



Nation's First Center of Excellence  
for Tourette Syndrome

# YEAR IN 20 REVIEW 19

Celebrating 15 Years of Excellence and Innovation in  
**Education. Advocacy. Research.**



# YEAR IN REVIEW 2019

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## Our Mission

**The New Jersey Center for Tourette Syndrome (NJCTS) 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.**

# Welcome



**In 2019 NJCTS celebrated 15 years of excellence and innovation.**

**Thank you to our partners, collaborators, funders, volunteers and families for your support in helping build the nation's first Center of Excellence for Tourette Syndrome. NJCTS was started with the belief on the part of many people that we could change the lives of individuals and families living with Tourette Syndrome and complement any efforts that were already underway elsewhere in the country. In 2004 following years of advocacy with the state of New Jersey, we received funding to create the nation's first center of excellence for Tourette Syndrome. Through NJCTS advocacy the first federal legislation for Tourette Syndrome was introduced calling for the establishment of collaborative research Centers of Excellence for TS. Through the years kids and families across the state were taught the importance of advocating for themselves. Our program to educate school faculty, doctors, nurses, mental health workers and students going into these fields has resulted in reaching tens of thousands professionals annually. We've focused our education outreach on urban and underserved areas within our state, presented to community and professional groups, police and**

**other first responders statewide in an effort to gain acceptance, improve diagnosis and make life better for all people with Tourette Syndrome. And just three years ago our collaborative efforts with Rutgers University, the National Institutes of Health and researchers from around the world resulted in breakthroughs in understanding the genetics of Tourette Syndrome. All while supporting the daily needs of families living with Tourette Syndrome.**

**These 15 years for NJCTS have been filled with excellence and innovation and a core group of people focused on a common goal, a shared vision and mutual respect. In the years to come I look forward to greater understanding and acceptance of all people living with Tourette Syndrome, better treatments and continued collaborations and partnerships.**

**Sincerely,**

A handwritten signature in blue ink, appearing to read 'Faith Rice', written over a light blue circular background.

**Faith Rice**

**NJCTS Founder and Executive Director**



# 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 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
- Misunderstood by the public and educators
- Underdiagnosed by medical professionals
- Associated Disorders: Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), learning disabilities, panic attacks, depression, generalized anxiety disorder, sleep disorders





# NJCTS Celebrates 15<sup>th</sup> Anniversary

The NJ Center for Tourette Syndrome & Associated Disorders (NJCTS), the nation's first Center of Excellence dedicated toward helping individuals and families affected by the often devastating neurological disorder, is proud to announce that it is celebrating its 15th anniversary.

For the last 15 years, NJCTS has led the nation in providing programs and services to families, outreach to the education and medical communities, and support for collaborative research into better treatments and a cure for Tourette Syndrome (TS), which is characterized by involuntary sounds and movements known as tics. TS, which usually appears when a child is six or seven years old, affects as many as 1 in 100 children and adults.

“When we first established NJCTS, our goal was to provide support to New Jersey families needing diagnosis and services for this misunderstood and often misdiagnosed condition that can affect every aspect of an individual's life,” said Faith Rice, Executive Director and founder of NJCTS. “Today, we continue to provide those services and have grown to be recognized globally for programming and partnerships that have resulted in first-ever research findings into the genetic causes of Tourette Syndrome.”

Through its numerous collaborations and partnerships, NJCTS has developed one-of-a-kind programs on behalf of the TS community regionally and worldwide. It has established the world's first Cell & DNA Sharing Repository at Rutgers University, worked with New Jersey Congressmen to help draft and introduce the first federal legislation for Tourette Syndrome, founded the TS Clinic and doctoral training program at Rutgers, and pioneered the patient-centered medical grand rounds training in hospitals presented by professionals and youth affected by the disorder. And tens of thousands of people from all over the world have participated in the NJCTS Wednesday Webinar series.





## NJCTS Celebrates 15<sup>th</sup> Anniversary Cont.

In New Jersey, students, educators and parents have benefited from the School In-Service Program. Families have found camaraderie at the annual Family Retreat Weekend and through NJ Walks for TS events. Many kids and teens have been through our various youth development programs.

In addition to receiving support from New Jersey's families, legislators, medical and education professionals, and others, NJCTS has benefited from backing by legendary, US Men's National Team Goalkeeper and noted TS advocate, Tim Howard, who serves on NJCTS' Board of Directors. Howard also lends his name and vision to the NJCTS Tim Howard Leadership Academy, a four-day intensive program for high school students that takes place on campus at Rutgers University.

"As the parent of a son with Tourette Syndrome, it has always been my desire to see New Jersey's kids, parents and families receive the kind of support they need to combat this inherited, misdiagnosed and misunderstood neurological condition," Ricesaid. "Since establishing the Center in 2004, we have not only provided myriad programs and services to support the many needs of the TS community, we have also provided hope for a future of better treatments and a cure."

On December 9, in celebration of the 15th Anniversary, NJCTS presented an Award of Excellence to Congressman Albio Sires (D-8) on the Busch Campus of Rutgers University in Piscataway. In attendance and speaking at the ceremony were Chancellor Christopher Molloy of Rutgers, Dean Francine Conway of GSAPP, NJCTS Youth Advocate Paige Kowalski, and Dean Paranicas of the HealthCare Institute of New Jersey. Andrew Hendry, Chairman of the NJCTS Board of Directors, emceed.



# 15 Years of Impact

## By the Numbers



28,022

### Teachers/School Administrators Educated

NJCTS offers Faculty In-Service presentations geared toward elementary and secondary schools providing information about Tourette Syndrome (TS) and associated disorders. These presentations provide strategies and accommodations for the classroom as well as promote a more positive, inclusive, and successful classroom environment for all students.

10,408

### Health Professionals Educated

The NJCTS Medical Outreach Program creates a greater awareness of TS and associated disorders among medical practitioners and educates them on the needs of children and families coping with these disorders. This program fosters an understanding of the perspectives, stresses and needs of families living with TS.



51,856

### Webinar Views & Downloads

NJCTS's Wednesday Webinar series has featured more than 100 online seminars for parents, educators and medical professionals on topics of interest to the TS and associated disorders community, such as anxiety, OCD, sensory issues, bullying, school accommodations, and much more.

15,077

### Families Helped Through Phone Support

NJCTS' Physician Referral Network is comprised of more than 200 neurologists, psychiatrists, psychologists, counselors, and social workers with expertise in treating TS. Our intake specialists can also refer families to special needs lawyers, direct them to local and online support groups, recommend NJCTS Programs and offer a friendly voice during a difficult time.



3,113

### Genetic Donations to the Cell & DNA Repository

Thanks to the participation of NJCTS families, the repository became the world's first sharing resource of clinical data and genetic samples from which all qualified scientists could draw for their research. Prior to this, independent scientists had no access to large collections of DNA and clinical data to study TS.



## 15 Years of Excellence and Innovation in Tourette Syndrome Research

The NJCTS mission did not include research until we realized that we could lead an effort to bring researchers together to work collaboratively to find answers for the cause of TS.

In 2017, NJCTS research partners were responsible for first-ever breakthrough research findings into the genetics of Tourette Syndrome. Less than a year later the team's second breakthrough occurred which indicated that TS is indeed an inherited disorder and, like Autism, potentially 300–400 genes contribute to having the disorder. These breakthroughs changed the course of genetic research into Tourette Syndrome.

### HOW DID ALL THIS START?

NJCTS founder Faith Rice saw a newspaper article that Dr. Jay Tischfield, a professor at Rutgers University, was awarded more than \$20 million in federal funding to build and run the world's largest university-based biorepository for mental health disorders. Tourette Syndrome was not on the list of disorders to be included in the biorepository. Knowing about the lack of progress in TS research, Faith reached out to Dr. Tischfield.

"I didn't think such a prominent scientist would even take my call, but he did and we talked for more than an hour about the need, the lack of collaboration among researchers, and lack of progress in finding answers for this overwhelming neuropsychiatric disorder," Faith said.

"Within a month of that call Dr. Tischfield agreed to add TS to the list if I could recruit enough families to provide genetics samples to show there was support for such research and in turn raise the money to add TS to the repository's portfolio."

So the effort began to recruit families to participate in this new and promising research. Over the

next two years, 200 New Jersey families stepped forward to participate.

Thanks to those families, a collaboration with Yale University, and funding from the State of New Jersey, NJCTS and Rutgers established the NJCTS Cell & DNA Sharing Repository – the world's first sharing resource of TS clinical data and genetic samples from which all qualified scientists could draw for their research.

Four years into the pilot study, the National Institute of Mental Health (NIMH) recognized the TS repository as an important federal research asset and funded its expansion to 25 collection sites around the world with the goal of identifying genetic factors that play a role in causing TS.

All of this was made possible because individuals and families answered the call! More research needs to be done to find answers, treatments and eventually a cure for TS. You and your family are critical to making that happen. Without participation from individuals and families, no research can be done.



# 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

## 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

## EUROPE

Denmark | University of Copenhagen

Germany | University of Lübeck

Germany | University of 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

**“Research into better treatments for TS cannot be done without the participation of individuals and families.”**

**- Dr. Jay A. Tischfield**

Email [familystudy@biology.rutgers.edu](mailto:familystudy@biology.rutgers.edu) to become part of this breakthrough research.  
If we can provide more information, please call NJCTS at 908-575-7350.

## Physician Referral List

**NJCTS maintains a Physician Referral List 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 List 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).

## School Support



### Youth Advocate Presentations

These presentations can be provided on behalf of students in the school living with Tourette Syndrome or as part of a more general anti-bullying effort. Students gain an in-depth understanding of TS and associated disorders.



### Faculty Presentations

NJCTS offers faculty in-service presentations geared towards educators, administrators, and staff, to describe TS and associated disorders and provide strategies and accommodations for the classroom.



### IEP and 504 Plan Support

NJCTS has an updated list of lawyers and firms that handle issues with IEPs, IDEA and 504 plans. In addition, webinars are held each year about managing your child's education plan.







## Family Retreat Weekend: 15 Years of the Best Weekend of the Year

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.

**“It means everything to us to be surrounded by other families that understand.”**

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.





## Tourette Syndrome Clinic

### Creating a New Generation of Doctors with Interest and Expertise in Tourette Syndrome

One of the biggest problems associated with Tourette Syndrome is that too few psychologists, mental health professionals and other healthcare practitioners know enough about TS to help the many individuals and families dealing with this often devastating neuropsychiatric disorder.

“It took seven years to get a diagnosis for my son,” said Faith Rice, founder and Executive Director of NJCTS. “You see doctor after doctor but finding the one who understands, truly has the knowledge of the disorder, was like finding a needle in a haystack.”

The NJCTS Tourette Syndrome Clinic (TSC) and Practicum Program at Rutgers University’s Graduate School of Applied and Professional Psychology (GSAPP) was created to help close that gap and give those individuals and families a place where they not only could seek treatment, but also feel reassured that the clinicians administering the treatment have a strong knowledge base. The TSC is the nation’s only university-based, stand-alone, student-clinician teaching practicum and clinic for the psychological evaluation and cognitive-behavioral treatment of TS in the nation.

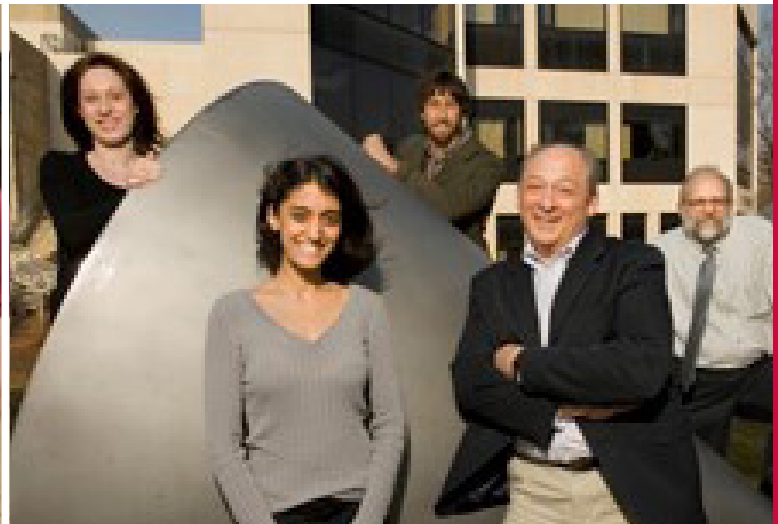
“We approached Rutgers in the early 2000’s with the idea of creating a training program for doctoral candidates and perhaps even a clinic that would see patients and their families,” said Rice. “After more than two years of discussion with professors, directors and the Dean, they agreed to pilot this one-of-a-kind program. NJCTS’s thinking was that doctoral students would train for months before they saw patients but Rutgers had a different idea. They wanted their doctoral candidates, with close clinical supervision, to see clients right away – while they were learning the ins and outs of TS.”

The concept and clinic were a success from the start – families were treated individually, they became part of support groups, the kids benefitted from social skills training and the doctoral students became involved in advocacy for their clients. The clinic soon became one of the most sought after “practicums” in psychology at Rutgers and four years into the partnership was awarded the Rutgers President’s Award for Innovation.

Since the clinic opened over 15 years ago, more than 70 psychologists have been trained, including its current director Dr. Graham Hartke, Psy.D.







**“These graduate students are future practitioners for individuals with Tourette Syndrome, an area of psychological care that currently has few specialists. The more psychologists that we can train, the easier it will be for families across the country to find the treatment they need.”**

**- Faith Rice**

Clients consist of children, adolescents and adults with tics, and the parents and other family members of individuals with TS.

The clinic specializes in providing diagnostic assessment and cognitive behavioral therapy (CBT) with a focus on evidence-based interventions, including Comprehensive Behavioral Intervention for Tics (CBIT). The American Academy of Neurology’s current guidelines for treating tics recommends doctors first consider prescribing CBIT before considering medication and other therapeutic treatments.

“We specialize in treating individuals and families with TS, OCD, ADHD, and other associated conditions, using Cognitive Behavioral Therapy (CBT),” Dr. Hartke said. “Treatment at the TSC is tailored to the unique needs of each individual and family, with a focus on improving symptoms and teaching proactive skills. Our hope is to turn the treatment over to the families, so we teach them skills of how to manage the behaviors at home.”

Clinic therapists are advanced doctoral students from the Rutgers GSAPP clinical and school

psychology programs who are trained and supervised by Dr. Hartke. The program provides a unique, hands-on learning experience for students striving to increase awareness of TS in the professional community. In addition, research obtained through the observation and treatment of children and families provides important insight into the needs of the TS community and evidence-based treatment approaches.

Doctoral students also participate in NJCTS programs including in-services, family retreat weekend and Leadership Academy to improve their understanding and ability to treat families living with TS. Many graduates of the program continue to be involved with NJCTS by presenting at hospital grand rounds and teacher in-services and by making themselves available to families through the NJCTS Physician Referral List.

To schedule an appointment with the TS Clinic, please call 848-445-6111, ext. 40150, or email [tsc@gsapp.rutgers.edu](mailto:tsc@gsapp.rutgers.edu). The offices are located on the Livingston campus of Rutgers University in Piscataway.

## Youth Scholarship

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 2019, 15 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing themselves as outstanding advocates for Tourette Syndrome.

### FIRST PLACE



**Maya Wagner – Hillsborough**

Maya is a graduate of Hillsborough High School where she was a member of the choir, theatre and participated in dance and music lessons. She was also a NJMEA All-State choir member and CJMEA Region Choir Member. She also was a member of the Borotones a capella group. Additionally, Maya was a member of the Rider University Gifted and Talented Program, in which she enrolled in college classes as a high school senior. She is attending Berklee College of Music to follow her main passion in life: music.



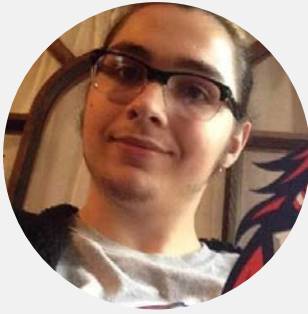
**Dylan Wallace – Toms River**

Dylan is a graduate of Toms River High School South where he was an honor roll student and a member and president of many clubs and organizations including Habitat for Humanity, Recycling Club and the LGBTQ Alliance. He was also on the varsity basketball team. However, Dylan's passion is filmmaking. He does not let his tics get in the way of this dream, even when it poses difficulties in filming and editing. He is continuing his education at the University of Tampa to pursue his dreams of becoming a filmmaker.

NJCTS Scholarship recipients attended the Tourette Syndrome Awareness event at the War Memorial in Trenton where they were presented with their awards by State Assemblyman Dan Benson.



## SECOND PLACE



**David Gustavson**  
**West Orange**

David is a graduate of West Orange High School. In his spare time, he does martial arts, specifically Tae Kwon Do and he enjoys partaking in art. David was also a math tutor. David is continuing his education at NJIT.



**Christian Pisano**  
**East Windsor**

Christian is a graduate of Newgrange School in Hamilton Township. He hopes to pursue a career in the medical field so he can help people the same way some have helped him. He is now continuing his education in the Nursing School at Mercer County Community College.



**Michael Carroll**  
**Linwood**

Michael is a graduate of Mainland Regional High School where he spent most of his time swimming on the varsity swim team. He was also part of the French honor society, French club, Interact club and GT Wind Ensemble. Michael is continuing his education at Rutgers University.

## HONORABLE MENTIONS



**Tara Barr**  
**Nutley**



**Brandon O'Leary**  
**South Plainfield**



**Trey Donovan**  
**Chester**



**Damion Sanderson**  
**Gloucester City**



**William Donovan**  
**Chester**



**Connor Staine**  
**Clinton**



**Dana Lutsky**  
**Manalapan**

Not pictured:

**Elyse Bell – Hillsdale**  
**Thomas Romeu – Manalapan**  
**Matthew Vitella – Bloomfield**



The objective of the NJCTS Youth Development Program is to provide youth with TS a variety of opportunities, ranging from presenting to other kids to participating in mentor panels, to develop their strength, courage and confidence while embracing their differences and advocating for themselves and others.

## **Presentations**

A large component of the Youth Advocate Program is presentations. Advocates present to students at schools across the state. While the presentation is informational, there is a strong anti-bullying message that promotes acceptance, tolerance, and self-advocacy. They also participate in Grand Round medical presentations and share briefly with medical professionals about their experiences with TS including diagnosis and treatment.

## **Dare to Dream**

These NJ Department of Education conferences focus on strategies and information aimed to prepare high school students with disabilities for college and careers. As a keynote speaker, the Youth Advocate would write and present a speech about 4 minutes in length, which focuses on living with TS, the challenges they have faced and how it doesn't stop them from reaching their goals.

## **Legislative Testimony**

At certain times throughout the year, NJCTS will meet with legislators in New Jersey regarding a number of issues. Often, a Youth Advocate will accompany someone from the office to meet and speak with the legislators and share their story.

## **Mentor Panels**

Each year, NJCTS comes together at YMCA Camp Bernie for some family fun. Included in our activities is a mentor panel, where camp attendees have the opportunity to ask questions of our seasoned advocates. These panels are also utilized at other events including advocacy trainings.

## **Blogging**

A chance for the Youth Advocate to share their thoughts, ideas and accomplishments, the NJCTS Teen Blog is another avenue for kids with TS to connect with one another, and to be reminded of the fact that there are others out there facing the same struggles.





## June 4th Proclamation

One of the ways we encourage our advocates to spread awareness is to request that their mayor make a TS Awareness Day proclamation. This will involve sending an email and/or making a phone call to the Mayor's office. Often when someone succeeds in getting a proclamation declared, there is the chance to meet the mayor and have photos taken.

## Event Involvement

One of NJCTS' popular fundraisers is our annual walk. The NJ Walks for TS virtual walk spans the months of March through May, and is a great opportunity for the Youth Advocate to spread their wings as a leader and become a team captain!

## Tim Howard Leadership Academy

The Academy is designed to develop self-leadership, advocacy skills, and resilience in teens with TS. The program increases the participants' understanding of their disorders and provides opportunities and a safe environment to explore and identify their strengths, challenges, needs, and skills. The Academy provides an intentional space to build critical skills that will help young people with TS to excel and inspire others.

## Scholarship

NJCTS has offered scholarships to graduating New Jersey high school seniors in public or private school who have been diagnosed with TS and will be attending a college, university, or trade school in the fall.





## Tim Howard Leadership Academy

The NJCTS Tim Howard Leadership Academy is designed to develop self-leadership, advocacy skills, and resilience in teens with Tourette Syndrome (TS) and its associated disorders. The program increases the participants' understanding of their disorders and provides opportunities and a safe environment to explore and identify their strengths, challenges, needs, and skills. The Academy provides an intentional space to build critical skills that will help young people with TS, like Tim Howard, to excel and, through that success, inspire others.

The 6th annual NJCTS Tim Howard Leadership Academy took place at Rutgers University from August 1-4. The intensive four-day training promoted self-advocacy, self-leadership, resilience and grit—all important skills to succeed while living with Tourette Syndrome.

Created in 2014 in partnership with former MLS and United States Mens National Team goalkeeper and TS advocate Tim Howard, the Academy is the only leadership program for teens diagnosed with TS in the nation. The teens who participated in 2019 represented New Jersey, New York,

Pennsylvania, Florida, Massachusetts, Texas, California, and Puerto Rico.

Tim Howard, who was diagnosed with TS as a teen, surprised the teens by calling in to video chat with the group. During the 30 minute conversation, he fielded questions about growing up with TS and what his life with TS looks like now.

Throughout the four days, participants had the opportunity to learn from neurologists, psychologists, social workers, and others about their diagnoses. In addition, sessions

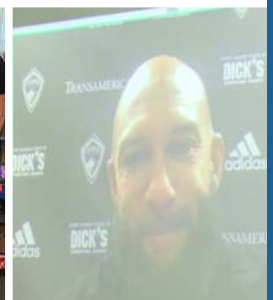


were conducted on asking for and receiving accommodations at college and in the workplace. During their downtime, the teens formed connections with new friends through small group activities or a friendly game of kickball.

“We really can’t thank you all enough,” said one parent. “You changed our child’s life and gave him such a much better outlook on life.”

The program also included a tour of the Cell and DNA Sharing Repository which is conducted by Dr. Jay Tischfield from Rutgers Department of Genetics and the Director of the Human Genetics Institute of New Jersey. Special guests included past participants who shared their college experience and Sarah Baldwin, creator of Twitcha, who signed books for the teens.

“It’s a great experience to help you realize that you’re not alone and connect to others. It’s a place where you can realize that it doesn’t matter what people think of you. You do you, and be an advocate for yourself and others that you see going through the same things. I felt alone before this academy. But now I have so many strategies to use that help me make friends in school and deal with situations.”



## Youth Advocate Presentations

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.



**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 500 presentations to individual audiences as large as 800 students, raising awareness, standing up to bullying, and increasing understanding of this often-misunderstood disorder. In 2019, Youth Advocates reached thousands of students, teachers, first responders and health professionals across the state, including 17 elementary and middle schools and more than 2,200 students.

Schools Our Youth Advocates Presented In:

- Memorial Middle School
- Mt. Olive High School
- Ranney School
- Holdrum Middle School
- Jefferson School
- Bradley Gardens Primary School
- Roosevelt School
- Pascack Valley Council for Special Education
- Wemrock Brook School
- Warnsdorfer Elementary School
- Shepard Prep High School
- Bergen Family Center
- Woodbine Avenue School
- Ocean Avenue Elementary School

## 2019 Youth Advocates



- |                      |                  |                  |
|----------------------|------------------|------------------|
| • Dominic Dominguez  | • Riley Burke    | • Tara Barr      |
| • Jatin Nayyar       | • AnaClaire Sems | • Paige Kowalski |
| • Brennan Skirzenski | • Eliza Lederman | • Jacob Gerbman  |
| • Jonah Grossman     | • Jeff DeCicco   | • Ally Abad      |
| • Sam Regen          | • Eric Baldwin   | • Jenna Smith    |
| • Ben Mars           | • Ethan Lederman | • Anna Baldwin   |
|                      | • Kyle Swords    |                  |



## Faculty In-Service

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 programs are also presented at professional conferences like the NJEA and NJCEC.

In-service presentations and workshops 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. They also provide educators with specific classroom strategies and accommodations that can have a positive impact on a student's academic success. NJCTS presenters are teachers, 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.



### 2019 In-Service Presenters

- |                         |                        |
|-------------------------|------------------------|
| • Dr. Tracy Lederman    | • Carolyn Baldwin      |
| • Dr. Michelle Lubonski | • Dr. Anton Scherbakov |
| • Dr. Graham Hartke     | • Pat Phillips         |
| • Dr. Rob Zambrano      | • Dr. Barbara Chabner  |
| • Dr. Lisa Cox          |                        |
| • Dr. Marla Deibler     |                        |

### Faculty In-Services were conducted at the following schools:

- |   |   |   |
|---|---|---|
| • Morris County School Nurses Association | • The Willow School                               | • Lincoln School  |
| • Hess School                             | • Camden & Burlington County Special Ed Directors | • Fort Lee High School                                  |
| • Jefferson School                        | • North Hudson Community Action Program           | • Division of Children's Services Education Partnership |
| • Holdrum Middle School                   | • Mario Drago School                              | • New Road School                                       |
|   | • Heritage Middle School                          | • Union County School Nurses Association                |
|   | • State Special Education Advisory Council        | • North Hunterdon High School                           |
|   | • Burlington County School Psychology Association | • Oak Street School                                     |
|   | • Cherry Hill High School-West                    | • Ironbound Early Learning Center                       |
|   | • Passaic County School Nurses Association        | • Fords Middle School                                   |
|   | • Egg Harbor Township High School                 | • New Jersey Principals & Supervisors Association       |



## Medical Outreach

NJCTS works with hospitals throughout New Jersey to present Grand Rounds 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 25 and 100 physicians and/or students. The NJCTS Youth Advocate or family 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 2019, NJCTS reached more than 650 medical professionals through 20 Grand Rounds at hospitals throughout the state, in addition to the hundreds that receive our regular distribution of the latest TS-related research articles.

**“I would definitely recommend that other primary care practitioners come to an education session on TS. There is so much to be learned!”**

**- Dr. Katherine Robison**



### 2019 Grand Rounds Presenters



- Dr. Marla Deibler
- Dr. Roger Kurlan
- Dr. Diane Antinoro-Burke
- Dr. Justin Misurell
- Dr. Jeremy Lichtman
- Dr. Jennifer Gola
- Dr. Michelle Miller
- Dr. Harvey Bennett



## Webinars

In 2019, NJCTS presented ten webinars that covered everything from comorbid disorders and homeopathic treatment to school IEPs and biology of the brain. This is in addition to the more than 100 webinars that are available in our online archive.



### Exploring and Managing the Impact of ADHD Across the Lifespan

Presenter: Hilary Murphy, Ph.D.

While Attention-Deficit/Hyperactivity Disorder is commonly associated with childhood, research indicates that deficits in attention and executive functioning can persist well into adolescence and adulthood. These misunderstood and unaddressed deficits are associated with academic underachievement, underemployment, and psychosocial difficulties.

### PTSD: Unpacking the Myths About Trauma and Exploring Solutions

Presenter: Dr. Zachary Infantolino

Posttraumatic Stress Disorder is often thought of as a disorder that only impacts military veterans. However, nearly 90% of people will experience a traumatic event in their lives. The goal of this webinar is to discuss the events that can lead to PTSD, how symptoms can manifest across the lifespan, and how to help those who may be experiencing symptoms of PTSD.

### Understanding and Tracking Implicit Biases

Presenter: Milton A. Fuentes, Psy.D

In this webinar participants will be able to: (a) define and explain the science of implicit bias; (b) discuss the empirically-based challenges of implicit biases in their respective settings; and (c) identify strategies that could address implicit biases.

### Tourette Syndrome: Help Control Your Tics by Learning What Triggers Them

Presenter: Sheila Rogers DeMare

TS research has primarily focused on genetics along with disappointing attempts to find suitable drug therapies. Yet for decades, patients have reported that they have noticed an association between tics and allergic, dietary, and environmental triggers. In this webinar we will explore some of these triggers.

### Insight into the Anxious Learner: Research and Intervention

Presenter: Hilary Murphy, Ph.D.

This webinar will provide a review of the theories of academic anxiety, discuss facets of executive functioning, and clarify the relationship between these factors and student performance in individuals with and without learning disabilities.

### Freedom from Panic: Learn to Identify and Manage Panic and Anxiety in Adults

Presenter: Rachel Strohl, Psy.D.

This presentation will discuss panic attack symptoms in adults. Learn how to identify panic attack symptoms in several of the common anxiety disorders, including Panic Disorder, Social Anxiety, Generalized Anxiety Disorder (GAD), and Obsessive Compulsive Disorder (OCD).

### NJ Harassment, Intimidation and Bullying (HIB) Law: Know Your Rights As Victim and Accused

Presenter: Beth C. Manes, Esq.

Webinar attendees will learn the basics of the HIB law, and what types of incidents are covered, what schools should be doing, and how are victims and accused students protected under the law.

### Understanding and Dealing with Children Who Refuse or Avoid Going to School: A Cognitive-Behavioral Approach

Presenter: Meir Flancbaum, Psy.D.

This workshop will present an overview of school refusal behavior, including a discussion about why children avoid school and research-supported strategies to increase attendance. Topics such as treatment using cognitive behavior therapy, developing school-based accommodations, and the importance of collaboration between parents and school staff.

### IDEA and Section 504 of the Rehabilitation Act of 1973: What Every Parent Needs to Know

Presenter: Staci J. Greenwald, Esq.

This webinar covers the origins and intent of the IDEA and what free and appropriate public education in the least restrictive environment should look like. Placement in the appropriate learning environment will be discussed and what an IEP should contain. 504 plans and accommodations will also be covered.

### I Wasn't Aware. Brain Function: Why Do We Have One?

Presenter: Dr. Vincent Kiechlin

This webinar covers the primary function of the brain and why we have one in the first place, including the basic workings of brain cells, why they communicate with each other and how their function can be changed.





## Community Outreach

**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 2019, 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.**

**In addition to 35 community presentations, NJCTS was present at 26 professional conferences and health fairs in 2019, including the NJEA Conference in Atlantic City and First Lady Tammy Murphy's Family Festivals.**



## First Responder Training

**Introduced in 2018 and designed for law enforcement personnel, emergency first responders and firefighters, NJCTS' new community awareness program strives to bring awareness of TS, associated disorders and symptoms to those responsible for public safety.**

**Participants review the implications of TS and how it may impact an individual's actions in a high stress situation. They also learn de-escalation techniques and how to respond to the typical TS behaviors to avoid further confrontation.**

### 2019 Law Enforcement In-Services

- Ocean County Police Academy
- Crisis Intervention Team (CIT) -NJ
- Union County Police Academy
- Middlesex County CIT Training
- CIT Bergen County
- Care Plus NJ





## Community Presentations Conferences

- Bayonne SEPAC Fair
- NJ Youth Suicide Prevention Advisory Council
- Franklin Township Interfaith Council
- Norwescap Morris County Council for Young Children (CCYC)
- Community Networking Association of Bergen
- Superior Court of New Jersey
- Bergen County Council for Young Children
- Children's System of Care
- Bound Brook High School
- Community Mental Health Clinic
- Special Child Health Services
- Division of Vocational Rehabilitation Services
- South Plainfield School District
- Health & Healing Through Horses
- Palisades Family Success Center
- Ocean County Council Young Children
- Passaic County Department Of Health
- West Bergen Mental Healthcare
- Middlesex Regional Black Nurses Association
- Ocean County Council Young Children
- East Orange Hospital
- Parents for Great Camden Schools
- National Association of Social Workers
- Morris County Child Care Directors Association
- Hispanic Family Center-Evolution Family Success Center
- MonmouthCares
- Pioneer Family Success Center
- Bayonne SEPAC
- New Destiny Family Success Center
- Middlesex Regional Black Nurses Association
- Safe and Sound Teen Conference
- OCD-NJ
- MindingYourHealthFairBound Brook School District
- Family Festival Newark
- Latino Institute Education Conference
- NJ Council for Exceptional Children (NJCEC)
- NJEA Conference
- NJSACC Conference
- ASAH
- NJ Child Care Association
- NJ State School Nurses Association (NJSSNA)
- NASW - NJ Chapter
- Congressman Norcross Constituent Fair
- NJAMHAA/AIR
- NJAAP School Health Conference
- Latino Institute Parent Education Conference
- NAMI
- Parent Education Conference







# Advocacy & Awareness

**NJ Walks for TS**

**TS Awareness Day**

**Dare to Dream**

**Award Winners**

**Advocates in Action**

**Families Give Back**

**Building Community**





## NJ Walks for TS: 10 Years of Inspiration

NEW JERSEY



WALKS FOR TS

For nearly a decade, the advocate-formed event “NJ Walks for TS” has been serving as a day of fun, advocacy, awareness, and empowerment on behalf of NJ kids and families living with Tourette Syndrome.

The first New Jersey walk for TS took place in Mendham, New Jersey in 2010. The idea for “Mendham Walks for TS” was created by a teenager who was inspired by one of her cousins who had Tourette

Syndrome. It was extremely successful, bringing in more than 300 participants and funding for NJCTS youth and education outreach programs.

Since that first walk, NJCTS has hosted events in Mahwah, Princeton, Medford Lakes and Ridgefield Park. But families wanted more – they wanted to advocate in their own towns and not just with a walk – they wanted to design their own events. So we answered the call for a “Virtual” walk, in order to meet the needs of our on-the-go families and to ensure the greatest impact.



During 2018, NJCTS introduced the very first virtual walk. Virtual walks encourage every participant to host their own fundraising and awareness event within their community anytime in March, April or May. The teams organized local walks, held family fun days, organized beach clean-ups, and even planted trees to celebrate Tourette Syndrome Awareness. They also met with their local officials to obtain proclamations supporting June 4 as TS Awareness Day.

Participants like the freedom to advocate as they choose – at their own pace and leisure. NJ Walks for TS Virtual Walks encourage self-advocacy and close-knit support among those living with TS and their friends, family and community.

NJ Walks for TS promotes awareness, acceptance, action, and advocacy of Tourette Syndrome and its associated disorders. This event is about fun and empowerment for kids, by kids, and about kids. It is a chance to stand up and step out to break the stigma attached to TS and show your

support for friends, family, and neighbors living with this misunderstood neurological disorder. All funds raised support NJCTS programs including education outreach, scholarships and awareness.

Today, NJ Walks for TS program raises awareness in every corner of the state – from High Point to Cape May – and raises thousands of dollars for NJCTS programs. Adults, kids and families: join us in making a difference.

### 2019 Top 5 Virtual Walk Teams

1. Team Jatin
2. Nicholas' Trek with Tourette
3. Trabilcy Tackles Tourette
4. Team Jamo
5. Team Tourette-o-saurus

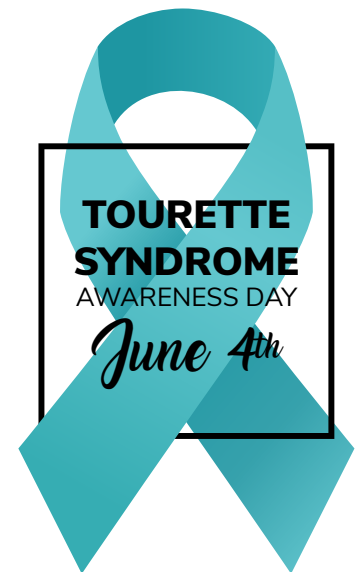
## TS Awareness Day

To mark the occasion of Tourette Syndrome Awareness Day in New Jersey, NJCTS celebrated with an awards ceremony at the Trenton War Memorial on June 6. During the ceremony, NJCTS presented college scholarships, recognized the top fundraising teams, and awarded the Youth Advocates of the Year.

Scholarships were given by NJCTS to accomplished high school seniors who live with Tourette Syndrome. These awards were all presented by Assemblyman Daniel Benson (District 14). The top fundraising individuals and team captains were awarded certificates of achievement along with their fundraising incentives by Assemblywoman Serena DiMaso (District 13).

Youth Advocate of the Year awards were presented to the graduating advocates 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. Youth Advocates receiving the award this year were Tara Barr, Ethan Lederman, Jeff DeCicco, Victoria Franco, Jonah Grossman, and Brennan Skirzenski.

The joint resolution which officially designated June 4 of each year as "Tourette Syndrome Awareness Day" in New Jersey was signed by Governor Murphy in 2018.



**Far Left: Two of our Youth Advocates of the Year, Ethan Lederman and Tara Barr.**

**Left: Our top fundraisers of the year with Assemblywoman DiMaso and Faith Rice.**

**Below: All of our families who attended the event.**





## Dare to Dream

In 2019, nine 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.

More than 200 students attend each conference which includes a variety of workshop sessions that provide opportunities to gain insight into the transition from school to adult life. The conferences give 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 2019 Dare to Dream Conferences:

- St. Joseph's School for the Blind - Dominic Dominguez
- Rider University - Sam Regen
- Raritan Valley Community College - Brennan Skirzenski
- William Paterson University - Liane Sturrock
- Middlesex County College - Jenna Smith
- Rowan College at Burlington - Sarah Baldwin
- Salem County College - Eric and Sarah Baldwin
- Stockton University - Anna Baldwin
- Montclair State University - Liane Sturrock
- Fairleigh Dickinson University - Paige Kowalski





## Award Winners

On April 17, The New Jersey Chapter of the American Academy of Pediatrics held their Ninth Annual New Jersey Children's Ball at The Palace at Somerset Park in Somerset, NJ, where they recognized doctors who are making a genuine difference in the lives of children. Also among the honorees, was Sam Regen who received the prestigious Youth Achievement Award for his Tourette Syndrome advocacy and educational outreach.

Regen is an NJCTS Youth Advocate and regularly represents NJCTS at community events and fundraisers, telling anyone who stops by his table his story. He speaks to children at schools about his journey with TS and the importance of accepting other's differences and not bullying them for it.



NJCTS friend and collaborator, Dr. Jay Tischfield, who is CEO, founder and scientific director of RUCDR Infinite Biologics and the Duncan and Nancy MacMillan Distinguished Professor of Genetics at Rutgers, received the 2019 HealthCare Institute of New Jersey Research Recognition Award "in recognition of innovative and creative leadership in genetics research, scholarship and commercial collaborations."

In 2007, NJCTS and Dr. Tischfield's team established the NJCTS Cell & DNA Sharing Repository as a resource for sharing clinical and genetic data related to TS research. Last year, Dr. Tischfield and an international team published a study reporting significant progress in understanding the genetic causes of Tourette Syndrome.

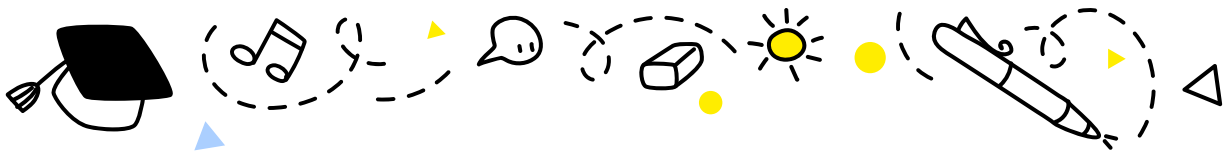


Amanda Silvers was recognized for her Volunteer Service to Youth at the Jefferson Awards for Public Service held at the War Memorial in Trenton on May 19. Amanda was nominated by NJCTS for her years of advocacy for the organization that has included addressing school assemblies, meeting with politicians, serving as a peer mentor and working as a coach at the Leadership Academy, all with the goal of improving the lives of children and teens living with Tourette Syndrome.

The Jefferson Awards are the nation's oldest and most prestigious recognition program for volunteer/public service. The New Jersey State Governor's Jefferson Awards is a joint program administered by The Community Foundation of New Jersey, The Star-Ledger Powering NJ.com, and The Governor's Advisory Council on Volunteerism.



## Advocates in Action



Several of our Youth Advocates including Jenna Smith, took part in a video for Anti-Bullying Month. They encouraged their peers to be upstanders and spoke about the pain that bullying causes and what they have experienced in their own life. The video was shared across the NJCTS social media platforms and can be found on our YouTube channel.



Leadership Academy Coach Sara Henya appeared in both a Philadelphia Inquirer story about women with TS and on a Philadelphia morning news program about the new treatment protocols for TS. She's a wonderful spokesperson for the TS community. Thank you Sara!



Friends, advocates and Leadership Academy alumni Jake Hudgeons, Sam Regen and Jordan Rullo attended comedian Samuel J. Comroe's show in New Brunswick and brought him a GreaTS shirt. Samuel, who has TS, shared this photo across his social media. Great job guys!



Jake Hudgeons reserved space at his school during TS Awareness Month and created educational materials and buttons to hand out to all of the students. He even designed a great infographic about TS that NJCTS shared with our friends and partners. Nice work Jake!



Youth Advocate Sarah Baldwin took Twitcha, the comic book character she created with her Leadership Academy group, on the road in 2019. She met with US Congressman Jeff VanDrew and signed copies of the book in downtown Somerville where she met Mayor Sullivan.





## Families Give Back



Youth Advocate Jacob Gerbman landed the role of Uncle Fester in his high school production of *The Addams Family* and used the opportunity to raise money and awareness for Tourette Syndrome. Jacob vowed to actually shave his head for the role if he raised \$5,000 for NJCTS. He ended up raising more than \$8,000!! True to his word, he shaved his head live on YouTube with his friends, family and castmates in attendance. Bravo!



Hunter Gunning sold bracelets at his school to raise TS awareness and funds for NJCTS.



### Facebook Birthday Fundraisers

- Amanda Silvers
- Angel Fitzpatrick
- Sarah Casamalhuapa
- Gayle Forman
- Glen Minch
- Lisa Vidak
- Maria Hurst
- Eddie O'Keefe
- Christine Lara
- Mary Kate Donahue
- Tara Clancy
- Manny Arroyo
- Joyce (no last name)
- Danielle Allen Weber
- Serry Ubinas
- Barbara Rivera
- Austin Denice
- Liane Sturrock
- Brian Challender
- Priscilla Grover
- Cheryl Fiengold Gilberg



The Spotswood High School girls varsity basketball team took the court in an annual charity game that benefited Nicholas' Trek with Tourettes, Nicholas DeLieto walk team.



## Building Community



NJCTS Outreach team Claudia Lijo and Pat Phillips met up with NJ Governor Phil Murphy and First Lady Tammy Murphy at one of the several Family Festivals Mrs. Murphy organized across the state. The events are part of the First Lady's NurtureNJ initiative to combat the maternal and infant mortality crisis in the state.



Thanks to the Somerset County Board of Chosen Freeholders, NJCTS families enjoyed a Somerset Patriots baseball game in a suite. It was a beautiful day and a wonderful opportunity to connect with other families.



Families from across the state (and Pennsylvania) attended our second Family Picnic at Johnson Park. They enjoyed a barbecue, family games, and great conversation.



Our kids are proud to show that they Stand With The GreaTS! Here is Nicholas with the swag he earned fundraising for NJ Walks for TS.

### Stay Connected. Join the Community.

Follow us on Facebook, Twitter, Instagram, and YouTube



Visit our Teens4TS and TSParentsOnline blogs

## Our Corporate & Community Partners

\$1,000 +

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\$500 - \$999

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DJ Mike Levitt Entertainment  
Spotwood PBA Local #225  
Hoffman Creations  
Walmart Flemington Store  
Victory Insurance Agency  
Tower Players Student Organization  
Tarnsfield Swim Club

\$250 - \$499

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Fulton Bank of New Jersey  
Spotwood Girls Basketball Team  
Merrill Lynch  
Medford Lakes Lions Charities



## 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 Support NJCTS

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

Online giving was a main source of donations and fundraising for NJCTS. Our supporters gave generously during our year-end campaign, on Giving Tuesday and to our Virtual Walk teams. All of these donations, no matter how small, help us provide continued education outreach, youth development opportunities, and awareness activities throughout the year. Thank you!

### 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 parent or teen blog
- Help us with mailings
- Assist with mission-critical grant proposals
- Help our staff organize, set up, and run an event
- Serve on a committee



# NJCTS Volunteers **Thank you!**

- Allen Jones
- Ally Abad
- Amanda Rasmussen
- Andrew Travis
- Andy Friedrich
- Anna Baldwin
- AnnaClaire Sems
- Azure Rae
- Ben Mars
- Beth Bliss
- Beth Liquore
- Beth Manes, Esq
- Bob King
- BrennanSkirzenski
- Carolyn Baldwin
- Charlotte Regen
- Christina Coates
- Claudia Lijo
- Danielle Ostroski
- David Gustavson
- Dominic Dominguez
- Elaine Hardy
- Emilie Thorstensen
- Eric Baldwin
- Ethan Lederman
- Fred & Kelly Storer
- Gary Heiman
- Graham Hartke
- Jacob Gerbman
- Jake Hudgeons
- Jatin Nayyar
- Jeff DeCicco
- Jeffrey DeCicco
- Jenna Smith
- Jonah Grossman
- Ken Ellis
- Kim Rice
- Kyle Swords
- Lia Sturrock
- Maria & Brendan Carew
- Michelle Lubonski
- Mickey Shulter
- Mike Meyer
- Mile Meyer
- Muzzammil Syed
- Paige Kowalski
- Riley Burke
- Roger Kurlan
- Sam Regen
- Sarah Baldwin
- Sean Bacchus
- Sharen Sheldon
- Staci Greenwald
- StevenLindenbaum
- Susan Everett
- Tara Barr
- Wyatt Gray



**NJCTS Board Member, soccer legend, and TS advocate, Tim Howard, retired from professional soccer in 2019. Tim continues to support the NJCTS Tim Howard Leadership Academy and other NJCTS initiatives.**

**Congratulations Tim on a successful and meaningful career!**

## Board of Directors



**Faith W. Rice**  
Executive Director



**Andrew Hendry**  
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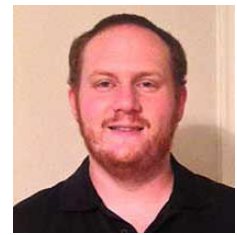
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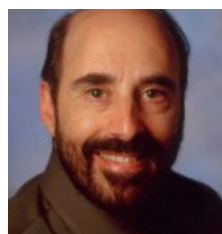
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**Santina Reichenbach**  
Finance & Human  
Resources Director



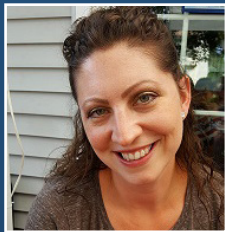
**Barbara Chabner, Psy. D**  
Program Manager



**Doreen Pustizzi**  
Communications  
Manager



**Patricia Phillips**  
Education Outreach  
Coordinator



**Lisa Augliera**  
Youth Development  
Coordinator



**Kelley Teabo**  
Project Coordinator



**Sarah Holt**  
Medical Outreach  
Coordinator



**Marty Butterfield**  
Webinar & Volunteer  
Coordinator



**Daryl Ball**  
Finance & Data  
Management



**Brianna Burkert**  
Communications &  
Development Associate



**Claudia Lijo**  
Outreach  
Coordinator



908-575-7350  
www.njcts.org  
50 Division St.  
Suite 205,  
Somerville, NJ 08876





# Our Future

**LET'S NOT PRETEND TOURETTE SYNDROME (TS) DOESN'T MAKE US ANY DIFFERENT. IT DOES. IT HAS ITS IMMENSE CHALLENGES. ITS SETBACKS. BUT BECAUSE OF THESE DAILY HARD-FOUGHT BATTLES. WE'RE STRONGER. WE FEEL MORE. SENSE MORE. SEE MORE. IT'S WHEN WE STOP HIDING AND START ACCEPTING OUR BEAUTIFUL QUIRKS THAT WE CAN BEAT DOWN THIS CONDITION. LET'S HARNESS OUR FOCUS ON THE GOOD. THE THINGS WE LOVE. A SOCCER FIELD OR STAGE OR BLANK CANVAS OR SCIENTIFIC EQUATION. LET THE TICS AND DISTRACTIONS INSPIRE THE BURSTS OF BRILLIANCE. THE IMPULSIVE GENIUS. THE ATHLETE, WRITER, TEACHER, MUSICIAN, MOTHER. THAT'S WHEN WE'RE FREE. FREE TO STEP OUT FROM BEHIND THE SHADOW OF TS. FREE TO DREAM. FREE TO BE OUR AMAZING SELVES. SURE, WE'LL HAVE OUR HARD DAYS, BUT NOTHING CAN STOP US FROM HAVING THE GLORIOUS ONES. BE ANYTHING WE WANT TO BE.**

**BE ONE OF THE GREATS.**



**Education. Advocacy. Research.**




The NJ Center for Tourette Syndrome & Associated Disorders, Inc. (NJCTS) is the nation's first Center of Excellence for Tourette Syndrome (TS). 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.



 908-575-7350

 [www.njcts.org](http://www.njcts.org)

 50 Division St.  
Suite 205,  
Somerville, NJ 08876

