



NJCTS

NJ Center for Tourette Syndrome
and Associated Disorders, Inc.

2022 Year in Review



YEAR IN REVIEW 2022

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Our Mission

To ensure children and adults with Tourette Syndrome and associated disorders are empowered and accepted through education, advocacy and research.

Our Vision

A community in which those with TS and associated disorders are understood and empowered.

Our Values

Forward Thinking
Accepting
Inspiring
Transformative
Holistic

Welcome

2022 was the year for greater opportunities and new beginnings as we saw a shift around the country from virtual events to more outdoor and indoor gatherings. It was the year NJCTS was able to welcome families back to in person events. We introduced many excited families to Black Rock Retreat in Quarryville, PA, the new location for the Family Retreat Weekend. This weekend get-away brought together approximately 100 children, teenagers and adults from all across New Jersey, Delaware, New York and Maryland for 2 ½ days of fun filled activities, campfires, and opportunities to meet others they could connect with and share their stories of living with Tourette Syndrome.

After a two year hiatus, we were delighted to welcome 20 participants to the Tim Howard Leadership Academy held on the campus of Rutgers University. No more Zoom links and breakout rooms. Teens were able to come together face to face, share their experiences and make life-long friendships. We opened with remarks from Tim Howard and our young participants were full of questions and eager to listen to his words of encouragement. The Academy brought together teens from not only New Jersey but from Florida, Pennsylvania, New York, Massachusetts and even the United Kingdom. During those four days, these young people got to learn more about Tourette Syndrome and, equally important, they learned more about themselves, and left the Academy empowered and unapologetic about having TS.

Not only were we able to bring back in person events for families in 2022, but more opportunities opened up for education outreach as schools started to allow more in



person trainings for staff. Education about Tourette Syndrome and the associated conditions is a critical component of the work we do. The ability to educate teaching professionals brings huge rewards for both the student and the teacher.

In 2022, we continued to listen to our families, partners, and professionals about programming needs, and made enhancements and created new programs like Tourette Talk, which provides an open interactive forum for participants to engage in conversation on a variety of topics such as ADHD, maintaining healthy relationships, and supporting siblings of children who are neurodivergent.

As the nation's first Center of Excellence for Tourette Syndrome, we are approaching our 20th year as an organization serving the Tourette Syndrome community. We are proud of the work we have done and look forward to our future because the best is yet to come. We are stronger today and will continue to serve with compassion, commitment and an understanding that elevates the quality of programs and services we deliver.

Patricia Phillips

Patricia Phillips

Executive Director

New Statistic from the CDC: 1 in 50 School-Age Children Have Tourette Syndrome or Other Tic Disorder

According to a new study by the CDC, **1 in 50** school-age children have Tourette Syndrome or a persistent Tic Disorder. This is more than **DOUBLE** the amount that experts previously believed.

The article, titled “Estimating the number of people with Tourette Syndrome and persistent tic disorder in the United States,” was published in August of 2022 in the journal *Psychiatry Research*.

The researchers estimate that 350,000–450,000 U.S. children and adults have Tourette syndrome. About one million U.S. children and adults have other persistent tic disorders.

However, they also concluded that estimating the number of people affected by these disorders is challenging and that more precise measurement is needed to reflect everyone impacted by these disorders.

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 50 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, palilalia, 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 – cause 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

2022 NJCTS Impact

**More Than
3.1 Million
Social Media
Impressions.**

**Continued
partnerships
with Rutgers Medical
School and Rutgers
Graduate School of
Applied and Professional
Psychology, Educating
the Next Generation of
Tourette Syndrome
Practitioners.**

**Nearly 4,000 in
attendance at 100
LIVE, in-person and
virtual events, support
groups and educational
presentations.**

**\$10,000
in college
scholarships
awarded to New
Jersey students
with TS.**

**Provided 758
clinical sessions to
children, teens, and
families through the
TS Clinic at Rutgers
University.**

**Collected 177
DNA samples in
support of the NJCTS
DNA & Cell Sharing
Repository and TIC
Genetics Research.**

The NJCTS mission includes research because 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 the 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.

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.

“Research into better treatments for TS cannot be done without the participation of individuals and families.” - Dr. Jay A. Tischfield

www.ncjts.org/research

NJCTS Tourette Syndrome Practicum and Clinic

Training a New Generation of Professionals in the Treatment of Tourette Syndrome

NJCTS, in collaboration with Rutgers University's Graduate School of Applied and Professional Psychology (GSAPP), presents the nation's first university-based, stand-alone teaching practicum and clinic for the psychological evaluation and cognitive-behavioral treatment of TS. Clinic therapists are advanced doctoral students from the GSAPP clinical and school psychology programs who are trained and supervised by a licensed psychologist with expertise in TS and common associated conditions.

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

Dr. Amanda Ferriola, Psy.D.
Clinical Director of the
Tourette Syndrome Clinic



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



Email 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.

Medical professionals in the NJCTS Physicians Referral List include:

- Neurologists
- Psychiatrists
- Psychologists
- Social Workers

Collaboration Creates More Opportunities for Families



NJCTS and NYU Langone Health's Child Study Center designed a program to provide increased education, support, and treatment options to families affected by TS in New Jersey. This collaboration allows families to receive services provided through a graduate student training externship located at the Child Study Center's Hackensack, NJ office. Services, including CBIT, treatment for associated disorders, and neuropsychological evaluations, are offered at a significantly reduced rate. Learn more: www.njcts.org/nyu



Through a partnership with NJCTS, Rutgers GSAPP created specialized treatment programs to address the needs of individuals with TS and their families. While providing a unique, hands-on learning experience for advanced graduate students, the program also strives to increase awareness of TS in the professional community. The clinic specializes in providing diagnostic assessment and cognitive behavioral therapy (CBT) with a focus on evidence-based interventions. Learn more: www.njcts.org/clinic.

School Support

Youth Advocate Presentations

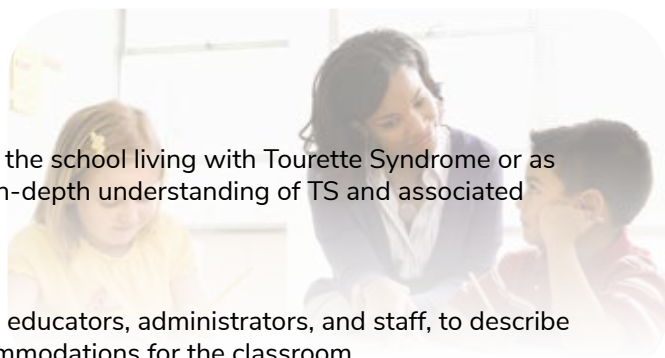
These presentations can be provided on behalf of students in the school living with Tourette Syndrome or as part of a more general anti-bullying effort. Students gain an in-depth understanding of TS and associated disorders. (see more under Youth Development)

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.



Virtual Support Group

This online support group is an avenue for parents who are new to a TS or tic disorder diagnosis to seek support and guidance from parents who have more experience, as well as an opportunity for parents with more familiarity in coping with TS or tic disorder to also learn and seek guidance. The group is facilitated by Dr. Jeremy Lichtman, an expert in the treatment of TS, who is there to answer questions and provide guidance wherever you may be in your journey. Sign up at www.njcts.org/support.

Family Events

Together Again at Camp FantasTIC

Camp FantasTIC, a family retreat weekend, was held for the first time at Black Rock Retreat in Pennsylvania. Several families joined NJCTS staff for fun activities, campfires, water games, and the opportunity to make forever friendships. The June event was the first in-person camp since 2019.



2022 Global Parent Summit & Global Teen Summit



Parents of children, teens, and young adults diagnosed with Tourette Syndrome had the opportunity to connect virtually at the **Global Parent Summit** in January. Teens had the opportunity to connect at their own virtual event, the **Global Teen Summit** in February. Both parents and teens received information on transitioning through high school, college, and beyond, as well as tips on fostering healthy relationships with immediate and extended family.

2022 Tourette Talk Presentation Topics

Tourette Talk is a monthly online informational series for parents, educators and individuals with Tourette Syndrome, a tic disorder, or associated disorders. Each month a different facilitator, an expert in the topic, will lead the discussion and take questions from participants.



- Helping Children with TS Succeed in the Classroom
- An Overview of Comprehensive Behavior Intervention for Tics (CBIT)
- How “Losing it” Can Actually Help You Win
- Harassment, Intimidation and Bullying (HIB)
- Virtual Career Day
- Just for Dads
- Keeping Your Relationship Intact in the Midst of Raising a Child with TS
- Are IEPs and 504s on Your Back to School List?
- Starting the Conversation on Teen Suicide Prevention
- Bullies Can Be Beaten – Understanding Your Rights
- Supporting Siblings of Children with Special Needs
- Supporting Your Child with ADHD: How to Effectively Work With Them, Not Against

Youth Scholarship

Since 2001, the NJCTS Youth Scholarship Award has been given to more than 220 outstanding high school seniors in New Jersey who have excelled in their schools and communities. In 2022, 16 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing themselves as outstanding advocates for Tourette Syndrome.

Faith W. Rice Memorial Scholarship

Kyla Butler - Jefferson Township



Kyla Butler was awarded the Faith W. Rice Memorial Scholarship, named after NJCTS founder and former executive director, Faith Rice, who passed away in 2021. Kyla was diagnosed with TS at eight years old, but the disorder did not stop her from succeeding in academics or athletics. An honor roll student, Butler was an Elite Alpine Ski Racer and played club soccer with World Class Futbol Club(WCFC). She committed to continue her ski racing career with Clarkson University in upstate New York.

But Kyla is more than just a star athlete. At a young age, Kyla was requesting proclamations and meeting with local politicians. She has spoken to community groups and participated in the NJCTS Teen Summit as a panelist sharing her story with other kids. She wrote a blog about dealing with the stress and anxiety of the pandemic hoping to help others. She started a school club, “Not Just Tourette Syndrome Awareness” – to create more understanding about TS and other disorders and disabilities among her peers.

“Tourette Syndrome has shaped me as a person because it taught me to own who I am and not let anyone make me feel that I am less of a person,” Butler said in her scholarship essay. “When I play my best and I ski to my true potential, my Tourette Syndrome takes a back seat. That makes the good days even better and my confidence and energy go through the roof.”



FIRST PLACE



Adyan Khondker – North Brunswick

Adyan was a straight-A honor student who captained the North Brunswick High School varsity lacrosse team for two years and also played varsity soccer. He served as the Vice President of DECA and the National Honor Society.

In his scholarship essay he says about Tourette Syndrome, “Yeah, it may suck, but coping through my Tourette has made me stronger, taught me to show humility and have resilience, and kindled my passion for helping others.”

Adyan continued his academic career at Rutgers University School of Engineering.



Noelle Powers – Jackson

Noelle Powers was an A student with a GPA over 4, and a varsity athlete. She was a stand-out on both the Jackson Memorial High School Track & Field team and the Softball team. She excelled in DECA, where she served as President, competing on both the state and international level. She has also found time to give back to her community, volunteering at several organizations.

She said in her scholarship essay, “Having Tourette gives me new perspectives, pushes me to work harder, and opens up new opportunities.”

Noelle is attending the University of Michigan.

SECOND PLACE



Ava DeFino - Fair Lawn

Ava DeFino was an honor student in English, Science and Social Studies at Fair Lawn High School. She was the president of the poetry club and was in both the marching band and the orchestra.

She said this of her TS diagnosis at the age of 15: “The world is indeed a place of hate and ignorance but the presence of those who don’t fit into the molds are what make it beautiful. My perspective changed from not being normal to being remarkable. I was no longer ordinary.”

Ava continued her journey at Fairleigh Dickinson University.



Anna Heicklen - Medford

Anna Heicklen was diagnosed as a young child and struggled with acceptance and stigma, but that didn’t stop her from wanting to spread awareness. At age 11, Anna hosted one of the very first NJ Walks for TS! Her public service didn’t stop with being a Youth Advocate. She was a member of Girl Scouts, the Yellow Ribbon Club, and Helping Hands of CHOP.

“Being diagnosed with a neurological disorder is a life-altering moment for anyone that experiences it,” Anna said in her essay. “But what we aren’t taught, is that our disorders don’t define who we are as human beings.”

She started at East Stroudsburg University in the fall.

The NJCTS Youth Development Program provides youth diagnosed with Tourette Syndrome mentorship, support, leadership and self-advocacy training, public speaking opportunities, networking, and social skill development as well as an opportunity for kids and teens to explore the creative arts. The children and teens develop their strength, courage and confidence while embracing their differences and advocating for themselves and others as a Youth Advocate. Our advocates present at locations across the state to bring awareness to Tourette Syndrome with the hope of destigmatizing the disorder, increasing the quality of treatment, and preventing bullying.

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 the Executive Director to meet and speak with the legislators and share their story.

Mentor Panels

Each year, NJCTS families come together at the Family Retreat for some 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 NJCTS events.

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. The Academy takes place in August and the application is available every November.

Scholarship

NJCTS offers 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. Applications are due in the Spring.

Youth Council

The purpose of the NJCTS Youth Council is to empower youth (ages 13-18) living with TS, tic disorders and the associated conditions, or some form of lived experience with TS, to educate, advocate and increase awareness of Tourette Syndrome and tic disorders. The Youth Council provides an open forum for communications where youth can share information and ideas and discuss relevant topics inherent to the TS and tic disorder community. Through these conversations, making connections and participating in activities teens will create and develop ways for increasing awareness and furthering the mission of NJCTS.

Parent-Teen Summit

Our Parent-Teen Summit offers a unique opportunity to connect with other families navigating life with TS. Activities include general discussion centered around TS and its associated disorders, mentor panels with doctors and young adults traversing the TS journey, all while incorporating the importance of self-advocacy. It is a wonderful opportunity to actively participate in programming that supports parents AND teens and gives both groups the chance to come together in community!



Graduating Youth Advocates

CONGRATULATIONS to our NJCTS Youth Advocates who graduated in 2022.

Kyla Butler and AnnaClaire Sems



Young Adult Virtual Meet-Ups

Young adults with TS, age 18-35 are invited to come together to build community and connect with others navigating both the TS journey and adulthood. At Community Connections for Young Adults, participants can comfortably discuss experiences, share advice, and build relationships with those who understand their unique challenges. The new group meets once a month and is self-moderated. It is an opportunity for former Youth Advocates and Academy participants and coaches to stay connected, as well as a place for those new to NJCTS and looking for a safe space to engage candidly about a variety of topics that impact them on a day to day.





NJCTS · TIM HOWARD
LEADERSHIP
ACADEMY



Academy Returns to Rutgers Campus!

On Thursday, August 4, 2022, parents were once again dropping off their teens on Busch Campus of Rutgers University to participate in the four-day NJCTS Tim Howard Leadership Academy. There were many new faces and some familiar ones who we had met at camp or who have previously participated with NJCTS as Youth Advocates. Our amazing coaches were also onhand to guide the teens throughout the long weekend.

Things kicked-off on Thursday with a special live welcome from Tim Howard himself. In between recreational activities, educational sessions, and

group discussions, the participants worked on learning to tell their story. They even had the opportunity to tell their story through an art project facilitated by Arts Horizon. Each teen created a pair of personalized shoes that they could use to express their story. And, of course, it wouldn't be an Academy without a personal tour of the DNA and Cell Repository on campus.

Participants left with new-found friendships and a new determination to advocate for themselves and others moving forward.



Thank you , Tim!



Creative designs by the participants. Each pair told a story.



Our amazing coaches and junior coaches, our wonderful nurse Jillian, our fearless leader Melissa, her trusty assistant Drew, and everyone's favorite, Kelley.



Group shot after one of many amazing sessions by our presenters and special guests.



Kickball in the quad!

Group discussion and teamwork takes place throughout the weekend.



Touring the NJCTS Cell and DNA Repository.



Another year, another group of superheroes!

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.

Faculty 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.

Since 2020, we have revised our faculty presentations and incorporated information about managing stress and anxiety and online learning tips. Additionally, we now include a youth advocate in faculty presentations to share their experience of living with TS.



2022 School In-Services were conducted at the following schools:

- Shrewsbury Borough Elementary School
- Robert Hunter Elementary School
- Lincroft Elementary School
- Rutherford High School
- Memorial Middle School
- Brick Memorial High School
- Livingston Public Schools
- Mt. Olive Middle School
- East Hanover Middle School
- Lincoln Elementary school
- J. Mason Tomlin School
- Grace M. Breckwedel Middle School

Presenters for Faculty In-Services:

- Dr. Tracy Lederman
- Carolyn Baldwin
- Dr. Robert Zambrano
- Dr. Marla Deibler
- Claudia Lijo
- Lisa Augliera
- Karen Benjamin

YA Presenters for Faculty In-Services:

- Savannah Porter
- Colin Deibler
- Kyle Swords
- Shylah Gahles
- Sarah Baldwin
- Eric Jones
- Paige Kowalski
- Sofia Trabilcy
- Demetrio Loukatis



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.

This outreach has provided NJCTS with the opportunity to collaborate with a wide range of social and human service agencies with the goal to connect families in need with the support and services available through NJCTS.



2022 Community Presentations

- Ocean County Council for Young Children
- Family Support Organization of Burlington
- Family Partners of Morris & Sussex Counties
- New Jersey Parents Caucus
- Mental Health Association of Essex and Morris Inc.
- SPAN Parent Advocacy Network
- United Advocacy Group
- The Arc of New Jersey
- Women's Literacy Club of Bound Brook
- Camden ECCS
- Family Partners of Morris and Sussex Counties

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.



Schools Our Youth Advocates Presented For in 2022:

- Oxford Central School
- J. Mason Tomlin School
- Lincoln Elementary School
- Mt. Olive Middle School
- Grace M. Breckwedel School

Youth Advocate Presenters:

- Kyle Swords
- Sam Regan
- Gili Ben-nun
- Gavin Kiley
- Savannah Porter

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.

Presenters:

- | | |
|---------------------|-------------------|
| Dr. Jeremy Lichtman | Dr. Jeffrey Segal |
| Dr. Rob Zambrano | Dr. Graham Hartke |

The goal of the medical education program is to help medical professionals

enhance their understanding of the perspectives, stresses, and needs of patients with tic disorders and their families, and to improve interpersonal and communication skills in patient encounters.



2022 Grand Round & Medical Presentations:

- Youth Consultation Service (YCS)
- Penn Medicine Princeton Medical Center
- Kearny School District Nurses
- Stress and Anxiety Services of NJ
- Rutgers Graduate School of Applied and Professional Psychology



First Responder Training



2022 Law Enforcement In-Service

- Middlesex County Prosecutor's Office Police Training Center CIT

Presenters:

- Cheryl Ludwig
- Youth Advocate Kyle Swords

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.

Conferences

2022 Conferences Attended by NJCTS

- SEPAG Parent Retreat
- NJCIE Summer Inclusion Leadership Conference
- NJ Education Association (NJEA)
- Act Now Foundation's Dementia Center
- Ocean County College's Disability Resource Fair
- New Jersey School Conference Association
- NJAAP School Nurse Health Conference
- New Jersey Child Care Association
- Oldmans Township School District
- Plainfield Family Success Center Health & Resource Fair



Webinars

In 2022, NJCTS presented ten webinars that appealed to educational and medical professionals as well as parents. This is in addition to the more than 140 webinars that are available on our YouTube Channel.

Understanding and Responding to Sudden Onset Tics in Teens: An overview for individuals, families, schools, and clinicians

Presented by *Graham Hartke, Psy.D*

The impact of sudden onset FTLBs on individuals and families has often been very disruptive, anxiety provoking, and confusing. The goals of this webinar are to (1) provide an overview of what is currently known about FTLBs and the rise in cases, and (2) review treatments and strategies to address the condition.

The Benefits of a Neuropsychological Evaluation

Presented by *Cristina Sperrazza, Psy.D*

Dr. Sperrazza provides a brief explanation of neuropsychology, an overview of the neuropsychological evaluation process, differences between neuropsychological testing and school evaluations, and possible outcomes after a neuropsychological evaluation (e.g., diagnosis, treatment and school recommendations).

Addressing Perfectionism in Youth

Presented by *Devora Scher, Psy.D*

This webinar aims to help parents and teachers support a child or teen with perfectionism that gets in the way, rather than enhances their daily life. Participants will learn to apply skills to help children reduce anxiety and impairment associated with maladaptive perfectionism. Participants will also obtain familiarity with empirically supported treatment protocols related to perfectionism concerns.

Medication Management of Tourette Syndrome and Co-Occurring Conditions

Presented by *Takijah Heard, MD*

In this presentation, Dr. Heard, a Pediatric Neurologist with NeurAbilities, reviews the recommended medication treatments and side effects for treating Tourette Syndrome along with other neurological and neuropsychiatric conditions that can co-occur.

Attentional and Neuropsychological Difficulties Experienced with Epilepsy

Presented by *Hilary Murphy Ph.D*

This webinar focuses on a review of the common cognitive and attentional difficulties faced by individuals with epilepsy. Information is provided about how epilepsy can impact the brain and behavior. Additional focus is given to review the role of neuropsychological assessment in guiding academic and behavioral treatments.

Collaborative Problem Solving

Presented by *Jeremy Lichtman, Psy.D*

Applicable for parents and educators (and others), this presentation provides a basic understanding of CPS, which is an evidenced-based treatment. As a result of this webinar, attendees will be able to view children's behavior differently and reflect on how they can work more effectively with the children in their lives.

Understanding Executive Function Concerns in Tourette Syndrome and Related Disorders

Presented by *Richard Gallagher, Ph.D*

We discuss the assessment process and treatment strategies for youth that struggle with executive function. Training methods, including computer-based games, have shown some, but limited potential for impacting day-to-day behaviors at home and at school. In contrast, treatments in the form of training in organization, time management, and planning and motivational enhancement have demonstrated significant changes. This presentation and discussion will discuss these treatment methods and their promise in working with children and teens with TS.

Obsessive Compulsive Disorder 101

Presented by *Robert Zambrano, Psy.D*

We discuss the mechanisms that maintain OCD, the importance of not giving in to compulsion, and how to cope with the distress that this can cause the individual suffering from OCD. You also learn about effective treatment options and how they work as well as the difference between using coping strategies versus doing compulsions aimed at suppressing uncomfortable thoughts and feeling.

Treatment Approaches to Help Manage Bothersome Tics

Presented by *Peter Morrison, DO*

This webinar focuses on both the pharmacologic and non-pharmacologic treatment approaches to bothersome tics, including painful tics. This includes an evidence-based review of Comprehensive Behavioral Intervention For Tics (CBIT), medications (Guanfacine, Topamax, dopamine antagonists), and considerations for botulinum toxin injections for specific tics.

What Does It Mean To Have ADHD?

Presented by *Eric Deibler, M.S. Ed., Psy.D*

We delve into what ADHD is, the signs and symptoms, as well as the reasoning behind misdiagnoses. We cover the role that gender stereotypes play in the rate at which boys and girls are diagnosed and the impact it can have on self-esteem and mental health. We also talk about the different ways ADHD can present itself in children versus adults and why it is not uncommon for individuals to get diagnosed later in life.



NJCTS

Advocacy & Awareness

Annual Awards and Scholarship Luncheon

NJCTS awarded college scholarships and celebrated our top professionals, walk teams, Youth Advocate of the Year, and our very first Faith W. Rice Legacy Award Winner at a special luncheon at Maggiano's Little Italy in Bridgewater, NJ on Friday, June 3. Joining the honorees and NJCTS staff and board members was State Senator Andrew Zwicker (D16) who presented each honoree with a special citation.



The NJCTS professional awards are designated for health care and education professionals in New Jersey who have had a positive influence on the Tourette Syndrome community through education, outreach or research efforts.

2022 Health Care Professional of the Year:

Dr. Marla Deibler, Founder and Executive Director of Cherry Hill-based The Center for Emotional Health of Greater Philadelphia (CEH)

2022 Educator of the Year:

Stephanie Logan, Director of Special Services at Mantua Township Public Schools

The Youth Advocate of the Year award is presented to a graduating advocate who went above and beyond for NJCTS during their time in high school. 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.

2022 Youth Advocate of the Year:

AnnaClaire Sems

“We are always so proud of our youth advocates and the amazing things that they set out to do against all odds,” says Patricia Phillips, Executive Director of NJCTS. “Tourette Syndrome should not hold you back from your dreams and AnnaClaire went for hers.”



First Faith W. Rice Legacy Award Presented to Dr. Jay Tischfield

Dr. Tischfield was already a well-established leader in genetics research when Faith walked into his office at Rutgers University. She had read that he had been awarded more than \$20 million in federal funding to build and run the world's largest university-based biorepository for mental health disorders. But Tourette Syndrome was not on the list.



Faith being Faith, was not going to be happy (or stop harassing Dr. Tischfield) until TS was included. At the time there was a lack of collaboration among TS researchers and a lack of progress in finding answers into the cause, treatments and a cure. Within a month of their initial conversation, it was added to the list and Faith recruited the families they needed to make it happen.

200 New Jersey families stepped forward to donate genetic material. And thanks to Faith and Dr. Tischfield, 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.

Just four years into the pilot program, the National Institute of Mental Health funded its expansion which led the Rutgers/NJCTS partnership to establish TIC Genetics and 25 collection sites across the world. This international team of researchers have had some of the first breakthroughs and progress in understanding the genetic causes of Tourette Syndrome.



This collaboration, and the progress made because of it, is Faith and Dr. Tischfield's legacy.

We created the Faith W. Rice Legacy Award to honor someone who has been a vanguard, who has gone above and beyond in education, advocacy and research. Someone whose accomplishments have enriched the lives of those living with Tourette Syndrome. That is why we have chosen Faith's friend, and favorite collaborator, as the first recipient of this Legacy award.

NJ Walks for TS

In Spring of 2022, NJCTS conducted the virtual NJ Walks for TS. Several new teams joined the cause and rallied support for Tourette Syndrome awareness and NJCTS programs throughout New Jersey. Sofia Trabilicy of Flemington was one of the top fundraisers for the fourth year in a row, rallying support from her community, family and schoolmates.

On board in 2022 were sponsors Dietz & Watson, Black Bear Brand Deli Meat, The Wawa Foundation, The Center for Emotional Health of Greater Philadelphia, and Smile More Dentistry. The top fundraising award was provided by the Downtown Somerville Alliance and included merchandise and gift cards from Somerville restaurants and stores.

Thank you to NJCTS Board Members Tim Yingling and Tim Omaggio for their continued support of the Walk.

NEW JERSEY



WALKS FOR TS



2022 Top Fundraiser Sofia Trabilicy, who raised more than \$5,000 with her team Trabilicy Tackles Tourette IV.

2022 Top 5 Walk Teams

1. Trabilicy Tackles Tourette IV
2. NJCTS Academy Coaches
3. Montclair Drifters, Inc.
4. The Pierce Family
5. Rahway Valley JerseyAires



Members of The JerseyAires, a mixed a cappella chorus located in Rahway, spent the morning walking and singing to raise awareness for TS. Their team was captained by Heidy Moretti.

NJCTS | Support

Our Corporate & Community Partners

\$5,000 +



\$2,500 - \$4,999



\$1,000 - \$2,499



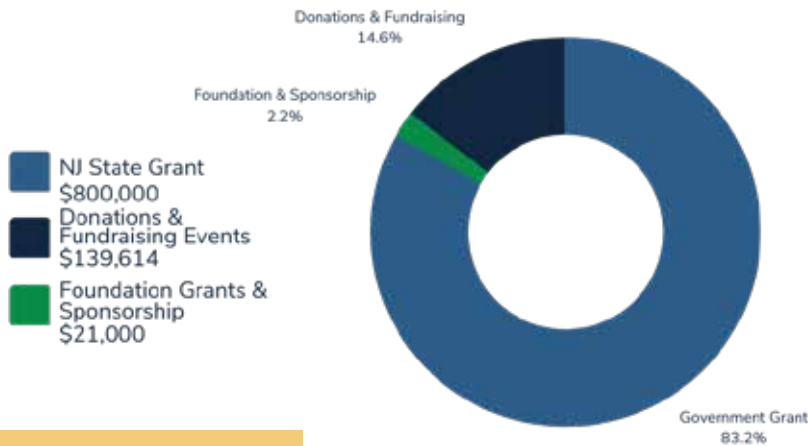
\$250 - \$999

Penn Medicine Princeton Medical Center
Johnson & Johnson
The Center for Emotional Health
Merck Foundation
AmazonSmile Foundation
Fusion Academy Princeton
Medford Lakes Lions Charities, Inc.

Financial Review

Fiscal Year July 2021 - June 2022

Revenue



Total Revenue: \$960,614

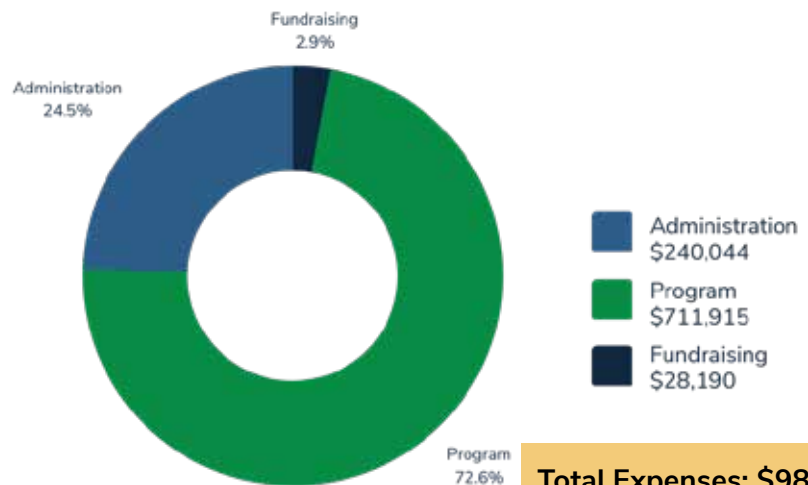
The effects of COVID-19 were still being felt through the end of 2021. By 2022, in-person events were back to being the norm and sponsorships and donations for these programs started to return.

We received unwavering support from individual donors and partners, and with the state of New Jersey's full support of NJCTS, was able to maintain a strong financial position going into the second half of the year.

NJCTS continued to work hard to create new programs and enhance current ones to serve the TS community through education, advocacy, and research. Programs include awareness, medical and educational outreach, family programming, youth development, support of the TS clinic and the DNA repository at Rutgers, TIC Genetics research studies, and TS community support.

72% of every dollar spent during the 21/22 fiscal year went to the Tourette Syndrome community.

Expenses



Total Expenses: \$980,149

NJCTS Cashes in the Chips at Casino Night

What a night! The Financial Resources Federal Credit Union Foundation hosted a fun Casino Night themed fundraiser on September 12 to benefit and support NJCTS. That evening FRFCU Foundation presented Executive Director Pat Phillips and board members Andrew Hendry and Tim Kowalski a check for \$20,000 in support of the NJCTS mission.

The evening included a variety of casino table games, games of chance, a tricky tray raffle, and wonderful food at The Palace at Somerset Park.



Families Give Back

Mark Roth celebrated his 60th birthday with donations in his honor and raised \$428!



Facebook Birthday Fundraisers

Christopher Ubinas

Teri Blank Neidich

Michele Jackson Newman

Jonathan Yu

Lori Souder McCline

Steven Lindenbaum

Donna Samek Friedrich

Nick Buckley



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 or call 908-575-7350.

Ways to Support NJCTS

NJCTS offers a beacon of hope for individuals and families affected with TS through programs, services, support, and professional assistance. The first Center of Excellence of its kind in the nation, NJCTS is at the forefront of education, advocacy, and research.

From blazing trails in addressing education and support needs, to advocating for access to treatment and services, NJCTS has become the voice for individuals and families in need. Still, there is much work to be done to educate the public, reach new families, and forge ahead with research ever searching for more effective treatments.

Your generous support is key to making those advances and our ongoing services possible. There are myriad ways to support NJCTS.

Your financial support is vital, and simply put, we cannot do what we do without you!

Donate online at 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
- Use Shop with Scrip to purchase gift cards

2022 NJCTS Volunteers

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

- Mr. Mateo Acevedo
- Ms. Anna Baldwin
- Ms. Sarah Baldwin
- Mr. Scott Baldwin
- Mrs. Carolyn Baldwin
- Ms. Limor Ben Nun
- Mr. Ari Bramson
- Ms. Jordan Chervin
- Mr. Colin Deibler
- Mr. Dominic Dominguez
- Mr. David Firenze
- Dr. Meir Flancbaum
- Ms. Sarah Freeman
- Ms. Shylah Gahles
- Dr. Richard Gallagher
- Mr. Jacob Gerbman
- Ms. Staci Greenwald, Esq.
- Mr. Andrew Hendry
- Mr. Kenneth Higdon
- Ms. Hallie Hoffman
- Ms. Hannah Horner
- Mr. Eric Jones
- Mr. Gavin Kiley
- Ms. Paige Kowalski
- Ms. Tess Kowalski
- Dr.. Tim Kowalski
- Ms. Eliza Lederman
- Dr. Jeffery Lederman
- Dr. Tracy Lederman
- Mr. Michael Leopold
- Mr. Michael Lewis
- Mr. Tommy Licato
- Dr. Jeffrey Lichtman
- Dr. Jeremy Lichtman
- Mr. Steven Lindenbaum
- Ms. Emily Liu
- Mr. Demetrio Loukatis
- Ms. Mollie Mars
- Dr. Michelle Miller
- Mr. Ray Nardella
- Mr. Joseph Nowacki
- Mr. Timothy Omaggio
- Mr. Jeffrey Osborn
- Mr. Ferdinando Palumbo, MSW, LCSW
- Mr. Peter Frantz Pendell
- Ms. Stephanie Pendell
- Ms. Savannah Porter
- Mr. Adam Regen
- Mr. Samuel Regen
- Ms. Sydney Regen
- Ms. Katrina Reichenbach
- Mr. Paul Romano
- Mr. Conrad Roncati Jr.
- Dr. Michael Rubenstein
- Ms. Amanda Silvers
- Mr. David Silvers
- Mr. William Sooy
- Ms. Rebecca Spar, Esq.
- Mr. Benjamin Stark
- Ms. Liane Sturrock
- Mr. Kyle Swords
- Ms. Sofia Trabilcy
- Ms. Sara Weinstein
- Mr. Tim Yingling
- Dr. Robert Zambrano

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

Board of Directors



Patricia Phillips
Executive Director



Andrew Hendry
Chairman



Tim Kowalski, PhD.
Vice Chairman



Paul Romano
Treasurer



Steven Lindenbaum
Secretary



Rebecca Spar, Esq.



Conrad Roncati



Tim Yingling



Tim Omaggio
Non-Officer
Executive Committee



Tim Howard
Honorary Member

Advisory Board



Sol Barer, PhD
Celgene Corporation
(retired)



Linda Brzustowicz, MD
Rutgers University
Dept. of Genetics



Lew Gantwerk, PhD
Director Emeritus,
Rutgers GSAPP



Stuart Green, DMH
Overlook Medical
Center



Gary Heiman, PhD
Rutgers University
Dept. of Genetics



Robert King, PhD
Yale University



Bernice R. Rydell, EdD
VP Emeritus
Millersville University



Jay Tischfield, PhD
Rutgers University
Dept. of Genetics

NJCTS 2022 Staff



Patricia Phillips
Executive Director



Santina Reichenbach
Finance & Human
Resource Director



Doreen Pustizzi
Communications
Manager



Kelley Teabo
Project Coordinator



Lisa Augliera
Youth Development
Coordinator



Daryl Ball
Finance & Data
Management



Brianna Burkert
Communications &
Development Associate



Claudia Lijo
Outreach
Coordinator

NEW STAFF



Alina Lawas Osborn
Program Coordinator



Katie Delaney
Family & Medical
Outreach Coordinator



Hilary Kruchowy
Director of
Development



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



Not GoodBye, But See You Later!

Kelley Teabo worked with founder Faith Rice before NJCTS was even a reality. They set up shop in a small office serving the TS community through TSA-NJ. It's an understatement to say that Kelley played an integral role in the creation of NJ Center for Tourette Syndrome – the nation's FIRST center of excellence for TS. That is why we were sad to learn that Kelley made the decision in the summer of 2022 to leave New Jersey and move to Virginia where she has family roots.

Kelley was often the first voice on the other end of the line when families called for support. She spent hours and hours comforting parents, letting them know they are not alone, and giving them the help they needed.

At camp, she not only organized the whole dang thing, but she was chief-fun-maker-in-charge. (Do you know how hard it is to find Shrinky-Dinks these days?) She was also everyone's alarm clock! Waking everyone up with her signature "Good morning, good morning, good morning!"



Young campers were not the only ones who were treated with Kelley's early morning greeting. Tim Howard Leadership Academy teens were also woken up by Kelley each morning, right after she set up their breakfast and made sure everything was ready for their day. Most importantly, it was Kelley who the teens would seek out when they needed a break from the day. She would patiently sit behind the desk at Rutgers and listen, give advice, or laugh with them.

Kelley's role was not just being a friend to our families and organizing our great events. Kelley, with Marty Butterfield, grew the Webinar program into what it is today, with nearly 150 presentations given in the last 13 years. Through that she built relationships with doctors and educators throughout the region. She was the face of NJCTS at the NJEA teacher conference each year. She was also the force behind our scholarship program and many other activities and projects throughout her years at NJCTS.

We will miss Kelley's smile, her voice, and mostly...her heart.



Education. Advocacy. Research.


Supported by:




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.



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and Associated Disorders, Inc.

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