



The Year The World Stayed Apart, We Were Together



YEAR IN REVIEW 2020

Education. Advocacy. Research.



YEAR IN REVIEW 2020

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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

The year 2020 was unlike any year in recent times. Starting with the outbreak of the coronavirus, NJCTS faced new challenges as well as successes as we navigated uncharted waters. Last year, we demonstrated the resiliency of our organization as we swiftly managed the changing times and embraced the virtual platform to continue our work in educating, advocating and serving the Tourette Syndrome community. Providing 85 programming events that included education and medical outreach, youth chats, family support groups, game nights and a 48% increase in webinar attendance, NJCTS remained strong.

However, the monumental change in 2020 was the retirement of our beloved and incomparable leader, Faith W. Rice. Under Faith's leadership, NJCTS trained over 28,000 educators and 10,000 medical professionals through in-services and Grand Round presentations, and nearly 100 psychologists at the Tourette Syndrome Clinic, and with Rutgers University established the world's first Cell & DNA Sharing Repository for TS.

We all came to love Faith not only for her work but for who she was, and how she made you feel. Faith believed in you when you didn't believe in

yourself and she taught us all how to think big. The passing of Faith on March 22, 2021 reminds us that it is not how long we live, but how well we serve. Faith served the TS community well and left us all the priceless gift of her legacy, the NJ Center for Tourette Syndrome. We at NJCTS will continue to build upon her legacy and serve the TS community.

Faith dedicated her life to ensuring those living with Tourette Syndrome and the associated disorders could live full productive lives. Whether it was through educating others, investing in research, or offering words of hope to a family, she was there. Faith was committed to changing minds and changing lives. She will forever remain in our hearts.

Thank you, Faith. Without you, there never would have been NJCTS.

Patricia Phillips

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, 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:

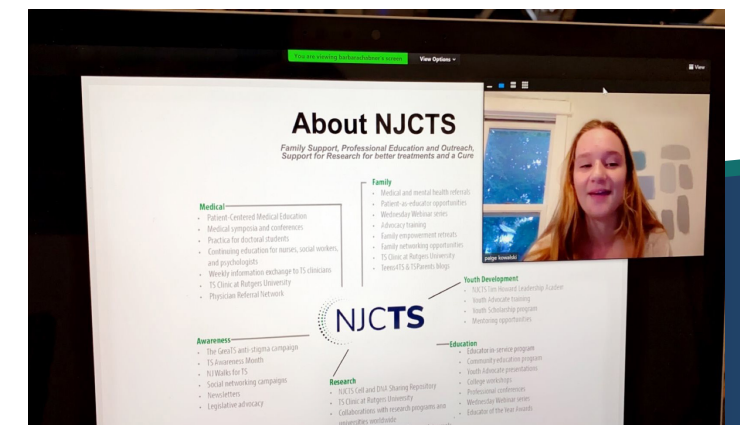
- Usually appears when a child is 6 or 7 years old
- Affects all ethnic groups
- Boys are affected 3 – 4 times more often than girls
- Lifelong condition – cause unknown –no cure
- No standard treatment protocol
- Average time from onset to diagnosis is still 7 years
- Psychological, social, educational, 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

2020: Making An Impact During a Pandemic

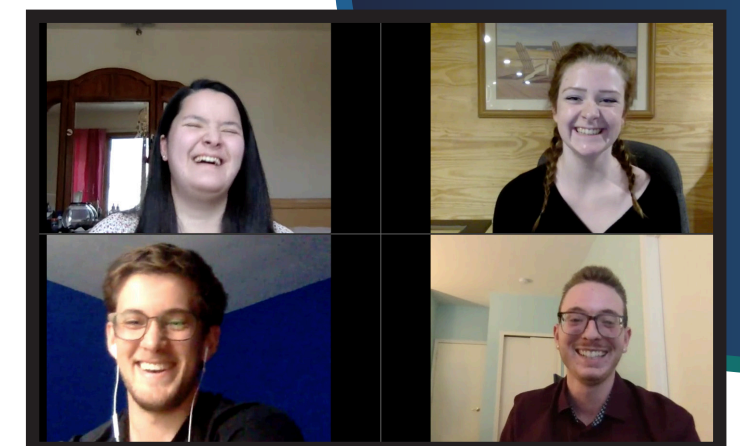
In March of 2020, NJCTS was looking at a full calendar of Youth Advocate presentations, faculty in-services, Grand Rounds and conferences. Then the world stopped. We like, the rest of the non-profit world, had to “pivot” and figure out a way to continue to serve the TS community. And so, from our homes, and with the help of our amazing clinicians and volunteers, we went virtual...reaching people far and wide through 85 presentations and events.



- 13 Webinars
- 48% Increase in Webinar Attendance
- 23 Virtual Family Events and Support Groups
- 17 Virtual Youth and Teen Events
- Nearly 450,000 Social Media Impressions
- More than 82,000 Website Page Views



Youth Advocates and Academy coaches led the way in this virtual world.



Thank You, Faith



Faith W. Rice, founder and executive director of NJ Center for Tourette Syndrome and Associated Disorders announced her retirement near the end of 2020. Then we were all shocked and saddened to learn of her death in March of 2021.

Under Faith's leadership, NJCTS trained more than 28,000 educators and 10,000 medical professionals through faculty in-services and Grand Round presentations. Nearly 100 psychologists were trained at the NJCTS Tourette Syndrome (TS) Clinic, a program Rice created in partnership with Rutgers Graduate School of Applied and Professional Psychology. Youth Advocates gave over 500 presentations spreading awareness throughout the state. Additionally, with her guidance, NJCTS and Rutgers established the NJCTS Cell & DNA Sharing Repository—the world's first sharing resource of TS clinical data and genetic samples.

Faith began her advocacy journey when her son was 10 years old and started having uncontrollable movements like head jerking and shoulder shrugging in addition to clearing his throat hundreds of times a day. It took nearly 10 more years of pediatricians, psychologists, allergists and psychiatrists before he was diagnosed with Tourette Syndrome. But the relief of a diagnosis was short-lived.

"I took a leave from my job to care for my son and line up resources," Rice recalled, "but quickly found there were none – few doctors, no family support, no services or network that we could tap into. I needed to do something to bring about change and make life better any way I could."

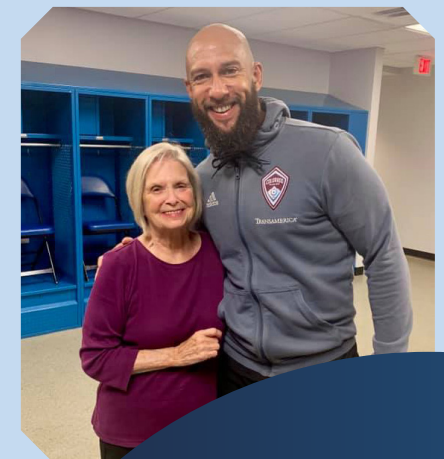
Faith did what you did at that time, she put an ad in the newspaper inviting those that have been touched by TS to attend a meeting. Eighty people showed up. "I left the meeting with a handful of dedicated volunteers and a determination to bring services to families living with this devastating disorder," she said.

That meeting was the start of a long journey to create quality programming for families living with TS and to bring awareness to New Jersey state officials which eventually led to funding from the state in 2004 to establish NJCTS – the nation's first Center of Excellence for Tourette Syndrome. With as many as 1 in 100 individuals living with a TS or a similar tic disorder, there was much work to be done to raise awareness and decrease the stigma associated with TS.

From recruiting a handful of teachers in the 90's to go into New Jersey schools to educate the educators about TS, to partnering with Rutgers University and universities from around the world for the last 10 years on one of the most successful TS research projects to date, Faith has led the way. Not to mention the countless hours she spent on the phone, at all hours of the day, listening to other families' struggles and giving them the support she had so desperately needed all those years ago.

"Faith Rice leaves us with an amazing legacy to continue on behalf of families living with TS," said Patricia Phillips, NJCTS's new Executive Director. "Her perseverance to knock on every legislator's door to ensure our families had the programs they needed and her innovation in creating those programs to empower these kids who may have faced amazing challenges like bullying and mental health issues, is truly inspiring."

NJCTS has created the Faith W. Rice Legacy Fund to ensure Faith's work will continue on.



"I had a vision to build an organization that changed the course of research, improved public awareness and acceptance of people living with TS, and created daily support for families and professionals dealing with TS, and that vision has been fulfilled."



NJCTS | 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

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 Director Dr. Graham Hartke, PsyD, who is 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

During 2020, the clinic offered its services virtually, including therapy and support groups, and were able to reach more individuals without the worry of distance.

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.

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.

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 Events



In 2020, we could not get together for the Family Retreat Weekend, Family Picnic, a day at the Patriots game, and all of the other fun things we did in years past. So we had to get creative.

Events like Family Game Night and our Virtual Campfire provided our families an opportunity to catch up and get away from the stress of at-home learning, working from home, and the 24 hour news cycle.

The introduction to monthly, online **Family Support Groups** also gave families an opportunity to hear from experts in their field and have an open conversation about many relevant topics, from coping with stress during the pandemic to managing tics and OCD. These sessions will continue into 2021.



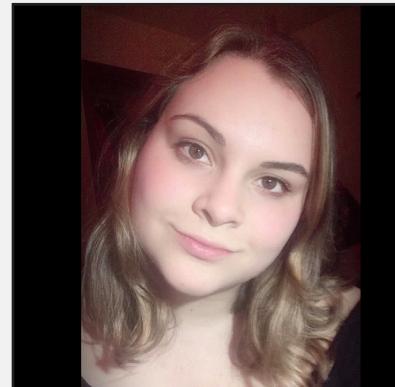
2020 Family Support Groups

- Helping our Children Manage TS During the Pandemic
- Disabilities and Employee Rights: What You Need to Know
- Getting Into The Weeds with Medical Marijuana
- Help is on the Way: At-Home Learning Tips for Parents
- Helping Parents Keep a Balance with Siblings
- How Can Parents Work With Their Children During the Covid 19 Pandemic
- Keep Calm Mom and Dad: Discussing the Impact of Covid 19 on Your Child's Education
- Learning Disorders - What You Need to Know
- Managing Tics During the Challenging Time
- Managing Tics During the Pandemic with CBIT
- OCD During the COVID-19 Lockdown
- Put Your Mind to Rest: Practicing Mindfulness
- Straight Talk: Mental Health & Addiction
- TS Then and Now: Transitioning After the Quarantine Ends

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 2020, 14 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing themselves as outstanding advocates for Tourette Syndrome.

FIRST PLACE



Sara Deudicibus – Middletown

Sara graduated from Middletown High School North and is attending Stevens Institute of Technology. Sara's early academic career was marred with bullying and teachers who didn't understand her disorder. But after a change of schools and a new found love of basketball, Sara hit her stride. Once in high school, she focused on academics. She was a member of five honor societies, became a published poet, tutored underclassmen and volunteered as an EMS cadet. She even started a Mindful Psychology and Wellness Club at school.



Matthew Calloway – Haddon Heights

Matthew graduated from Haddon Heights High School and is attending Drexel University. Matthew found his passion in music, specifically percussion. He played drums in the marching band and played at school functions in a student garage band. A member of the National Honor Society, Matt participated in the school's service club, chess club, robotics club, and volunteered at a local animal shelter. All of this while nearly achieving straight As throughout High School.

Educator of the Year Tara Loughlin

Wemrock Brook School, Manalapan, NJ



NJCTS awarded the 2020 Educator of the Year to Tara Loughlin, a second grade teacher at Wemrock Brook School in Manalapan. Loughlin was nominated by Tracy Straley on behalf of her son Dylan.

"Mrs. Loughlin was a godsend to our family. She went above and beyond in every way. She made Dylan feel comfortable with himself despite his unusual looking constant tics and she encouraged all students in her class to be kind and accept differences."

SECOND PLACE

Dominic Dominguez
Bloomfield



Dominic was a member of the National Honor Society, an officer on the math team, and made varsity for Track and Field and Cross County. He attended the NJCTS Tim Howard Leadership Academy and was a Bernie Buddy at the NJCTS Family retreat where he mentored and entertained younger participants with Tourette Syndrome.

Jacob Gerbman
Fair Haven



After his TS diagnosis, Jacob looked to the stage for relief. Drama club, choir and marching band. He truly shined on the stage and found a way to combine his TS advocacy with his role of Uncle Fester in the Addams Family. Pulling his friends, family and fellow actors together, Jacob raised more than \$8,000 for NJCTS with the promise of shaving his head, live on the internet, for the role.

HONORABLE MENTIONS



Brendan Bukowski
Riley Burke
Mason Fenton
Rachel Flynn
Carson Grabowski

Emma Marsico
John McElroy
Evan Patiño
Debra Reinhardt
Madilynne Sliffer

NJCTS | Youth Development

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 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 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

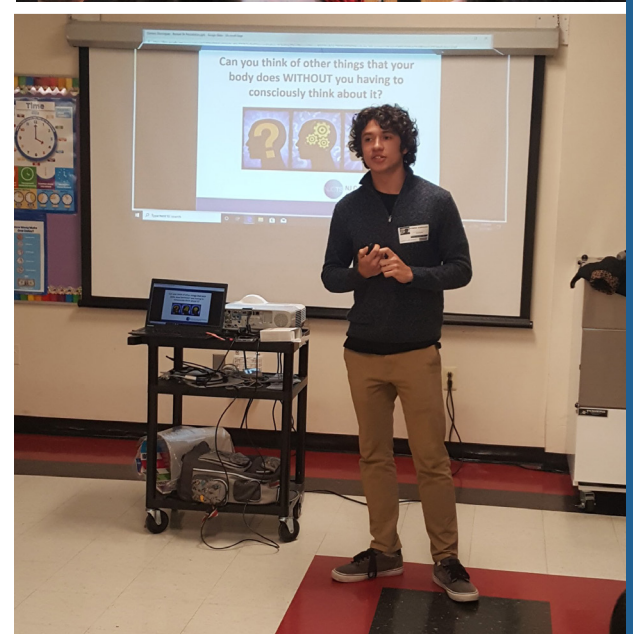
One of NJCTS' popular fundraisers is our annual walk. The NJ Walks for TS virtual walk spans the months of March through May, and is a great opportunity for the Youth Advocate to spread their wings as a leader and become a team captain!

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.





New Virtual Series For Youth Advocates



NJCTS introduced four new interactive information sessions for parents and children that were designed to give families the knowledge and skills they need to advocate today, tomorrow and every day. The Empowerment Advocacy sessions were held virtually and led by talented professionals and some of our own youth advocates.

Topics:

Advocacy Works
Beating the Bully
Putting your Voice into Action
The Power of Social Media

Tim Howard Leadership Academy & Global Teen Summit

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.

NJCTS hosted their first ever Global TS Teen Summit on August 7 and 8. The fully virtual event was held in conjunction with the annual NJCTS Tim Howard Leadership Academy.

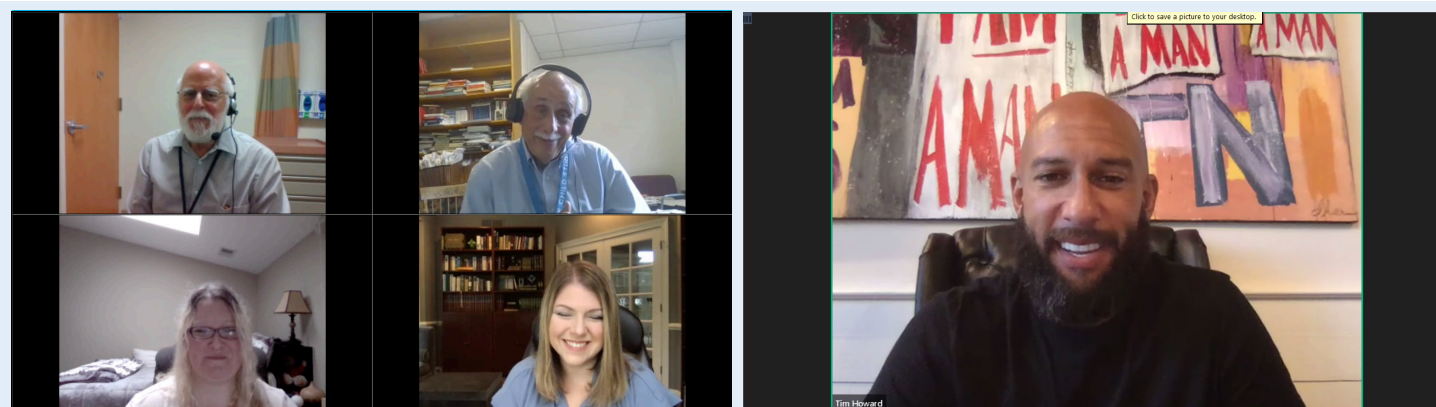
When the Leadership Academy was moved online because of the pandemic, NJCTS saw it as an opportunity to open the educational sessions to teens from around the globe. Attendees were given the chance to learn about their Tourette Syndrome and connect with other teens who share their experiences.

The participants represented 16 states from

California to Massachusetts, and six countries including England, Canada, Italy and New Zealand.

In addition to the presenters of each session, the teens heard from young adult mentors, or coaches, throughout the two days. Some of the topics covered included navigating through high school and college with TS, coping strategies and therapies, and being your own advocate.

Tim Howard even made his traditional appearance via Zoom to speak to the participants and answer their questions.



Graduating Youth Advocates

CONGRATULATIONS to our NJCTS Youth Advocates who graduated in 2020.



Jatin Nayyar



Jacob Gerbman



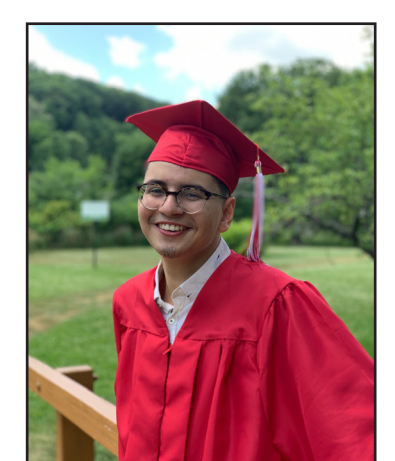
Dominic Dominguez



Rachel Flynn



Riley Burke



Evan Patiño

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 2020:

- Lafayette School
- Smalley School
- Community Middle School

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.

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.

In light of COVID 19, we revised our faculty presentations and incorporated information about managing stress and anxiety and online learning tips. Additionally, for the first time, we included a youth advocate in faculty presentations to share their experience of living with TS.



2020 Faculty In-Services were conducted at the following schools:

- Jersey City Public Schools
- Midtown Community School
- Bound Brook School District/ Bound Brook High School
- Roy W. Brown Middle School
- NJ Department of Education (DOE) County Education Specialists and County Supervisors
- Memorial Elementary School
- Association of American Educators
- Lincoln School
- Bergen County School Counselor Association



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 2020, 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.



2020 Community Presentations & Conferences

- The Latino Institute, Inc.
- Suburban Essex Nurse Supervisor Association
- SEPAG - Passaic Valley High School
- Morris County Partnership for Employment and Transition
- Passaic County Department of Human Services
- Division of Mental Health and Addiction Services
- Parent Education Conference (The Latino Institute)
- NJ Coalition of Latino Pastors and Ministers
- Community Networking Association Union County
- Ocean County Dept of Human Services - CIACC
- Children's Inter-Agency Coordinating Council (CIACC)
- Ocean County Department of Human Services"
- MCCYC General Council Committee Norwescap
- Division of Children's Services
- Office of Human Services
- Department of Community Services
- CCYC Toms River Subcommittee (Spanish)
- CCYC Seaside Subcommittee (English only)
- CCYC/SR Lakewood Subcommittee (Spanish)
- NJCIE
- NJEA
- Learning Disabilities Association of New Jersey

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-Service and Grand Round Presenters:

Dr. Meir Flancbaum
Dr. Barbara Chabner
Ms. Patricia Phillips
Dr. Anton Shcherbakov
Dr. Michelle Miller
Dr. Diana Antinoro Burke
Ms. Claudia Lijo
Dr. Rob Zambrano
Dr. Michael Rubenstein

2020 Grand Rounds Presentations



- Centrastate Family Medicine
- Hunterdon Pediatrics
- Penn Medicine Behavioral Health
- Cooper Family Medicine
- Trinitas Regional Medical Center

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.

2020 Law Enforcement In-Services

- Union County Crisis Intervention Team (CIT)
- Middlesex County Prosecutor's Office



Webinars

In 2020, NJCTS presented thirteen webinars that covered everything from parent burnout during COVID-19 to therapy dogs. This is in addition to the more than 120 webinars that are available in our online archive.

Introduction to Mindfulness for Stress Reduction

Presenter: Anton Shcherbakov, Psy.D, BCBA

Dozens of research studies show that engaging in regular mindfulness practice can reduce stress, anxiety, depression, and improve overall well-being. During this webinar, participants can expect to learn about the origins of mindfulness practice, hear about psychological research regarding its benefits, and participate in a guided meditation practice

Improving Social Outcomes for Children with Tourette Syndrome and Other Neurodevelopmental Disorders

Presenter: Azlen Theobald, Psy.D.

Finding ways to help peers better understand the symptoms and presentation of neurodevelopmental disorders, such as Tourette Syndrome, can greatly improve social outcomes and reduce mental health risk among this vulnerable population. This webinar will focus on strategies to help increase positive social interactions for children with neurodevelopmental differences.

Developmental Considerations for OCD in Kids, Teens, and Adults

Presenter: Jacquelyn Gola, Psy.D.

Although OCD is diagnosed using one set of criteria, it manifests differently across the lifespan. This presentation will explore OCD across different age groups. Webinar attendees will learn how OCD presents in children, adolescents, and adults and how Exposure and Response Prevention therapy (ERP) could be adapted for each age group.

Parenting the Anxious Child

Presenter: Marla Deibler, Psy.D.

When feelings of anxiety are excessive and become overwhelming, children instinctively rely on their parents to help them cope and rid them of these unwanted feelings. And, many well-meaning, caring parents do just that; however, this can become unintentionally problematic, impairing the ability of the child to function independently and preventing them from developing the ability to cope on their own.

Parent Burnout in the Face of Covid 19

Presenter: Azlen Theobald, Psy.D.

In the current pandemic setting, parents are wearing even more hats than they usually do and have found themselves very swiftly and without much preparation time playing the role of parent, educator, behavioral therapist, and coach. For children with neurodevelopmental disorders, the COVID-19 environment has meant a drastic change from their daily routine and left parents and caregivers feeling overwhelmed and burned out.

Assistive Technology to Help with Anxiety

Presenter: Matt Dennion

This presentation focuses on apps that can assist students from kindergarten to 12th grade in dealing with anxiety in school and in functional settings. The presentation highlights mobile technology that can help create schedules with detailed directions, support reading and writing for students with dyslexia and dysgraphia, assist with writing research papers, and programs that can support independent functioning in a community setting.

"In These Uncertain Times": Returning to School in an Age of Anxiety

Presenter: W. Eric Deibler, M.S Ed., Psy.D

In this talk, we will examine the long-term psychological experience of children during episodes of societal disruption, including factors that are associated with a higher degree of symptoms, as well as things that schools and others can do to try and ensure better outcomes. We will cover important concepts such as psychological triage and other effective interventions that can support children who are struggling emotionally.

Youth Suicide: Starting the Conversation

Presenters: Maureen Brogan and Wendy Sefcik

This presentation will provide an overview of the scope of youth suicide, who may be at risk and what we can all do to prevent our youth from dying by suicide. It will be an open and honest conversation about the second leading cause of death for youth. Participants will leave with a better understanding of what to look for and how to have open and honest conversations about a very important topic that impacts many.

Ask the Advocate

Presenter: Staci Greenwald, Esq.

Do you have a question for an education advocate? Here is your opportunity to ask. Staci Greenwald has 27 years experience as a lawyer in this field and has a personal connection to making things right.

AIR Therapy Dogs: Paws For Minds

Presenter: Tricia Baker, Attitudes in Reverse

Discussion on how dogs are good for our mental wellness. We will cover the different types of legal support dogs and the laws they fall under. We will also discuss how the role of therapy dogs have expanded in the past 10 years.

Non-Medical Treatment of Tics: An Overview of CBIT and the Rutgers Tourette Syndrome Clinic

Presenter: Dr. Graham Hartke

This webinar will provide an overview of Comprehensive Behavioral Intervention for Tics (CBIT), a structured evidenced-based non-medical intervention for tics based on cognitive behavioral therapy. CBIT helps individuals of all ages learn tic management strategies and reduce tic symptoms. There will also be a discussion about how CBIT can be best integrated with other psychological, medical, and educational interventions. Finally, a brief overview of the Rutgers Tourette Syndrome Clinic will be provided.

Ask the Doc: A Neurologist's Perspective

Presenter: Dr. Michael Rubenstein

Do you have a question about your Tourette Syndrome or your child's Tourette Syndrome? Dr. Rubenstein is answering questions about TS in all its stages.

Neurodevelopmental Conditions and Anxiety: Common Causes and Effective Solutions

Presenter: Christopher Lynch, Ph.D

High rates of anxiety have been reported across a range of neurodevelopmental conditions including ADHD, Autism, Tourette Syndrome, and Learning Disability. In this webinar, Dr. Lynch explores the reasons why these conditions are so often accompanied by anxiety. Practical and effective strategies for addressing anxiety in children with these conditions will also be covered.

NJCTS | Advocacy & Awareness

NJ Walks for TS
TS Awareness Day

Advocates in Action
Families Give Back



NJ Walks for TS

In Spring of 2020, NJCTS conducted NJ Walks for TS. Typically, several families participate by creating their own local walk event to raise awareness and funds for TS. The COVID-19 pandemic may have put a stop to in-person events but that didn't stop the determined team captains from reaching out to their networks to continue their efforts. The top five walk teams were Frank and Friends, led by Frank Yingling of Medford Lakes, Trabilcy Tackles Tourettes, led by Sofia Trabilcy of Flemington, Team Jatin, led by Jatin Nayyar of Morganville, Team Jamo led by Jameson Dougherty of Newfoundland, and Team Levitt, led by Dylan Levitt of Randolph. Also on board this year were sponsors Dietz & Watson, Black Bear Brand Deli Meat, Asurion, Walmart and Wawa.



Tourette Syndrome Awareness Day in NJ

June 4, 2020



www.njcts.org

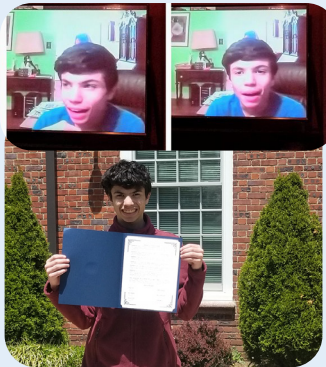
908.575.7350

To mark the occasion of June 4 as Tourette Syndrome Awareness Day in New Jersey, NJCTS celebrated with a virtual awards ceremony where they awarded college scholarships, recognized the top walk teams, awarded the Youth Advocates of the Year, and announced the Educator of the Year.

State Senators Kip Bateman, Troy Singleton and Anthony Bucco participated in the ceremony. Dr. Kim Buxenbaum, Director of the Office of Special Education at the NJ Department of Education recognized our graduating Youth Advocates.

Tim Howard also made an appearance via a pre-taped message of congratulations to all of the award winners.

Advocates in Action



A big THANK YOU to Ben Mars who requested a proclamation from his mayor declaring June 4th TS Awareness Day in the city of Teaneck! Ben joined the city council at their virtual meeting to accept the proclamation.

Paige Kowalski had the opportunity to travel to Washington, DC in March to train as a Tourette Association of America Youth Ambassador and participate in #Rally4Tourette on Capitol Hill. The ambassadors spoke with Senators, Representatives, and their staff members to advocate for the most pressing public policy issues facing the Tourette Syndrome community.



In September of 2020, AnnaClaire Sems decided it was time for a new adventure. She applied and was accepted to the Oakcliff Sailing program, the top training program for sailing in the United States. They train both youth and adults to participate in the three big sailing competitions, including the Olympics. AnnaClaire lives there full time and has a busy schedule of schoolwork and sailing. She looks forward to her first offshore race in the summer of 2021.

Shylah Gahles (aka Simply Tourettes) spent 2020 building her social media presence and being interviewed by TS advocates and social media heavyweights, One Tic at a Time and Tourette's Podcast. She also helped NJCTS with several online programs geared toward teens with TS.



Families Give Back

2020 was challenging for so many families, yet our NJCTS families stepped up to help us in so many ways. They raised awareness and money through the walk, asked their local law makers for a proclamation for TS Awareness Day in NJ, volunteered to facilitate an online support group, or created their own online fundraisers to celebrate their birthday. We cannot thank you enough!



Facebook Birthday Fundraisers



Barbara Rivera
Maria Clara Casas-McGown
Nick Buckley
Pam Lear
Raquel Silva
Susan Hipko Everett

Giving Tuesday Fundraisers

Tyler Storer
Gayle Foreman
Isabel Uribe
Lindsay Chavez
Maria Clara Casas-McGown



Dominic Dominguez decided to put Princeton University off for a year while he continued his work as an EMT and took on an internship with NJCTS working with our Youth Development Coordinator. As part of his new responsibilities, Dominic helped with outreach to potential advocates to share the many ways they can advocate, practice their leadership skills, and build the TS community.

2020 Youth Advocates

Ben Mars
Hallie Hoffman
Jonah Grossman
Liane Sturrock
Brennan Skirzenski
Anna Claire Sems
Jatin Nayyar
Kyle Swords
Dominic Dominguez
Jenna Smith
Paige Kowalski
Eric Baldwin
Kyla Butler

NJCTS | Support

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

Donate online at www.njcts.org, over the phone by calling 908-575-7350, or by mail to:

NJ Center for Tourette Syndrome & 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
- Use Shop with Scrip to purchase gift cards

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

NJCTS Volunteers *Thank you!*

- Katrina Bergeon
- Amanda Bossi
- Kyla Butler
- Marty Butterfield
- Maria & Patrick Carew
- Dr. Lisa Cox
- Sophia Cristaldi
- Dr. Marla Deibler
- Dominic Dominguez
- Maggie Esposito
- Drew Friedrich
- Jillian Firenze
- Staci Greenwald, Esq.
- Jonah Grossman
- Mike Hayden
- Dr. Caroline Hayes Rosen
- Dr. Gary Heiman
- Sara Henya
- Hallie Hoffman
- Dr. Robert King
- Paige Kowlalski
- Tim Kowalski
- Tim Howard
- Robert Haugh
- Dan Leopold
- Michael Leopold
- Ronnie Li
- Thomas Licato
- Dr. Jeremy Lichtman
- Chris Marculic
- Ben Mars
- Ray Nardella
- Jatin Nayyar
- Joseph Nowacki
- Sam Regen
- Katrina Reichenbach
- Dr. Michael Rubenstein
- AnnaClaire Sems
- Brennan Skirzenski
- Jenna Smith
- Liane Sturrock
- Kyle Swords
- Muzzamil Syed
- Dr. Azlen Theobald
- Emilie Thorstensen
- Dr. Jay Tischfield
- Eryn Travis
- Analise and Robyn Twemlow
- Sue Vitek

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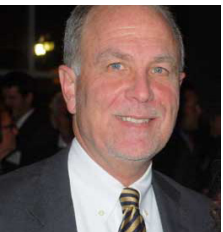
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Honoring One of the NJCTS GreaTS



Martha “Marty” Butterfield has worn many hats with NJCTS, from support group coordinator to volunteer coordinator. She, along with her partner in crime Kelley, ran the monthly webinars and made sure everyone enjoyed the Family Retreat Weekend.

In 2020, she permanently took off her NJCTS hat and retired. Marty wore her hats with humor and grace and we are grateful for her contributions to the growth and success of the organization. NJCTS would not be where we are today, if she wasn’t willing to roll with the punches and juggle her hats, all in service to the 1 in 100 children and adults living with Tourette Syndrome.

Thank you Marty!

NJCTS 2020 Staff



Faith Rice
Executive Director



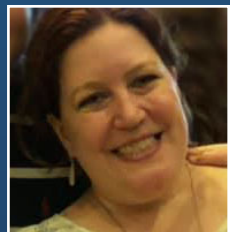
Patricia Phillips
Associate Director,
Program Development
and Outreach



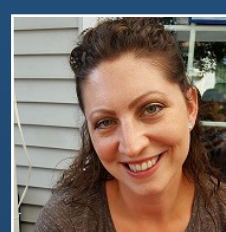
Santina Reichenbach
Finance & Human
Resource Director



Barbara Chabner, Psy. D
Program Manager



Doreen Pustizzi
Communications
Manager



Lisa Augliera
Youth Development
Coordinator



Kelley Teabo
Project Coordinator



Christine Whorton
Medical Outreach
Coordinator



Marty Butterfield
Webinar & Volunteer
Coordinator



Daryl Ball
Finance & Data
Management



Brianna Burkert
Communications &
Development Associate



Claudia Lijo
Outreach
Coordinator

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 GREAT**TS**.



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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.

Supported by:



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