Bronwen Perkins Sharon Small Kathy and John Kramer — "In memory of Jeff Vitek"

### Medical professionals in the NJCTS Physicians Referral Network include:

- Neurologists
- Psychiatrists
- $\cdot$  Psychologists
- Social Workers

For more information about accessing a professional in the network, or if you are a professional interested in working with the TS community, please call 908-575-7350 or email info@njcts.org.

### AWARENESS & ADVOCACY NJ Walks for TS Moves East in 2016

When NJ Walks for TS was founded in 2010 as the first and only advocacy walk/run for kids, by kids, to benefit children with Tourette Syndrome, it was made clear to NJCTS that families and friends enjoy stepping out in support of their loved one with TS. In order to reach more families, NJCTS created the first NJ Walks for TS at Bergen in 2016 at Overpeck Park. This new location for the North Jersey walk/run offers magnificent views and an impressive amphitheatre, where attendees were treated to rock classics from *The Good Works Band* and *Carl Gentry Trio.* Good tunes and good times were had at all three NJ Walks events in 2016.

NJ Walks for TS at Princeton, hosted by Tim Kowalski and his daughters Paige and Tess, returned to Mercer County Park. NJ 101.5 provided music and entertainment to the walkers and runners whose enthusiasm could not be extinguished by an early April windstorm. In September, NJ Walks for TS returned to Medford Lakes where attendees enjoyed a performance by Dawson Coyle—a rising star who is living with TS. This second-annual South Jersey advocacy event allows families from across the region to engage with other parents, children and teens living with TS and its associated disorders.

Every registration, donation, and sponsorship comes as a vote of confidence in the NJCTS Education Outreach Program which aims to reach every teacher, student, and healthcare provider in NJ. Through school in-service workshops and hospital grand rounds, NJCTS educates professionals about TS and associated disorders to make the classroom a safer environment for a student struggling with TS and to train doctors, nurses, and mental health professionals to diagnose and treat TS more effectively than ever.





Runners and walkers stepped out in support of friends and neighbors with Tourette Syndrone.



Walking with a team makes the day more meaningful and so much more fun.



The warm sun, energized crowd, and picturesque views at Overpeck Park made for a great event.



The Youth Committee of the first annual NJ Walks for TS at Bergen welcomed the crowd of walkers.



The NJ Walks for TS at Medford Lakes Youth Committee kicked-off the South Jersey walk.



Hundreds walked in support of making a difference in the lives of those with the neurological disorder.

### NJ Walks for TS Committee

Princeton Youth Co-Chairs: Ally Abad Hallie Hoffman Paige Kowalski Tess Kowalski

*Committee:* Susan Everett Stephanie Hoffman Tim Kowalski

#### Medford Lakes Youth Co-Chairs: Anna Baldwin Eric Baldwin Sarah Baldwin Dante Hale Anna Heicklen Ava Heicken

*Committee:* Maureen Faber Jen Heicklen

### Bergen

Youth Co-Chairs: Tara Barr Noah Feldstein Mike Hayden Trevor Salvior Brennan Skirzenski Liane Sturrock

*Committee:* Judy Mars Tom O'Donnell Ellie Sturrock

#### 2016 NJ Walks for TS Honorary Committee

Congressman Donald Norcross (D-1) Congressman Albio Sires (D-8) Congressman Rodney Frelinghuysen (R-11)

State Senator Jim Whelan (D-2) State Senator Stephen Sweeney (D-3) State Senator James Beach (D-6) State Senator Dawn Marie Addiego (R-8) State Senator Christopher "Kip" Bateman (R-12) State Senator Christopher "Kip" Bateman (R-16) State Senator Christopher "Kip" Bateman (R-16) State Senator Christopher (R-21) State Senator Michael Doherty (R-23) State Senator Anthony Bucco (R-25) State Senator Sandra Cunningham (D-31) State Senator Nia H. Gill (D-34) State Senator Loretta Weinberg (D-37) State Senator Robert Gordon (D-38)

Assemblyman Vincent Mazzeo (D-2) Assemblyman John Burzichelli (D-3) Assemblyman Adam Taliaferro (D-3) Assemblyman Arthur Barclay (D-5) Assemblyman Troy Singleton (D-7) Assemblyman Herb Conaway, Jr. (D-7) Assemblyman Christopher Brown (R-8) Assemblywoman Maria Rodriguez-Gregg (R-8) Assemblyman Joe Howarth (R-8) Assemblyman Ronald Dancer (R-12) Assemblywoman Amy Handlin (R-13) Assemblyman Daniel R. Benson (D-14) Assemblyman Wayne DeAngelo (D-14) Assemblyman Reed Gusciora (D-15) Assemblyman Andrew Zwicker (D - 16) Assemblyman Jack Ciattarelli (R-16) Assemblyman Joe Danielson (D-17) Assemblyman Patrick Diegnan (D-18) Assemblyman John Wisniewski (D-19) Assemblyman Jamel C. Holley (D-20) Assemblywoman Nancy F. Munoz (R-21) Assemblyman Jerry Green (D-22) Assemblyman Michael Patrick Carroll (R-25) Assemblyman Anthony Bucco (R-25) Assemblywoman Mila Jasey (D-27) Assemblyman Sean T. Kean (R-30) Assemblywoman Angela McKnight (D-31) Assemblyman Vincent Prieto (D-32) Assemblywoman Annette Chaparro (D-33) Assemblywoman Sheila Oliver (D-34) Assemblyman Thomas Giblin (D-34) Assemblywoman Shavonda E. Sumter (D-35) Assemblyman Gary Schaer (D-36) Assemblywoman Marlene Caride (D-36) Assemblyman Timothy Eustace (D-38) Assemblyman Joseph Lagana (D-38)

Princeton Mayor Liz Lempert West Windsor Mayor Shing-Fu Hsueh

### AWARENESS & ADVOCACY NJCTS, Creative Agency Baldwin & Obenauf, and Tim Howard

### **Expand The GreaTS Global Tourette Syndrome Awareness Platform**



The online hub of The GreaTS movement, standwiththegreats.org, launched in June 2016.

StandWithTheGreaTS.org was launched in the summer of 2016 as the digital hub for The GreaTS global Tourette Syndrome movement that educates, informs, and issues a powerful call to action to supporters of the TS community around the world. The site is a collaboration among creative agency Baldwin & Obenauf, Inc. (BNO), the NJ Center for Tourette Syndrome and Associated Disorders, Inc. (NJCTS), and Tim Howard.

A highlight of the site is Howard's personal story, from his TS diagnosis at age 10 to where he is today. The site also enables supporters to be part of the movement by promoting TS advocacy work and purchasing GreaTS gear, including custom designed T-shirts worn by Tim.

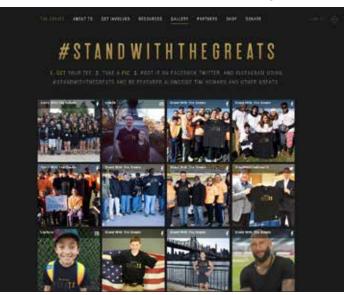
Howard has been an advocate and supporter of NJCTS for many years and believes TS has played a positive role in his life. Howard and other great athletes, artists, musicians, and professionals say that it was when they learned to embrace and "channel" their personal challenges that breakthrough success followed.

"What struck a chord, with me, right off the bat with The GreaTS was that it was bold, it was in your face, it was a statement...basically, get on board or get left behind," said Howard.

"We have received inquiries from TS advocacy groups all over the world asking how they can be a part of The GreaTS movement and how to adapt its empowering message for their communities," said Faith Rice, Executive Director of NJCTS. "We have clearly tapped into a feeling that is powerful and energizing for the TS community — there is nothing quite like it."

Beyond 2016, The GreaTS will focus on helping individuals with Tourette Syndrome — especially kids and young adults — develop the confidence, leadership, and self-advocacy skills necessary to overcome challenges and find their own paths to personal greatness. It will also allow supporters from around the world to get involved in meaningful ways and to encourage others to join the movement.

#### Learn more at StandWithTheGreaTS.org.



The GreaTS gallery features photos of GreaTS around the world.

### **AWARENESS & ADVOCACY** June 4th is Tourette Syndrome Awareness Day in New Jersey

For the 14th year in a row, a New Jersey governor has proclaimed June 4th as Tourette Syndrome Awareness Day in New Jersey.

NJCTS was presented with an official proclamation from the Governor's Office of New Jersey recognizing June 4th as Tourette Syndrome Awareness Day in the Garden State. Senator Christopher "Kip" Bateman of New Jersey's 16th legislative district presented the proclamation to NJCTS Executive Director Faith Rice and staff.

Families from all corners of New Jersey obtained proclamations from their towns to mark this important day. This was an opportunity for kids to advocate and become part of the NJCTS effort to spread awareness and acceptance for all people living with Tourette Syndrome.



Senator Christopher "Kip" Bateman (R-16) presented the proclamation marking June 4th as TS Awareness Day in New Jersey to NJCTS Executive Director Faith Rice and staff on the steps of the Somerset County Court House.



Families throughout New Jersey, like NJCTS Youth Advocate Kyla Butler's family, received proclamations from their towns.

#### NJCTS recruits legislators to Stand With The GreaTS

NJCTS staff and volunteers set up a photo booth at the State House in Trenton to advocate for the 1 in 100 New Jersey residents living with Tourette Syndrome and associated disorders. The photos, posted to social media tagged with #StandWithTheGreaTS were published on the GreaTS Gallery at standwiththegreats.org/gallery.

(Top to bottom) Congressman Albio Sires, Assemblywoman Patricia Egan Jones (D-5), Assemblyman Arthur Barclay (D-5), and Senator Richard J. Codey (D-27) were just a few of the legislators who Stand With The GreaTS.







## Community Health Law Project Honors Faith Rice for Improving the Lives of Individuals with Disabilities

Community Health Law Project selected NJCTS Executive Director Faith Rice as one of the 2016 honorees for the Ann Klein Advocate Award for her efforts to build a collaborative network of support and services for the Tourette Syndrome community.

Rice's grassroots efforts in Tourette Syndrome advocacy trace back to when her son was diagnosed with the disorder. Today, NJCTS is the nation's first Center of Excellence for Tourette Syndrome and promotes collaboration and partnerships among individuals, universities, hospitals and other resources to provide services and support for the 1 in 100 individuals and their families affected by TS and associated disorders.

The Ann Klein Advocate Awards are named for the late Ann Klein, former Commissioner of the New Jersey Department of Human Services, who was instrumental in establishing a community-based system of care for people with mental and physical disabilities. Other recipients of the 2016 Ann Klein Advocate Award were Julie Doerrman of the Recovery Network for the Deaf, Hard of Hearing, and Hearing Loss Center for Family Services; Military Family Support 360 Project at Joint Base McGuire-Dix-Lakehurst; Joe Young of Disability Rights New Jersey; and Wakefern Food Corp. Winners were announced at a ceremony held at The Wilshire Grand Hotel in West Orange, NJ on October 27, 2016. Past honorees have included legislators, scientists, advocates, corporate leaders, reporters, and entertainers.





Faith W. Rice, NJCTS Executive Director, accepts the Community Health Law Project's 2016 Ann Klein Advocate Award.

### Collaborative Academic Research Efforts for Tourette Syndrome Act of 2015

A bill to spur federal health officials to study TS and improve treatment for the neurological disorder was once again championed in Congress. The Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2015 (H.R. 619) was reintroduced by Congressman Albio Sires (D-NJ 8).

Inspired by the work of NJCTS, Rep. Sires first introduced the legislation in December 2011, with a Senate companion bill introduced by Senator Robert Menendez (D-NJ). The CARE act amends the Public Health Service Act for the inclusion of coordinated programs and activities by the National Institutes of Health to provide intensive research into Tourette Syndrome (TS).

The CARE act does not authorize any new funding for TS, but rather

reallocates existing funds towards new programs to more effectively research and collect data on TS. The Act would require the NIH to award grants and contracts to academic, healthcare, and other institutions to support the establishment of four to six Collaborative Tourette Syndrome Research Centers in different regions of the country. These centers will host world-class, targeted clinical research into TS and its associated disorders, which include mental health and learning disabilities.

That research would be used along with a wide-reaching collection of important data on various aspects of TS in an effort to provide better understanding of the disorder and guide strategy into the future of TS research.

### **Families Give Back**

We love it when our families initiate fundraising events, building local TS communities while supporting NJCTS. You can do it, too! Organize a family fun night in your community. Gather your friends for a "Paint-and-Sip" fundraiser or organize a bowling night. The possibilities are endless!



NJCTS Youth Advocate Anna Baldwin organized a pizza night fundraiser at Holy Tomato Too in Mullica Hill, NJ, and raised over \$800 for NJCTS.



Edison Police Chief Tom Bryan celebrates success during Wawa's hoagie-making challenge on December 9. Chief Bryan's team raised \$1,000 for NJCTS.



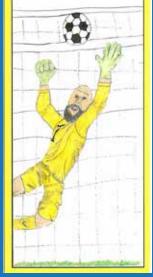
South Jersey TS Dad Scott Baldwin organized a Brew Pub Crawl fundraiser. With stops at Tonewood Brewing, Double Nickel Brewing Company, and Forgotten Boardwalk Brewing Co., Scott brought in over \$500 for NJCTS.



NJCTS Youth Advocate Mike Hayden inspired his high school English class to organize the group "Teens Tackle Tourette's" which spent the school year organizing, promoting, and producing a fundraising walk, which raised \$1,000 for NJCTS.

**Moorestown Upper Elementary School** students and staff were invited to donate \$1 for a Service and Spirit Tag on Spirit Day. The school selected The Keeper by Tim Howard for their "Read it Forward" program and chose this design as the winner of The Keeper bookmark contest. The school donated \$800 to the NJCTS Tim **Howard Leadership** Academy.

Today, I am blessed to be living a dream. And yet, if it all went away tomorrow, I know I would still have peace. - Tim Howard



### Youth Advocates Deliver Dare to Dream Conference Keynote Speeches





NJCTS Youth Advocate Mary Kate Donahue delivers a Keynote Speech at the Dare to Dream Conference at Stockton University.

In 2016, seven NJCTS Youth Advocates were selected to deliver keynote presentations at Dare to Dream High School Student Leadership Conferences.

Dare to Dream is sponsored by the New Jersey Department of Education Office of Special Education Programs and highlights strategies and knowledge to prepare high school students with disabilities for college and career readiness. Each conference features keynote presentations from accomplished students and young adults with disabilities who have demonstrated exemplary selfadvocacy and leadership skills.

As teens and young adults living with Tourette Syndrome, NJCTS Youth Advocates are uniquely positioned to speak to and inspire others who are overcoming obstacles.

Dare to Dream conferences include a variety of workshop sessions that provide attendees opportunities to gain insight into the transition from school to adult life. The conference gives students the opportunity to participate in workshops led by their peers on topics such as self-discovery, self-advocacy, learning styles, developing career paths, and understanding rights and responsibilities in college. Dare to Dream has long been a positive and empowering experience for thousands of New Jersey's students and NJCTS is proud to be involved in this program.

NJCTS Youth Advocates presented at the following 2016 Dare to Dream Conferences:

- Mercer County College, presented by Tess Kowalski
- Stockton University, presented Mary Kate Donahue
- Middlesex County College, presented by Hallie Hoffman
  - William Paterson University, presented by Mike Hayden
- Rowan University, presented by Anna, Sarah, and Eric Baldwin

### Girl Scouts Raise Tourette Syndrome Awareness for Silver Award

•

Three Girl Scouts have taken it upon themselves to raise awareness about Tourette Syndrome and associated disorders for their Silver Award. They selected NJCTS as the beneficiary of their service project and proved to be powerful advocates and volunteers all year long.

Ilina Joshi, Jaclyn Lenox, and NJCTS Youth Advocate Cami Jimenez from Girl Scout Troop 60808 met with Mayor Daniel J. Hayes to ask that he recognize June 4th as TS Awareness Day in their hometown of Bridgewater. They also met with Superintendent Dr. Daniel Silvia to have June 4th recognized in the Bridgewater-Raritan school district. The girls reached out to local radio station Magic 98.3 FM and were interviewed by host Maggie Glynn about their Silver Award project and their efforts to raise awareness of Tourette Syndrome. They also represented NJCTS at a community table in the Bridgewater Commons Mall, volunteered at NJ Walks for TS at Princeton, and more. Thank you for your tremendous effort to raise awareness of Tourette Syndrome in your community, Ilina, Jaclyn, and Cami!



Bridgewater Mayor Daniel J. Hayes presented a proclamation recognizing June 4 as TS awareness day and thanked the Girl Scouts for raising awareness in the Central Jersey town.

## **NJCTS IMPACT BY THE NUMBERS**

### **IN 2016, NJCTS REACHED:**

### 4,985

Educators and students through school in-service presentations

### 959

Medical professionals through Grand Rounds and PCME presentations and distributed research articles

### 6,420

Participants from around the world through the Wednesday Webinars series

### 811

Families—new and returning—through phone support

124 Teens and young adults living with TS through the NJCTS Tim Howard Leadership Academy Alumni Association

### 100 +

Individuals in a fun, safe, and supportive environment at the 12th annual **Family Retreat Weekend** 

### **IN THE LAST 6+ YEARS, NJCTS REACHED:**

18,916 Students and education professionals through in-service presentations

5,253 Medical professionals through NJCTS presentations and programs

37,756 Wednesday Webinar participants from around the world

11,755 Individuals served by family intake and phone support

259,484 Professionals at conferences and conventions

### 334,000+

Individuals through NJCTS core programs



NJCTS is the nation's first Center of Excellence for Tourette Syndrome (TS) and Associated Disorders. Through partnerships and collaborations, NJCTS provides a continuum of services, support, and education for families; outreach and training for medical and educational professionals; and advocacy for collaborative research for better treatments and a cure for TS.

### **Introducing the New NJCTS Website!**

In the summer of 2016, we proudly launched the newly redesigned website at NJCTS.org. The new website was designed with a fresh, clean look, user-friendly navigation, a mobile-responsive experience, and is regularly updated with the latest information about NJCTS programs and services.



### Ways to Give Back

NJCTS would not be able to provide essential programs and services if not for its vibrant, dedicated volunteers. We are always in need of help from individuals and families. If you would like to get involved and give back to an organization that has helped you, your family, or friends, please contact us at info@njcts.org or 908-575-7350.

Donate online at www.njcts.org, over the phone by calling 908-575-7350, or by mail to: NJ Center for Tourette Syndrome and Associated Disorders, Inc. 50 Division Street, Suite 205

Somerville, NJ 08876

#### **Donation options:**

- · General donations
- · Planned giving options
- $\cdot$  Monthly donations
- · Donate your vehicle
- $\cdot$  Matching gifts

#### Program & Technology needs:

- $\cdot$  Gift cards to Costco, BJs, Sam's Club, grocery stores, Staples
- $\cdot$  Office supplies
- Webcam
- · Camera/Camcorder
- · Netbook/Notebook
- $\cdot$  Silent auction items

#### Volunteer opportunities:

- · Become a community presenter
- · Train to be a Youth Advocate
- · Contribute to our TSParentsOnline or Teens4TS blog
- $\cdot$  Help us with mailings
- · Assist with mission-critical grant proposals
- Work with our development team on on-going fundraising initiatives
- · Help our staff organize, set up, and run an event
- · Serve on a NJ Walks for TS or Family Retreat Weekend committee

## **WE ARE NJCTS**

### **NJCTS Board of Directors**



. . . . . . . . . . . .

Faith W. Rice Executive Director



**Tim Omaggio** Board President Asurion



Rebecca Spar, Esq. **Board Secretary** Cole, Schotz, PC



**Conrad Roncati** Architectura



Tim Kowalski, PhD. Merck



**Andrew Hendry New Jersey Utilities** Association



Tim Howard **MLS Colorado Rapids** 



Amy Colcher, MD **Cooper Neurological** Institute



**Tim Yingling Giddyup Bronco** Productions, LLC



Steven Lindenbaum Deron School II



**Paul Romano** Treasurer

### **NJCTS Advisory Council**



Sol Barer, PhD Celgene Corporation (retired)



Dan Krivit, Esq. Krivit & Krivit, PC



Linda Brzustowicz, MD Lew Gantwerk, PhD **Rutgers University** Dept. of Genetics



Sandra Krivit Krivit & Krivit, PC



Director Emeritus, **Rutgers GSAPP** 



Bernice R. Rydell, EdD Jay Tischfield, PhD **VP** Emeritus **Millersville University** 



**Overlook Medical Center Rutgers University** 



Gary Heiman, PhD Dept. of Genetics



**Robert King, PhD** Yale University



Rutgers University Dept. of Genetics



## **WE ARE NJCTS**

### NJCTS Staff



Faith W. Rice Executive Director



Santina Reichenbach Finance Director



Barbara Chabner, PsyD. Lisa Fortunato Program Manager

**Maddie Pucciarello** 

Youth Development

Coordinator



**Communications & Public Relations Manager** 



. . . . . . . . . . . . . . . . . .

**Kelley Teabo** Project Coordinator



**Erin Caccavale-Boyle** Family Outreach & Volunteer Coordinator

**Marty Butterfield** 

Webinar Coordinator



**Patricia Phillips** Education Outreach Coordinator



**Amanda Silvers and Jennifer Hyland** 2016 Summer Interns



Daryl Ball Finance & Data Management



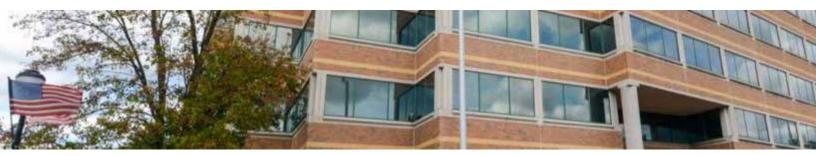
**Penny Dragonetti** Program Assistant to the Executive Director

#### **Stay Connected**

Follow us on Facebook, Twitter, and Instagram Visit our Teens4TS and TSParentsOnline blogs



NJ Center for Tourette Syndrome and Associated Disorders, Inc. 50 Division Street, Suite 205 Somerville, NJ 08876 908-575-7350 www.njcts.org



## **NJCTS SUPPORTERS**

NJCTS thanks our individual donors, foundations, and corporate sponsors for their support. Every dollar donated supports our programs and services critical to enhancing the quality of life for individuals and families living with Tourette Syndrome and associated disorders.

### **Top Corporate Donors**

Joemax Telecom, LLC · Virtua Health · Asurion · J. Fletcher Creamer Foundation · Otsuka America Pharmaceutical, Inc. · Horizon Services, Inc. · Advanced Dental Arts · The Arnold P. Gold Foundation · Pascack Valley High School Teens Tackle Tourette's

### **Top Individual Donors**

Ruth Eni • Michael and Faith Rice • Patrick and Susan Vitek • Dwyer Family Fund • Rebecca K. Spar, Esq. • Joseph and Joan Catuara • Tischfield Family Charitable Gift Fund • Timothy and Linda Omaggio • Stephen and Cindy Yingling • Bernice Rydell van Steyn • Kim Zambon • B.H. and M.J. Pucciarello • Nyree Anderson Miscia • Paul and Nancy Kurland • William and Kathy Hoffman • Alvin Garcia • Marc Bowen • The Baldwin Family

### NJCTS Tim Howard Leadership Academy Sponsors

Ruth Eni · Lawrence and Mary-Therese Stankovitz · Kim Zambon · Emily Fleischman · Alvin Garcia · Regal Homes · Marcia Seidner Siper · Kline Family Giving Fund · Joseph S. and Rachel Lehr · Lauren Lindenbaum · Ellen Lyle · Lance Moutner · Troy and Stacey Salvior

### **NJ Walks for TS Sponsors**

**Princeton:** Advanced Dental Arts, PA · Asurion · Chipotle · Harvest Moon Brewery · Horizon Services, Inc. · IPSOS · McCarter Theatre · Otsuka America Pharmaceutical, Inc. · Pinnacle Parkour · Rocky Hill Inn · Ruth's Chris Steak House · Salt Creek Frill · State Theatre NJ · Wegmans of Princeton · Yolanda's Clayhouse **Medford Lakes:** Beathan Industries, Inc. · Center for Emotional Health Elkins Chevrolet · Gary F. Gardner, Inc. · Jersey Pools and Spas · Holman Automotive Group · Horizon Services, Inc. · Murphy's at the Lakes Thriftway · Robinsons Waste Disposal · Original Lakes Appliance · Orthodontic Group, PA · Virtua Health **Bergen:** Architectura · Asurion · Bahrs Landing · The Cheesecake Factory · DCH Acura of Montclair · Dean's Natural Food Market · Dynamic Physical Therapy · Eco Lips · Foodtown of Washington Township · J. Fletcher Creamer Foundation · Jersey Mike's Subs · McLoone's Restaurants · Nyree Anderson Miscia · SAL Electric Company

### **Jeff Vitek Memorial Fund Supporters**

The Rice Family · The Concepcion Family · Edwin W. Whitehead · Edward and Linda Finn · Ruth Ely · William and Mary Ann Silber · James and Diane Wright · Jennifer Perkins · Richard and Janice Newport · Bronwen Perkins · Sharon Small · Kathy and John Kramer · Jennifer LeFevre

### Volunteers

Ally Abad · Blair Abney · Kathy Abney · Angelo Alago · Anna Baldwin · Carolyn Baldwin · Eric Baldwin · Sarah Baldwin · Scott Baldwin George Barnabic · Adam Bauser · Joe Buonadonna · Bill Bastan · Adrian Bernales · Bambi Bernales · Larry Brown · Kimberly Cable · Sara Carapezzi · Jordan Chervin · Amanda Cicchino · Lee Concepcion · Christian Concepcion · Lisa Cox · Ed Davis · Sean Dekhayser Sheryl Dekhayser · Cynthia Deng · Lily Deng · Mary Kate Donohue · Lauren Everett · Sue Everett · Mary Farmer · Andy Freidrich · Drew Friedrich · Sue Furrer · Lesley Geyer · Charles Griebell · Diana Griebell · Ken Griebell · Stuart Green · Mike Hayden · Jen Heicklen Sean Herb · Rob Hodgeson · Kelly Hodgeson · Hallie Hoffman · Stephanie Hoffman · Daniel Hwang · Nicole Janiec · Cami Jimenez Allen Jones · Annie Jones · Logan Jones · Rich Jones · Ilina Joshi · Pat Kennedy · Dianne Kidawa · Joan Kim · Bob King · Michelle Klapper · Julie Koch · Tim Kowalski · Leslie Kowalski · Paige Kowalski · Tess Kowalski · Elizabeth Kuno · Teruo Kuno · Joan LaLuna · Steven LaLuna · Yolanda Lawas · Michael Leopold · Jaclyn Lenox · Karen Licato · Tommy Licato · Cheryl Ludwig · Christopher Lynch · Ben Mars · Harvey Mars · Judy Mars · Petia Morozov · Erica Nagy · Emily Ortega · Lauren Ortega · Moo Yon Park · Terri Park · Young C. Park · Corrine Pineda · Mike Polhemus · Natali Puljols · Irene Quia · Sharon Ritz · Alexa Rivera · Stephanie Rivera · Michael Rosolowsky Anna Rubenstein · Mike Rubenstein · Martha Santiago · Matt Schreurs · Melissa Schreurs · Matt Singer · Somerset County RSVP · Ben Stark · Fred Storer · Donna Tischfield · Jay Tischfield · Ginny Thomas · Ellen Topiel · Chris Ulriksen · Rachel Ulriksen · Andi Vinci · Darren West · Suzy West · Sue Wingert · Yanxia Yu · Rob Zambrano



50 Division Street, Suite 205 Somerville, NJ 08876 908-575-7350 www.njcts.org Email: info@njcts.org