

# NJ CENTER FOR TOURETTE SYNDROME & ASSOCIATED DISORDERS

## 2017 YEAR IN REVIEW

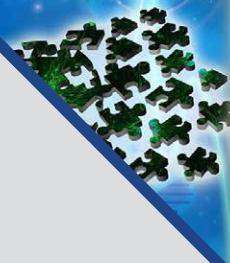


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ESTABLISHED IN 2004 AS THE NATION'S FIRST CENTER OF EXCELLENCE FOR TOURETTE SYNDROME

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## OUR MISSION

The New Jersey Center for Tourette Syndrome 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.

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### DEAR FAMILIES & FRIENDS,



I always feel that the current year is the best year yet for fulfilling the NJCTS mission. Well 2017 was certainly that - it was successful beyond all expectations. Not only did NJCTS provide services for families and kids and training for teachers and clinicians, but in May of 2017 our team of research collaborators announced the discovery of four genes that contribute to Tourette Syndrome! That discovery was the first-ever by scientists researching the genetic roots of TS and it gave direction to other scientists to continue research toward better treatments and a cure.

This breakthrough was made possible by families across the globe stepping up to being screened and providing blood samples to the NJCTS Cell & DNA Sharing Repository through the TIC Genetics program; funding from the National Institutes of Health; and by the dedication and collaborative efforts among our research partners around the world.

We will continue to reach out to you to participate in this and other critical research. And when we do, I ask that you step up and do your part to change the lives of kids and families for generations to come.

Sincerely,

Faith W. Rice  
Founder & Executive Director

PS: The NJCTS press release announcing the research breakthrough can be found on page 6. Stay tuned for more important announcements in 2018.





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 about 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

OUR IMPACT

LOCAL CONNECTIONS, GLOBAL REACH


From the moment they make contact with our organization, families are immediately supported through information and referral, access to training through webinars, and connections to other TS families.

6500   
Nearly 6500 families, educators and healthcare professionals viewed our educational webinars


28   
28 trainings were conducted in urban and underserved communities

  
More than 45,000 literature and research updates were distributed to medical and mental health professionals, educators and other school personnel  
45,000

4   
Breakthrough research identified 4 damaged genes as cause of TS

  
NJCTS responded to 1764 calls for support  
1764

NJCTS advocated at 23 professional conferences  
23 

5785 educators attended 63 training sessions throughout the state  
5785 

  
More than 2300 clinicians attended 19 NJCTS medical trainings  
2300

For support, please reach out to NJCTS at 908.575.7350 or [info@njcts.org](mailto:info@njcts.org). Learn more at [www.njcts.org](http://www.njcts.org).





# Rutgers Scientists Lead International Effort to Determine Cause of Tourette Syndrome

Four damaged genes that disrupt the normal development of the brain in those with Tourette syndrome have been identified by Rutgers scientists and researchers from across the country involved in an international effort to determine the cause of the disorder.

In a study published on May 3, 2017 in *Neuron*, researchers from Rutgers University-New Brunswick, UC San Francisco, Massachusetts General Hospital, the University of Florida, Yale University and other institutions across the world identified one damaged, or mutant, “high confidence” risk gene for Tourette’s as well as three others they believe are genes whose mutation is a probable risk for the disorder.

These findings are important because the genetics of Tourette syndrome has been a mystery. The goal of the continuing study is to identify inherited factors that play a role in causing Tourette’s and other related disorders, such as obsessive-compulsive disorder (OCD) and attention-deficit/hyperactivity disorder (ADHD).

“This research is the first of its kind establishing Tourette disorder as a genetic disease similar to other neuropsychiatric disorders like autism, where not just one gene has been identified as the cause,” said Jay Tischfield, a senior author of the study. “We are confident that this new information will lead us to the genetic and brain pathways that cause this disorder and enable the development of more effective treatments.”

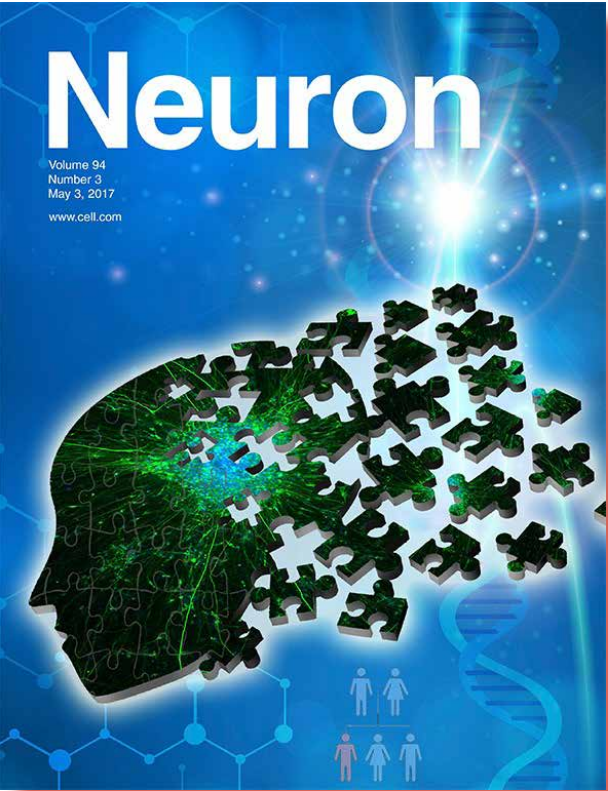
Tischfield, MacMillan Distinguished Professor of Genetics, and Gary Heiman, associate professor in the Department of Genetics in the School of Arts and Sciences, are part of the Tourette International Collaborative Genetics (TIC Genetics) study - the largest and most comprehensive genomic analysis conducted - that includes scientists and clinicians from the United States, Europe and South Korea.

“The fact of finding this one gene in two families would be like lightning striking the same individual twice,” said Heiman, a senior author on the project. “And it is the reason why it is crucial for us to continue studying families affected by this often debilitating disorder.”

In conducting the study, blood samples were collected from family members to identify rare genetic mutations that are not inherited from their parents but occur spontaneously in affected individuals at birth. While many inherited diseases, such as sickle cell anemia, hemophilia and cystic fibrosis, are caused by mutations to a single gene, this new research indicates that Tourette syndrome, like other neuropsychiatric disorders, is the result of multiple gene mutations. Rutgers researchers and their colleagues estimate that there are approximately 400 mutated genes that could pose a risk for Tourette syndrome.

Rutgers scientists say more samples from families in which only one child is affected with Tourette’s and both parents are available to participate are needed to better understand how these and other damaging mutations lead to Tourette disorder.

“I want to thank all the individuals with Tourette disorder and their family members from New Jersey, around the country, in Europe and South Korea, for their participation and advocacy, said Heiman. “Progress has been slow and disappointing up until now. But I think this research will lead to the development of more specific treatments that are personalized for individuals or groups of people.”



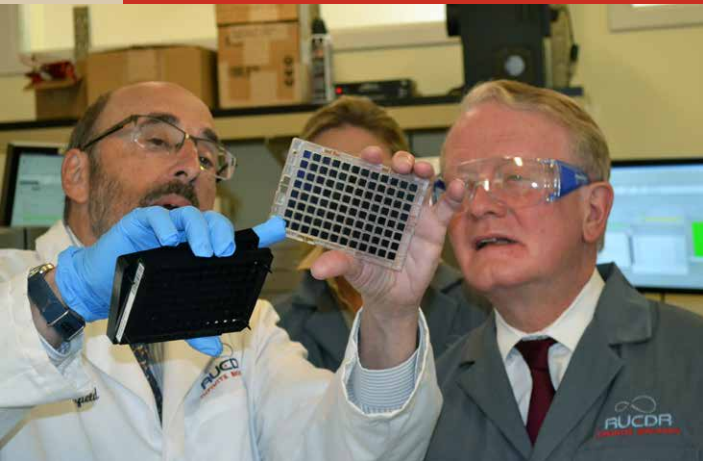
# RESEARCH

NJCTS continues to lead the way in research to find better treatments and a cure for Tourette Syndrome. Nearly a decade ago, NJCTS began its research partnership with Rutgers University and established the NJCTS Tourette Syndrome Sharing Repository. By 2011, the National Institutes of Health recognized this extraordinary accomplishment and declared it a federal asset, designating it as the federal repository for Tourette Syndrome and awarded funding to establish 26 collection sites around the world. This worldwide “sharing repository” for cell and DNA samples was now available to researchers across the globe to study the genetics of TS. This was the first program of its kind and changed the direction of TS research. Prior to establishing the repository, which contains over 2,800 genetic samples of individuals with TS and their relatives, there was nowhere for independent scientists and institutions to request TS samples.

In this past year, the Sharing Repository has played a major role in TWO major breakthroughs in genetic research. In May, our partner researchers were the first scientists ever to discover genes contributing to TS. Their study, the largest and most comprehensive genomic analysis conducted, aimed to identify inherited factors that play a role in causing Tourette’s and other related disorders. Our team then announced this fall that they took white blood cells obtained from participants in the TS genetic study and converted these cells to brain cells (neurons) to help researchers better understand the causes of TS.

## RUTGERS & NJCTS

“OUR PARTNERSHIP WITH RUTGERS HAS RESULTED IN THE IDENTIFICATION OF KEY GENES CONTRIBUTING TO TOURETTE SYNDROME, LEADING THE WAY TO A BETTER UNDERSTANDING OF THIS COMPLEX DISORDER. NEW JERSEY FAMILIES’ PARTICIPATION IN THE 2008 INITIAL PILOT LED TO ESTABLISHING 26 NATIONAL INSTITUTES OF HEALTH COLLECTION SITES AROUND THE WORLD AND TO THIS EXPANDED RESEARCH. BECAUSE OF THEIR PARTICIPATION, WE ARE CLOSER THAN EVER TO UNDERSTANDING TOURETTE SYNDROME.” — FAITH RICE





## THE WORLD'S FIRST CELL & DNA SHARING REPOSITORY FOR TOURETTE SYNDROME

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, London

### KOREA

**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

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 2017, 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.

## 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 kids 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 them, their siblings, and their parents.

The NJCTS Youth Development Program trains and supports children of all ages with TS. The program provides support, leadership, networking, education, and advocacy services to families dealing with Tourette Syndrome. From the moment they first make contact with our organization, families are immediately supported through information and referral, access to training through 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 our walk events by walking, fundraising and volunteering. The program was created by kids, for kids and supports the NJCTS Education Outreach programs.
- 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 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 which help to build empathy, tolerance, and acceptance as well as provide an anti-bullying message.

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 beyond the teenage years. We provide a variety of activities for teens and young adults including:

- Youth Advocate presentations: The NJCTS Youth Advocate Program trains teens to lead presentations about Tourette Syndrome and associated disorders to students, medical professionals, and community groups.
- As peer educators: In 2017, Youth Advocates presented to nearly 5,000 students and teachers at schools throughout the state. All presentations provide a strong anti-bullying message and promote acceptance.
- As patient educators: Youth Advocates work with our doctors to provide Grand Rounds and Patient-Centered Medical Education (PCME) presentations at hospitals throughout the region to educate doctors and medical staff about the unique needs of patients living with Tourette Syndrome and associated disorders.
- 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.



## The NJCTS Tim Howard Leadership Academy

The NJCTS Tim Howard Leadership Academy empowered a new set of leaders in the Class of 2017. Each of the 27 participants took part in an intensive four-day training promoting self-empowerment, self-leadership, 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.

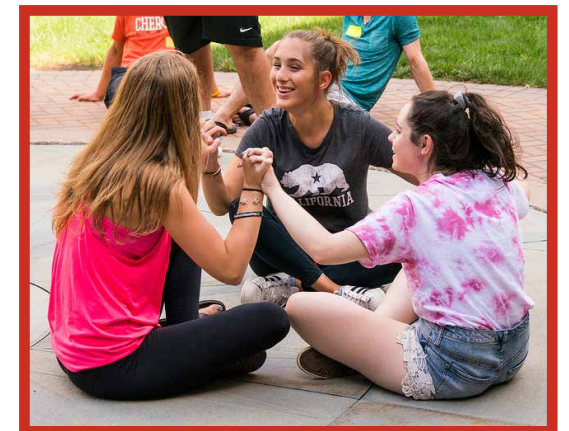
The 4th annual Academy took place at Rutgers University from August 3-6 where leading TS experts led presentations and workshops throughout the program. Participants had the opportunity to learn from neurologists, geneticists, psychologists, social workers, and others about their diagnoses.

"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."

The participants—who hailed from New Jersey, New York, Pennsylvania, Florida, Illinois, California and Canada—contributed thoughtful questions and were eager to share life-skills tips with each other. They were assigned to teams led by coaches who are successful young adults leaders with TS.

"The academy has been wonderful for my son's growth and development and advocating for himself," said one Academy parent. "I wish we found out about the academy sooner. My son would love to be a Coach someday. I really appreciate all the academy does for kids with TS. You all are angels in my eyes."

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.





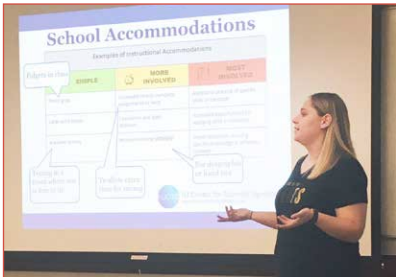
# EDUCATION OUTREACH

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 400 presentations to audiences as large as 800 students, raising awareness, standing up to bullying, and increasing understanding of this often-misunderstood disorder. In 2017, Youth Advocates led 37 presentations, 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.



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

Battle Hill Elementary School  
Bells Elementary School  
Camden's Promise  
Camden's Promise Charter School  
Chatham Middle School  
Community Park School  
Conley School  
Galloway Township Middle School

Green-Fields Elementary School  
Heywood Ave School  
Howard Brunner  
Indian Hill School  
J. Mason Tomlin School  
Mary Bray Elementary  
Memorial Middle School  
Philip Vroom School

R.W. Kershaw Middle Schools  
Riker Hill Elementary  
Roosevelt School  
Shongun Elementary  
Temple Emanuel  
Theunis Dey Elementary School  
Veterans Memorial School  
West Ridge Elementary School

## YOUTH ADVOCATES WHO PRESENTED IN 2017

Anna Baldwin  
Sarah Baldwin  
Eric Baldwin  
Tara Barr  
Rachel Flynn  
Victoria Franco  
Drew Friedrich

Wyatt Gray  
Charles Griebell  
Mike Hayden  
Hallie Hoffman  
Ethan Lederman  
Tommy Licato  
Sarah Lichtblau

Ben Mars  
Tyler Russell  
Brennan Skirzenski  
Jenna Smith  
John Sooy  
Liane Sturrock

## 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.



IN-SERVICE PRESENTERS:  
Diana Antinoro-Burke, Psy.D  
Barbara Chabner, Psy.D  
Lisa Cox, LCSW, MSW, PhD.

Graham Hartke, Psy.D  
Tracy Lederman, Ed.D  
Jeremy Lichtman, Psy.D  
Michelle Lubonski, M.Ed

Cheryl Ludwig, MA, CCC-LP  
Michelle Miller, Psy.D  
Patricia Phillips  
Madeline Pucciarello, MPH

## Faculty In-service Participating Schools in 2017 included:

- Atlantic County School Nurses
- Bear Tavern Elementary School
- Brookside School
- Burlington County School Nurses
- Camden Street Elementary School
- Camden's Promise Charter School
- CIACC Monmouth County Education Partnership
- Community Charter School of Paterson
- Conley School
- DCF Regional School (Union Campus)
- Essex County Special Education Dir Roundtable
- Family Guidance Center of Warren County
- Green Hills School
- HRH & PATH Int'l Conference
- Hudson County Child Study Teams
- Lake Riviera Middle School
- Lakeland Regional HS
- Mercer County Special Services School District High School
- Mt. Ephraim School
- Mt. Olive High School
- Neptune Middle School
- NJ Commission Blind
- Riker Hill Elementary
- Roosevelt Public School
- Roosevelt School
- Sussex County School Nurses
- Teaneck Community Charter School
- The College of New Jersey

# YOUTH SCHOLARSHIP WINNERS

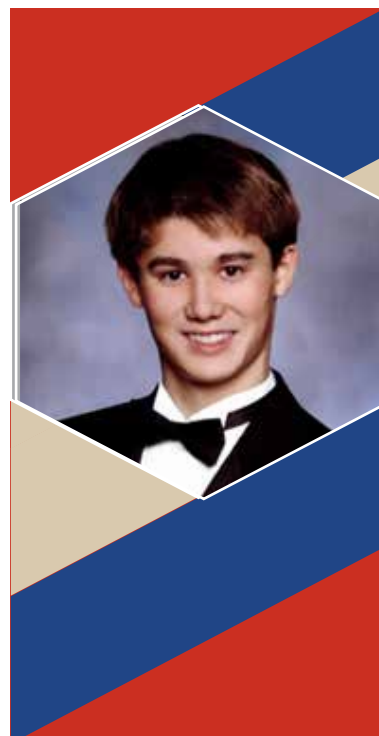
Since 2001, the NJCTS Youth Scholarship Award has been given to more than 200 outstanding high school seniors in New Jersey who have excelled in their schools and communities. In 2017, 13 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing themselves as outstanding advocates for Tourette Syndrome.

## First Place Winners



**THOMAS LICATO**  
SOUTH PLAINFIELD

Licato's award essay was titled "That's Life." He was a member of the National Honor Society, Passionately Pink, Chamber Choir, Madrigal Choir, Disney Choir, Jerseyan History Club, Model United Nations, and has served as an NJCTS Youth Advocate for many years. He was named president of his high school class.



**MICHAEL POIRIER**  
MONTGOMERY

Poirier's award essay was titled "The Imaginator." He was a member of the high school swim team and the X-Cel swim team. He was also a member of the National Honor Society and the National Art Honor Society.

## Second Place Winners

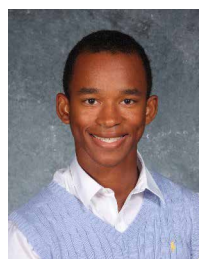
**PATRICK MCINTYRE**  
MULLICA HILL

McIntyre's award essay was titled "I Have Tourette. Tourette Doesn't Have Me." He was a member of the soccer team, TOPS Soccer program, math league, DECA, Key Club, National Honor Society, and science league.

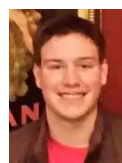


**DAVID CUMMINGS**  
MONTCLAIR

Cummings' award essay was titled "How Tourette Syndrome has Played a Role in My Life." An active community volunteer working with Toni's Soup Kitchen, he was also a member of the culinary club, anime club, stage crew, robotics club, and art garage.



## Honorable Mention Winners



**NICHOLAS ALVINO**  
WANAQUE



**ANNA BALDWIN**  
MANTUA



**NOAH FELDSTEIN**  
RANDOLPH



**TESS KOWALKSI**  
PLAINSBORO



**RACHEL MALEY**  
WOOLWICH TWP



**DANIEL ORTNER**  
WOODBURY HEIGHTS



**JAMES PATON**  
NEW MILFORD



**ROSE PETRICK**  
PERTH AMBOY



**TREVOR SALVIOR**  
RANDOLPH

# 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 disorder and their families and to improve interpersonal and communication skills in patient encounters.

In 2017, NJCTS reached more than 2,300 medical professionals through Grand Rounds and PCME trainings at hospitals throughout the state and through regular distribution of the latest TS-related research articles.

## GRAND ROUNDS & PCME SESSIONS

Newark Beth Israel Medical Center

Cooper University Hospital

Monmouth Medical Center

Presenters:

Dr. Rob Zambrano

Dr. Jeremy Lichtman

Dr. Roger Kurlan

Youth Advocates:

Ethan Lederman

Tara Barr

Jeff DeCicco





# WEBINARS

SINCE 2008, THE NJCTS EDUCATIONAL WEBINAR SERIES EXPLORES THE DETAILS OF LIVING WELL AND LEARNING WITH TS AND ITS ASSOCIATED DISORDERS

The need has never been greater for practical and accurate information about TS and associated disorders for parents, 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.

## 2017 WEDNESDAY WEBINARS

### DEMYSTIFYING DSM 5 DIAGNOSIS

Presenter: Dr. Colleen Martinez

Explains the history of the Diagnostic and Statistical Manual of Mental Disorders (DSM), and gives an overview of changes in the most recent version.

### CREATING A PLAN FOR SUCCESS THROUGH PSYCHOLOGICAL AND EDUCATIONAL ASSESSMENT

Presenter: Dr. Lisa Ahern

When to consider testing, what questions can be answered through psychoeducational testing, what recommendations can be made, and how testing information is used in a school setting.

### GAME-BASED COGNITIVE BEHAVIORAL THERAPY

Presenter: Dr. Justin R. Misurell

Discussion on how the games and activities included in the GB-CBT model can be easily used by clinicians to address anxiety, compulsive behaviors, tics and disruptive behavior disorders.

### LIFE CYCLE OF TICS

Presenter: Dr. Michael Rubenstein

Addresses the chronology, type, and development of tics, presented by a neurologist who not only treats tics but lives with them.

### GRIEF AND LOSS: HANDLING EXPECTATIONS

Presenter: Jesse Bassett, MDiv

Grief is a topic most would like to avoid, as it often makes us feel uncomfortable and we find ourselves feeling awkward while trying to say and do the right things for our co-workers and friends.

### UPDATE ON CURRENT MEDICATIONS FOR TS AND ASSOCIATED DISORDERS

Presenter: Dr. Roger Kurlan

Discussion on the medications that are commonly prescribed, those prescribed in the past and still used today as well as medications new to the market.

### SIBLING ISSUES

Presenter: Dr. Graham Hartke

Siblings of special needs children face unique challenges that are often overshadowed by other family needs.

### PARENTING STRATEGIES TO IMPROVE LIFE AT HOME

Presenter: Dr. Justin R. Misurell

Decades of research on behavior management has identified a number of core principles and techniques that have proven to be effective in addressing children's behavioral difficulties.

# 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 2017, 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.



## COMMUNITY PRESENTATION PARTICIPATING ORGANIZATIONS:

- Cape May Dept Human Services
- Catholic Charities
- CGS Family Support Organization
- CIACC Essex County
- CIACC Middlesex County
- CIACC Middlesex/Division of Children's Services
- CIACC Somerset County
- CMO Caring Partners of Morris/Sussex
- Community of Care Consortium (SPAN)
- Dept of Children & Families
- FSO Hunterdon, Somerset & Warren
- FSO State Directors
- Hudson County Dept of Health & Human Services
- Mercer County Superintendent Roundtable
- Partnership for Children of Essex
- Passiac County Association of School Administrators
- SPAN
- Superintendent Roundtable --Bergen County
- Superintendent Roundtable --Union County
- Warren County

## CONFERENCES:

- New Jersey Council for Exceptional Children
- NJ State School Nurses Association
- NJ Association of School Social Workers
- New Jersey Psychiatric Association
- Bergen's Promise
- NJ Coalition for Inclusive Education
- NJ Association of School Psychologists
- NJAAP-American Association of Pediatrics, NJ Chapter
- Somerset County CIACC Education Partnership
- ASAH
- New Jersey Education Association
- NJ Primary Care Association



# AWARENESS & ADVOCACY

## NJ WALKS FOR TS

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 2017, two walks were held: Central Jersey, at Mercer County Park, and North Jersey, at Overpeck County Park in Bergen. Once again our Walk Youth Committee fully committed to raising awareness around the walks and bringing out their family and friends to participate.

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

### NJ WALKS FOR TS YOUTH COMMITTEE

#### CENTRAL JERSEY:

Ally Abad

Hallie Hoffman

Paige Kowalski

Tess Kowalski

#### NORTH JERSEY:

Tara Barr

Noah Feldstein

Mike Hayden

Trevor Salvior

Brennan Skirzenski

Liane Sturrock

### NEW JERSEY



### WALKS FOR TS



## 2017 NJ WALKS FOR TS HONORARY COMMITTEE



State Senator Jennifer Beck (R-11)

State Senator Samuel Thompson (R-12)

State Senator Linda Greenstein (D-14)

State Senator Christopher "Kip" Bateman (R-16)

State Senator Bob Smith (D-17)

Senator Thomas Kean, Jr. (R-21)

Senator Anthony R. Bucco (R-25)

State Senator Robert Singer (R-30)

Senator Paul Sarlo (D-36)

Assemblywoman Joann Downey (D-11)

Assemblyman Eric Houghtaling (D-11)

Assemblyman Wayne DeAngelo (D-14)

Assemblyman Reed Gusciora (D-15)

Assemblywoman Elizabeth Maher Muoio (D-15)

Assemblyman Jack Ciattarelli (R-16)

Assemblywoman Nancy Pinkin (D-18)

Assemblyman John Wisniewski (D-19)

Assemblyman Jamel C. Holley (D-20)

Assemblyman John DiMaio (R-23)

Assemblyman Michael Patrick Carroll (R-25)

Assemblyman Sean Kean (R-30)

Assemblyman Vincent Prieto (D-32)

Assemblywoman Shavonda E. Sumter (D-35)

Assemblyman Kevin J. Rooney (R-40)



# AWARENESS & ADVOCACY

## TS ROCKS

The Jersey Shore’s most popular acts, including Bobby Bandiera, the Moroccan Shepherders, Carl Gentry Band and the Taylor Tote Band, played at TS Rocks on October 1 at the Charles Hesse Parish Center in Atlantic Highlands.

The name, TS Rocks, was first coined by a young member of NJCTS in gratitude for the skills she learned at a self-advocacy training.

In addition to music, concert goers enjoyed food, drinks, a 50/50, and a live and silent auction featuring travel stays, professional services, event tickets, sporting equipment, restaurant gift certificates and much more. New Jersey 101.5 FM’s Big Joe Henry also put in an appearance!

Special thanks to the creators of the 2017 TS Rocks, Kathie Sterzinar and Pam McCoy.

### TS Rocks Sponsors:

- Bank of America
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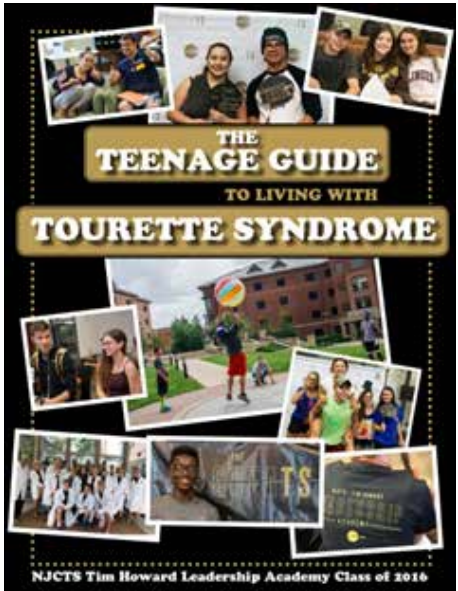
## THE TEENAGE GUIDE TO LIVING WITH TOURETTE SYNDROME

NJCTS announced the publication of The Teenage Guide to Living with Tourette Syndrome, an ebook created and developed by the NJCTS Tim Howard Leadership Academy Class of 2016.

Tourette Syndrome is often misunderstood by people who think that tics are controllable, or that TS is just something that means you curse a lot. But the truth is, having TS is much more complicated than that, and it can be difficult to understand, and hard to explain.

The Teenage Guide to Living with Tourette Syndrome is brought to you by the NJCTS Tim Howard Leadership Academy Class of 2016, and offers advice, guidance, tips, and suggestions for dealing with tics, friends, teachers, and others, for all teens living with TS.

This is advice for teens, by teens—“experts” who are offering their best advice of how to handle any situation. The contributors are also representatives of The GreaTS movement which empowers individuals with Tourette Syndrome. The Teenage Guide to Living with Tourette Syndrome upholds The GreaTS mission of breaking down social stigmas, generating awareness, and providing support. Its aim is to provide inspiration and language to help others understand TS. It is a valuable resource providing guidance and support that teens living with TS need.



## ASK THE GREATS: A NEW SERIES FOR TEENS & YOUNG ADULTS



The NJCTS “Ask The GreaTS” sessions encourage, facilitate, and engage youth and young adults in the global Tourette Syndrome community to participate in meaningful discussions and an exchange of ideas. This support service allows for session participants to talk about relevant TS-related life topics with experienced NJCTS young adult presenters and advocates. Participants will be able to watch the presenters have a candid, experience-based discussion, followed by the opportunity to engage in a Q&A session. The Ask The GreaTS sessions will bring together members of the global TS community in a supportive, friendly environment, and help participants develop TS awareness, self-confidence, resilience, and advocacy skills.

The first session, held on May 24, 2017, focused on self-disclosure and panelists shared their experiences disclosing their TS to friends, teachers, strangers, and others.



# AWARENESS & ADVOCACY

## AMERICA'S HIGHEST HONOR FOR PUBLIC SERVICE IS AWARDED TO NJCTS YOUTH ADVOCATES

Since 2007, the New Jersey State Governor's Jefferson Awards for Public Service has recognized volunteers who make a difference in their communities. Among the 2017 honorees were the NJ Center for Tourette Syndrome and Associated Disorders, Inc. (NJCTS) Youth Advocates who were recognized in the Youth Volunteer Group Category.

The Jefferson Awards were established in 1972 by Jacqueline Kennedy Onassis, Senator Robert Taft and Sam Beard and are America's highest honor for public service and volunteerism, honoring the "informed and involved" citizen. Honorees of the New Jersey State Governor's Jefferson Award achieve measurable community impact and represent outstanding acts of public service, without the expectation of recognition or compensation. Recipients demonstrate unique vision, dedication and tenacity of heroic proportion and serve as inspiration for others.

The 75 young volunteers who have trained as NJCTS Youth Advocates inspire others to understand and accept people with disabilities. To create awareness and understanding, they share their personal experience living with a highly visible disorder. All Youth Advocates, between the ages of 13 to 18, are trained to present to a variety of audiences including students and faculty in schools, medical professionals in hospitals, and peers in community organizations, in every corner of the state. These young volunteers provide much-needed support for youth and young adults living with TS, teaching empathy and encouraging an anti-bullying culture.

"I am proud of our Youth Advocates for the profound differences they are making in their communities and throughout New Jersey," said NJCTS Executive Director Faith Rice. "These young volunteers raise awareness of Tourette Syndrome—a stigmatized disorder effecting 1 in 100 individuals—by sharing their personal journeys with students in schools and medical professionals in hospitals. In leading by example, they teach kids that Tourette, or any difference, is not something anyone should hide behind."

Growing up with a neurological disorder has many challenges. For the children living with Tourette Syndrome and associated mental health disorders, those challenges are compounded by visible motor and vocal tics and the isolation and bullying that comes from being perceived as different. Youth Advocates have a strong desire to help others and sympathize with those who may be struggling with challenges. They draw from their own experiences struggling with their diagnosis to stand up for others and give back to others struggling with their diagnosis.

"NJCTS Youth Advocates are making a difference every day and at the same time, they are gaining skills in leadership, public speaking, and advocacy in spite of the unique challenges they face," said Rice. "I thank the New Jersey State Governor's Jefferson Awards committee for recognizing our outstanding volunteers."



## JUNE 4TH IS TOURETTE SYNDROME AWARENESS DAY IN NEW JERSEY

To mark the occasion of Tourette Syndrome Awareness Day in New Jersey, the NJ Center for Tourette Syndrome and Associated Disorders celebrated with a press conference and award ceremony at the New Jersey State House in Trenton on Monday, June 5.

Assemblyman Troy Singleton (D-7) partnered with NJCTS to recognize accomplished high school seniors who live with Tourette Syndrome (TS)—an inherited, neurological disorder that affects 1 in 100 individuals.

Singleton presented Youth Advocate of the Year awards to Tess Kowalski of Plainsboro and Anna Baldwin of Mantua in recognition of their contribution to making a difference in New Jersey's Tourette Syndrome Community. NJCTS Youth Advocates are dedicated to improving awareness and breaking the stigma of TS by educating the public, medical professionals, and educators, and by supporting kids and families living with TS. Tess and Anna were recognized for their outstanding leadership throughout the many years they have served as Youth Advocates.

Singleton also presented Youth Scholarship Awards to Tommy Licato of South Plainfield, Michael Poirier of Montgomery, David Cummings of Montclair, Patrick McIntyre of Mullica Hill, Daniel Ortner of Woodbury Heights, Rose Petrick of Perth Amboy, Trevor Salvior of Randolph, and Noah Feldstein of Randolph. Nicholas Alvino of Wanaque, James Paton of New Milford, and Rachel Malley of Woolwich Township were recognized in absentia. Winners were selected based upon academic achievement, community involvement, and accomplishments as individuals living with this challenging and complex neurological disorder.



2017 Youth Advocates of the Year

Tess Kowalski  
Anna Baldwin



# AWARENESS & ADVOCACY

## OUTSTANDING LEADERSHIP IN MENTAL HEALTH SERVICES AWARD PRESENTED TO FAITH RICE

The New Jersey Association of Mental Health and Addiction Agencies, Inc. (NJAMHAA) recognized individuals who contribute to the quality of life for children and adults throughout the state. The Courage and Compassion Awards are presented to professionals who demonstrate dedication and determination to enhance individuals' lives, as well as leadership that makes them role models for others in the mental health, substance use, and developmental disabilities system.

NJ Center for Tourette Syndrome and Associated Disorders Executive Director Faith W. Rice was among the 2017 recipients. Rice was honored with the Outstanding Leadership in Mental Health Services award for her efforts to build a collaborative network of support and services for the Tourette Syndrome community. Other recipients of the 2017 awards included Assemblyman Gary Schaer and Assemblywoman Valerie Vainieri Huttie.



## NJCTS HOSTS ROUNDTABLE DISCUSSION AFTER SWIM TEAM VIEWING

What would you do if your community gave up on your child? In New Jersey, the parents of a boy on the autism spectrum take matters into their own hands. They form a competitive swim team, recruiting diverse teens, including Kelvin, a teen with TS, and training them with high expectations and zero pity. Swim Team chronicles the extraordinary rise of the Jersey Hammerheads, capturing a moving quest for inclusion, independence and a life that feels winning.

The screening took place in November during the Teaneck International Film Festival. A roundtable moderated by NJCTS Education Outreach Coordinator Patricia Phillips followed. Participants included members of the cast, NJCTS youth advocate Mike Hayden and Dr. David Levesque.



## TIM HOWARD RECOGNIZED BY RED BULLS

Early in his professional soccer career, Tim Howard played with the New York Red Bulls, then the NY/NJ MetroStars. During the season opener against the Colorado Rapids, Howard's current team, the Red Bulls took the opportunity to recognize his charitable and advocacy efforts by presenting a donation to NJCTS.

Over the years, Howard has made it a priority to give back to the TS community and has been a long-time member of the NJCTS board of directors. He also collaborated in developing the NJCTS Tim Howard Leadership Academy.



# FAMILIES GIVE BACK

We love it when our families initiate fundraising events in their community and schools. They bring awareness to TS while supporting the programs of 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!

### 2017 Family Initiated Fundraisers

Haddon Heights High School Denim Day Donation  
West Freehold PTO  
Nutley High School Bake Sale  
Medford Lakes Lions Charities  
Haworth Teachers' Association - Dollars for Denim



## NJ DEPARTMENT OF EDUCATION SELECTS NJCTS YOUTH ADVOCATES TO DELIVER DARE TO DREAM KEYNOTES

In 2017, 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 self-advocacy 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 the more than 200 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 2017 Dare to Dream Conferences:

- Stockton University - Mary Kate Donohue
- Rider University - Tess Kowalski
- Raritan Valley Community College - Hallie Hoffman
- William Paterson University - Ben Stark
- Middlesex County College - Tommy Licato
- Montclair University - Mike Hayden



# PHYSICIAN 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.

Medical professionals in the NJCTS Physicians Referral Network include:

- Neurologists
- Psychiatrists
- 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](mailto:info@njcts.org).



## FAMILY RETREAT WEEKEND

Popular event returns in 2018!

Since 2004, NJCTS has welcomed families to enjoy some time away from it all at the NJCTS Family Retreat Weekend at YMCA Camp Bernie in beautiful Hunterdon County. The weekend allows children and their families to meet others with Tourette Syndrome (TS), learn more about their diagnosis, and engage with peer mentors in a fun, safe environment.

Kids enjoy canoeing, swimming, wall climbing, arts & crafts, participating in a talent show, rekindling old friendships, and cultivating new ones. Parents join in many activities with their children but also connect with other parents and share their stories. Powerful workshops provide a safe place for both youth and parents to ask questions about TS and learn from peer mentors.

The NJCTS Family Retreat Weekend is popularly known as “the best weekend of the year” to the many families who attend looking for camaraderie, a relaxing getaway from the stress of everyday life, and a chance to learn more about TS and self-advocacy.



# 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. To make a contribution to the Jeff Vitek Memorial Fund for Youth Development, visit our website at [www.njcts.org](http://www.njcts.org) or call 908-575-7350.

## 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](mailto:info@njcts.org) or 908-575-7350.

Donate online at [www.njcts.org](http://www.njcts.org), over the phone by calling 908-575-7350, or by mail to:

NJ Center for Tourette Syndrome & Associated Disorders, Inc.  
50 Division Street, Suite 205  
Somerville, NJ 08876

### Donation options:

- General donations
- Planned giving options
- Monthly donations
- Donate your vehicle
- Matching gifts
- Auction items
- In-kind goods or services
- Create a fundraising event
- Organize a jeans day at work
- Participate in an athletic event and raise funds through an online crowd-funding page

### Volunteer opportunities:

- Become a community presenter
- Train to be a Youth Advocate
- Contribute to our TSParentsOnline or Teens4TS blog
- 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

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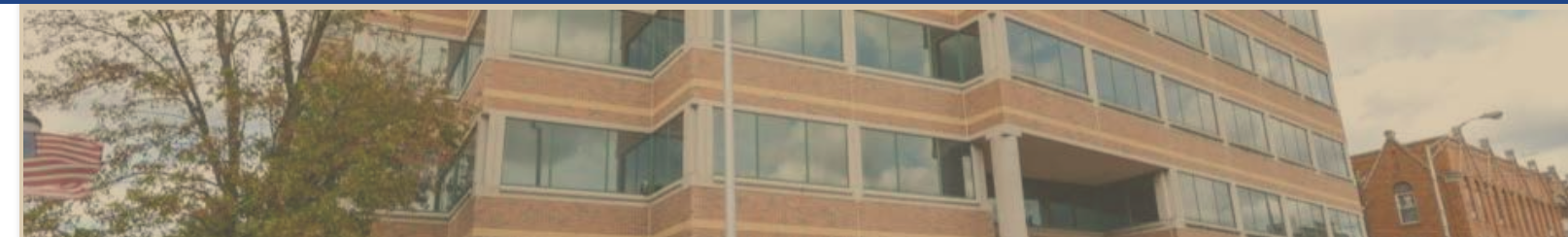
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Executive Director



Santina Reichenbach  
Finance Director



Barbara Chabner, PsyD.  
Program Manager



Lisa Fortunato  
Communications  
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Kelley Teabo  
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Youth Development  
Coordinator



Daryl Ball  
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Management



Penny Dragonetti  
Program Assistant to  
the Executive Director



Marty Butterfield  
Webinar Coordinator



Elise Petronzio  
2017 Summer Intern



Amanda Silvers  
2017 Summer Intern

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Follow us on Facebook, Twitter, Instagram, and YouTube  
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](http://www.njcts.org)

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- |                            |                                     |
|----------------------------|-------------------------------------|
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| Bayshore Recycling Corp.   | The Red Moose Charitable Trust      |
| Dietz & Watson, Inc.       | West Freehold PTO Walk-A -Thon      |
| Fifth Generation Inc.      | Woodhaven Lumber and Millwork, Inc. |

## Top Individual Donors:

- |                         |                          |
|-------------------------|--------------------------|
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# NJCTS VOLUNTEERS

- |                   |                    |
|-------------------|--------------------|
| Anna Baldwin      | Yolanda Lawas      |
| Eric Baldwin      | Ethan Lederman     |
| Carolyn Baldwin   | Tracey Lederman    |
| Tara Barr         | Tommy Licato       |
| Theresa Barr      | Cheryl Ludwig      |
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| Charles Greibell  | John Sooy          |
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| Hallie Hoffman    | Fred Storer        |
| Roberta Israelsky | Liane Sturrock     |
| Allen Jones       | Donna Tischfield   |
| Tess Kowalski     | Ellen Topiel       |



