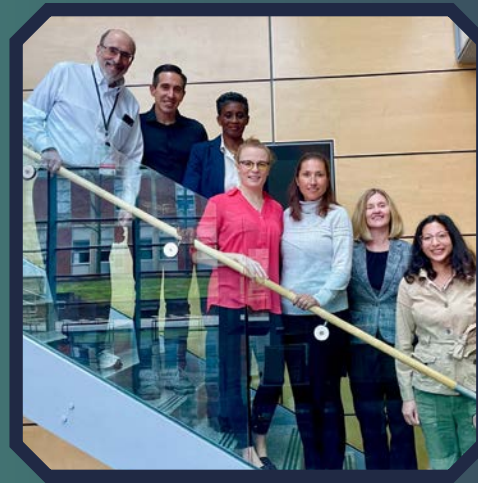


2023 Year in Review





YEAR IN REVIEW 2023

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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

In March of 2024, we unexpectedly lost our Executive Director, Patricia Phillips. This publication was already set to be printed, and we wanted to share her latest letter with the NJCTS community and supporters. She was excited about celebrating our 20th anniversary and proud of all that we had accomplished in the last year.



Welcome

January 2024

2023 was an exciting year for NJCTS as we engaged with more families, and provided new programming and in person events, from our Teen/Parent Summit and Family Retreat Weekend to our Family Fun Day at the Oasis Family Farm. It was a great opportunity to connect families with others living with Tourette Syndrome. Many times at these gatherings it is the first time a child meets someone else who has Tourette Syndrome. These moments of connection are priceless and life altering. NJCTS will continue to provide these opportunities for our families and strengthen the bond within the TS community.

Education and advocacy are also critical to the work we do. NJCTS was able to educate over 1000 teaching and medical professionals and present to over 3,000 youth about Tourette Syndrome. Our advocacy and outreach extended to diverse communities. University Hospital in Newark, New Jersey acknowledged June 4 as Tourette Syndrome Awareness Day with a proclamation from the Newark Municipal Council.

The NJCTS Youth Council and Youth Advocates are leading the way in increasing awareness of Tourette Syndrome. They have launched social media campaigns, presented at schools and in their communities, and even spoken before legislators in advocating for the TS community. We are very proud of these young people as they take charge despite the challenges they face living with Tourette Syndrome.

We have developed programming to meet the needs of adults 21 and over. There is so much that needs to be done to support this population. Community Connections for Young Adults meets in person and virtually to discuss issues pertinent to this adult group of

young professionals. Topics range from relationships to building financial security.

NJCTS is also proud to announce the launch of our first podcast, The UpTIC! The podcast allows NJCTS to increase awareness and outreach to new audiences! The UpTIC is a podcast that provides an opportunity for the eclectic voices of the TS community to be heard. The topics covered are as diverse as this neurodivergent population. Listeners will hear personal stories, learn more about Tourette Syndrome, and be inspired to live fully. Wherever someone is on their TS journey, the UpTic will inform and engage listeners and offer new insights and perspectives for self-reflection and action.

In 2023, we also held our first fall event at The Center for Contemporary Arts for donors, partners, and families. It was a unique opportunity to learn more about NJCTS programs and services, and hear from the scientists at Rutgers about the latest research innovations.

NJCTS is looking forward to the new year with a commitment to providing more programming for adults and children, additional outreach to diverse communities, investment in research, and new opportunities for engaging the TS community.

Patricia Phillips

Patricia Phillips

Executive Director

Celebrating 20 Years of Education, Advocacy, and Research

NJ Center for Tourette Syndrome and Associated Disorders is celebrating our 20th anniversary of serving the Tourette Syndrome community! Founded in 2004 by Faith Rice, the center has not only provided a myriad of programs and services to support the many needs of the TS community, it has also provided hope for a future of better treatments and a cure.

Through numerous collaborations and partnerships, NJCTS developed one-of-a-kind programs on behalf of the TS community regionally and worldwide. It established the world's first Cell & DNA Sharing Repository with Rutgers University, worked with New Jersey legislators to draft and introduce the first federal legislation for Tourette Syndrome, founded the TS Clinic and doctoral training program at Rutgers, and pioneered the patient-centered medical grand rounds training in hospitals presented by professionals and youth affected by the disorder.

Students, educators and parents have benefited from the School In-Service Program. Presenters have also brought educational programming to the classroom, hospitals, community organizations, law enforcement, and underserved communities. Families have found camaraderie at the annual Family Retreat Weekend and through NJ Walks for TS events. Many kids and teens have been through various youth development programs including the Tim Howard Leadership Academy.

Accomplishments of the last five years:

- NJCTS created a Youth Council where youth, age 13 to 18, can share information and ideas and discuss relevant topics inherent to the TS and tic disorder community. The council takes the lead on the Teen and Parent Summit, participates in fundraising efforts during the NJ Walks for TS campaign, and creates and develops ways for increasing awareness and furthering the mission of NJCTS.
- The pandemic created a need for online connections in the TS community. From initial online programming grew both a monthly family support group, led by a psychologist specializing in TS, and a young adult networking group that meets regularly online and in person.
- A podcast titled The UpTIC was created to explore topics that are important to the TS community, especially the young adult population.
- To compliment the free, professional webinar series that NJCTS hosts each month, NJCTS created an interactive online series called Tourette Talk allowing parents, educators, and those with TS to hear from experts in their field.

To celebrate 20 years, NJCTS is planning events throughout the year, including an October gala, appropriately named "Keeping the Faith," in honor of the organization's founder and past Executive Director.



2023 NJCTS Impact

More than 3,000 elementary and middle school students were reached by an NJCTS Youth Advocate.

Over 100 events hosted or attended, including education, awareness, family, and youth development events.

More than 900 attended online professional webinars.

193,500 website page visits and more than 300,000 social media impressions.

Nearly 700 teachers, staff, and school administrators participated in an educational In-Service.

More than \$10,000 in college scholarships awarded to students with TS.

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

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.

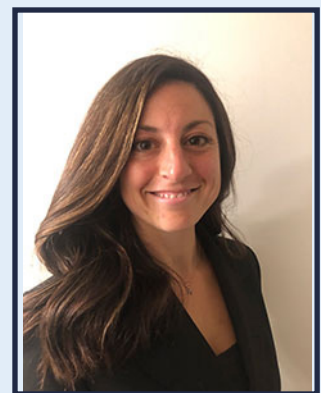
The NJCTS Tourette Syndrome Practicum and Clinic provides:

- Individual, family, and group therapy
- Cognitive-behavioral therapy
- Habit reversal therapy
- Social skills development sessions
- Referrals to physicians and testing services

2022-2023 TSC Doctoral Student Clinicians

Morgan Iskovitz
Allegra Gold
Ayomitunde Adebawale
Ellen Wilkinson

Sherrickah Thigpen Hayes
Jinmu Meng
Hui Jiang



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, autism, and depression.

Medical professionals in the NJCTS Physicians Referral List include:

- Neurologists
- Psychiatrists
- Psychologists
- CBIT Practitioners

Collaboration Creates More Opportunities for Families



**HASSENFELD
CHILDREN'S
HOSPITAL
AT NYU LANGONE**

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

RUTGERS

Graduate School of Applied
and Professional Psychology

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

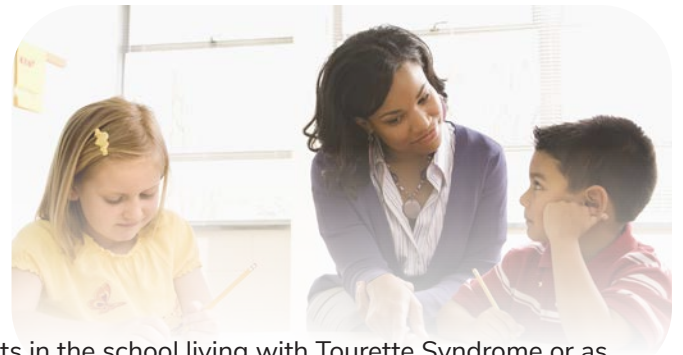
These presentations can be provided on behalf of students in the school living with Tourette Syndrome or as part of a more general anti-bullying effort. Students gain an in-depth understanding of TS and associated disorders. (see more under Youth Development)

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, Tourette Talk presentations are held each year about managing your child's education plan.





Virtual Family 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.

2023 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.



- Stress, Children, and Relationships
- Are IEPs and 504s on Your Back to School List
- Cultivating Calm: Principles in the Treatment and Management of Anxiety
- Just for Dads
- Navigating School Accommodations and 504 Plans for Children with Tourette's and Other Tic Disorders
- Navigating Social Stresses
- Autism Across The Gender Gap
- Reclaiming Cognitive Resources Lost to Social Stigma
- Taking Control of Your Financial Future
- Talking About Our Tourettes: adults 30 and over
- Ensuring Success of Neurodivergent Students in the Classroom

Community Connections for Adults With TS



Adults 21+ with TS are invited to come together to build community and connect with others navigating both the TS journey and adulthood. At Community Connections, participants can comfortably discuss experiences, share advice, and build relationships with those who understand their unique challenges. The group meets once a month, in-person or virtually, 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.

Teen & Parent Summit

Held at the Environmental Education Center in Basking Ridge, the Teen & Parent Summit includes separate, targeted programming for both parents and their teens. Parents have the opportunity to hear from and engage with other parents who are raising young adults with TS, talk to professionals who specialize in the treatment of TS, and chat with young adults in the workforce with TS to hear what was most valuable in helping them achieve success. Teens participate in activities to build confidence and form connections with their peers, chat with young adults who recently graduated high school to hear what the transition to college or the workforce is like, and hear from other teens with experience in advocating for themselves and others.



Family Events

Camp FantasTIC 2023

Camp FantasTIC, a family retreat weekend, was held at Black Rock Retreat in Pennsylvania. Several families joined NJCTS staff for fun activities, campfires, water games, and the opportunity to make forever friendships. Groups got together with a Camp Buddy, former Youth Advocates that now serve as mentors, while parents had time to talk and enjoy time with other adults.



Family Fun Day at Oasis Farm



“We attended Camp FantasTIC. What an amazing experience! There was swimming, archery, campfire s’mores, and tons of other activities. I even met older kids with very noticeable tics, doing amazing things in life. I felt such a sense of belonging and hope. THESE ARE MY PEOPLE. MY COMMUNITY.”
- Dylan Straley



Night at the Somerset Patriots

NJCTS was able to host the families that generously gave up their time to take part in our new outreach videos and our top NJ Walks for TS fundraisers in a suite at a Somerset Patriots game. The suite was generously donated by the Somerset County Board of County Commissioners. The group even had the opportunity to meet baseball great Sparky Lyle!

Scholarship

NJCTS Scholarship Awards have been given to more than 300 outstanding high school seniors in New Jersey who have excelled in their schools and communities. In 2023, 16 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing themselves as outstanding advocates for Tourette Syndrome.

Faith W. Rice Memorial Scholarship

Tess Kowalski - Rutgers University



Tess Kowalski, a Rutgers graduate student studying neuroscience, was awarded the Faith W. Rice Memorial Scholarship, named after NJCTS founder and former executive director.

Tess is pursuing a Ph.D. at Rutgers and is already working with top researchers in Dr. Max Tischfield's lab where she studies the underlying neuropathology of Tourette Syndrome. The work is personal to her as Kowalski, and her sister Paige, were both diagnosed with Tourette Syndrome as children. When she was 12, she started volunteering with NJCTS as a Youth Advocate. In that role she visited elementary and middle schools and spoke to the students about living with TS and why it's important to be accepting of others' differences.

"As an awkward 6th grader who was struggling with my disorder and the acceptance from others, seeing Tess on the stage speaking her mind truly inspired me," said Kyle Swords, a Youth Advocate himself. "The days after her presentation

felt different. I not only felt accepted by others, but almost felt cool in my own way."

Kowalski also spoke to healthcare professionals and community groups and met with legislators to advocate for NJCTS and the TS community. As she got older, she became a mentor to other teens with TS, including her sister. She would sit on panels and answer questions during the NJCTS Family Retreat each year, she chaired a fundraising walk in Princeton, and participated in the Tim Howard Leadership Academy.

"Our founder, Faith Rice, was well-known for her commitment to advocating and educating others about TS and Tess has followed in her footsteps," said Patricia Phillips, Executive Director of NJCTS. "She has made a difference in the lives of so many children with TS through her advocacy and now she is on track to impact the TS community through her life's work. We congratulate and thank her."



FIRST PLACE



Caitlin Fritz

Caitlin was an honor student at Immaculate Heart Academy in Washington Township, where she participated on the student council, the math league, and junior varsity spring and winter track and field. As a member of the National Honor Society, she tutored other students. She volunteered with children and adults with disabilities, and at the oncology department at Holy Name Medical Center.

Caitlin will be attending Case Western University as she prepares for a career in medicine.



Caroline Nieto

Caroline excelled in the arts as an honor student at Kinnelon High School. Caroline was a member of the National Music, Math, Spanish, Science, Social Studies, and English Honor Societies. She performed at the Paper Mill Playhouse and her School Theater, and part of the New Jersey All-State Honor Chorus and All-National Mixed Chorus. She also found time to volunteer for special education students, the American Cancer Society, and the Gay-Straight Alliance, to name a few.

Caroline will be attending Columbia University .

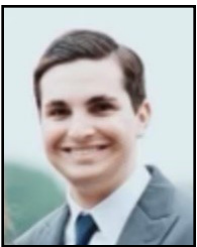


Parker Swift

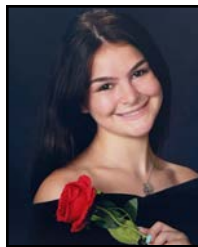
Parker was a varsity soccer and tennis player at Millville High School, while he attended Cumberland County Technical Education Center. He was also school ambassador, a member of the Youth to Youth Club and a volunteer at First United Methodist Church, Delanco Camp and Union Lake Sailing and Tennis Club. He also interned at a local broadcasting company while maintaining straight As as a member of the National Honor Society.

Parker will be attending Montclair State University.

SECOND PLACE



Francesco Coffaro



Madelyn Golden



Joshua Hinman



Van Nostrand



Kyle Swords



Fatima Villagran

HONORABLE MENTIONS

Cesar Arana - Ethan Bassett - Delaney Eskow - Jason Frolich - Mollie Mars - Jaiden Mendez - Jack Rochind

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 late November or early December each year.

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.

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! Event takes place during the first quarter of the year.

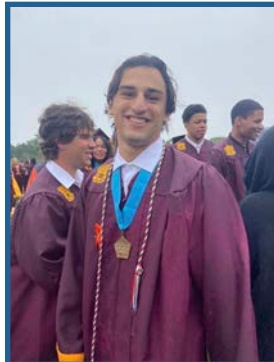


NJCTS Youth Council

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 communication 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.

Graduating Youth Advocates



CONGRATULATIONS to our NJCTS Youth Advocates who graduated in 2023.

**Mateo Acevedo
Mollie Mars
Demetrio Lukaitis
Kyle Swords**

Academy Celebrates 10 Years!

High school students learned about advocacy, self-leadership, and resilience from professionals and mentors as NJ Center for Tourette Syndrome and Associated Disorders (NJCTS) conducted their tenth Tim Howard Leadership Academy on the Busch Campus of Rutgers University in Piscataway, NJ on August 3 to 6.

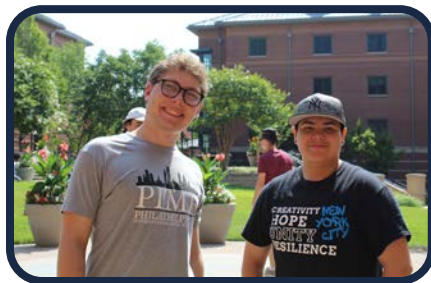
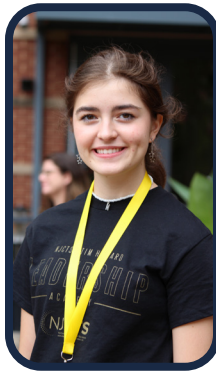
Created in 2014 in partnership with former professional soccer player, current broadcaster, and Tourette Syndrome (TS) advocate, Tim Howard, the Academy is the only leadership program for teens diagnosed with TS in the nation. The 19 teens who participated this year represented seven states and Canada.

Over the course of their four days on campus, when the participants were not interacting

with doctors, psychologists, and other experts in the field to learn more about their TS, they had the opportunity to form connections with new friends through small group activities like scavenger hunts, vision board creation, and friendly games of kickball in the quad.

On Saturday, Sampled Labs provided a tour of the new home of the NJCTS Cell and DNA Repository and the group learned about the latest advances in TS research from Dr. Jay Tischfield of Rutgers and the TIC Genetics Research project. On Sunday, before things wrapped up for the weekend, Tim Howard participated in a Zoom Q&A with the teens and talked about the importance of telling their own story.





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.

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.



School Youth Advocate Presentations

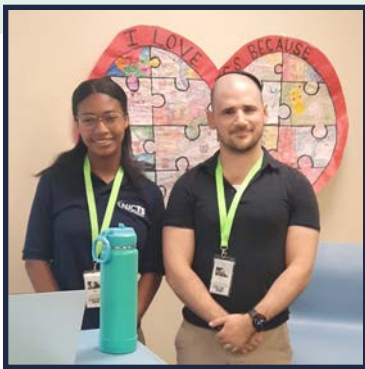
Classrooms and organizations across New Jersey gain invaluable perspective about life with Tourette Syndrome from NJCTS Youth Advocates. The Youth Advocate program provides teens and young adults—who are 13- to 18-year-olds and either have a diagnosis of TS or live with a family member with TS—with opportunities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

Since the program began, NJCTS Youth Advocates have conducted more than 600 presentations to individual audiences as large as 800 students, raising awareness, standing up to bullying, and increasing understanding of this often-misunderstood disorder.



2023 School In-Services were conducted at the following schools:

- Central School
- Pennsauken School District
- Cornerstone Day School
- Thomas Jefferson Middle School - Edison Public Schools
- Holland Brook School
- Forest Avenue School
- Ridgewood Avenue School
- Franklin Township Elementary School
- The Center School
- Harmony Twp Schools
- Central Elementary School
- Cornerstone Day School
- Monroe Township School District
- Sandshore Elementary School
- Green Grove School
- Horace Mann Community School
- Livingston High School



Presenters for Faculty In-Services:

- Lisa Augliera
- Claudia Lijo
- Dr. Tracy Lederman
- Dr. Meir Flancbaum
- Andrew Brandon
- Dr. Marla Deibler
- Dr. Jeremy Litchman
- Cheryl Ludwig
- Dr. Michelle Miller



YA Presenters for Faculty In-Services:

- Shylah Ghales
- Anna Claire Sems
- Jordan Fleishman
- Gavin Kiley
- Paige Kowalski
- Sofia Trabilcy
- Colin Deibler
- Reina Smith
- Peter Frantz Pendell
- Ari Bramson



Schools Our Youth Advocates Presented For in 2023:

- Walter Hill School
- Ridgewood Avenue School
- Franklin Elementary School
- John F. Kennedy Memorial High School
- Centre City Elementary School
- J. Mason Tomlin School
- Harmony Twp Schools
- Cornerstone Day School
- Ridgewood Avenue School
- Sandshore Elementary School
- Green Grove School
- Resurrection Catholic School
- Waterford Elementary School
- Kenneth Olson Middle School

Youth Advocate Presenters:

- Peter Frantz Pendell
- Kyle Swords
- Sam Regen
- Reina Smith
- Paige Kowalski
- Gavin Kiley
- Colin Deibler
- Jordan Fleishman
- Madaline Turula



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.

2023 Community Presentations

- CJSJA-Central Jersey Speech & Hearing Ass'n
- Middlesex County Office of Human Resources
- Generations Success Center

2023 Community Presenters:

- Cheryl Ludwig
- Dr. Tracy Lederman
- Claudia Lijo
- Dr. Eric Deibler

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.



2023 Law Enforcement In-Service

- Middlesex County Prosecutor's Office Police Training Center - CIT
- Bergen County CIT Training Center
- Union County CIT Police Training Center

Presenters:

- Claudia Lijo
- Dr. Richard Gallagher
- Dr. Michelle Miller

Youth Advocate Presenters:

- Peter Frantz Pendell
- Liane Sturrock
- Sarah Freeman
- Sofia Trabilcy

Conferences

2023 Conferences Attended by NJCTS

- Mount Laurel Township Schools - 2023 Mount Laurel Special Needs Resource Fair
- NJSSNA Spring 2023 Conference
- Brick Township School District 13th Annual Transition Fair
- Oldman's Township School District Resource Fair
- LDANJ 2023 Transitions & Beyond Conference
- Black Health Matters Conference
- NJAAP Annual Conference
- Cumberland County Children's Inter-Agency Coordinating Council (Ciacc) Conference
- 32nd Annual Connecting Resources to Communities Conference
- NJECC Agency Representation at Moorestown School District Health Fair
- New Jersey School Counselor Association Conference
- Rowan University-5th Annual Fresh Check Day
- NJAAP School Health Conference
- October Disability Awareness - Office of Disability Services at Ocean County College
- NJ Education Association - NJEA Conference
- NJPPC Dinner and Resources Event



New Jersey Chapter

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American Academy of Pediatrics
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Dare to Dream



NJCTS Youth Advocates Colin Deibler and Maria Sooy delivered keynotes at the 2023 NJ Department of Education Dare to Dream conferences at Rowan and Stockton University.

Dare to Dream is a positive and empowering experience that highlights strategies to promote self-advocacy skills for middle and high school students with disabilities. Each conference features keynote presentations from accomplished students from across the state.

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 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.



2023 Grand Round & Medical Presentations:

- Rutgers New Jersey Medical School
- Newark Beth Israel Medical Center
- Robert Wood Johnson Behavioral Health Community Medical Center
- Hackensack University Medical Center
- Morristown Medical Center

Presenters:

- Dr. Marla Deibler
- Dr. Meir Flancbaum
- Dr. Graham Hartke
- Dr. Jeremy Lichtman

Youth Advocate Presenters:

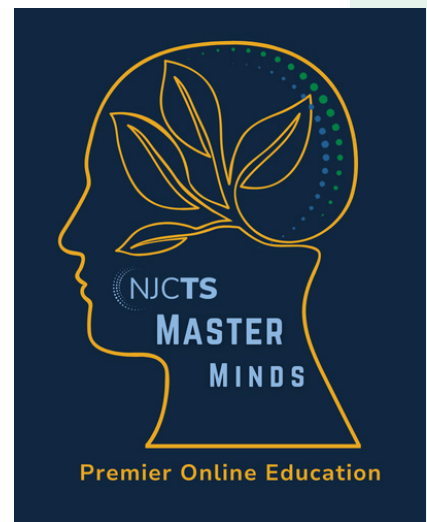
- Shylah Ghales
- Savannah Porter
- Jordan Fleishman
- Sarah Freeman



Webinars

NJCTS' free Wednesday Webinar series has been renamed into NJCTS MasterMinds, which are premier, online educational webinars conducted by professionals working in the field. New name but same great resource for educators, health care professionals, and parents alike.

Since 2008, NJCTS has hosted more than 150 webinars. All webinars are available to watch for free on the NJCTS website and YouTube channel. They have been viewed tens of thousands of times.



2023 MasterMinds Webinars

Identifying & Supporting Children with Anxiety and OCD in the Classroom

Presented by Devora Scher, Psy.D. from Central Therapy

Introduction to Transition Services

Presented by Melissa Zeidler, Managing Attorney of the Community Inclusion Team at Disability Rights NJ and Janna Sheiman, Managing Attorney of the Employment Team at Disability Rights NJ

Sensory Processing Disorder (SPD): When Everything Is Too Much

Presented by Felicia Castagna, MS, OTR/L, C/NDT, CKPT, CBIS, SIPT

Stop Making That Sound! Understanding Misophonia

Presented by Marla Deibler, PsyD, Executive Director of The Center for Emotional Health of Greater Philadelphia

Understanding & Treating Scrupulosity OCD

Presented by Ferdinando Palumbo, MSW, LCSW

Applied Behavior Analysis Therapy: Creating Habits That Stick

Presented by Jilian DeTiberis, M.A., BCBA, Clinical Director for Graham Behavioral Services

CBIT: Journey to Tic Relief

Presented by Meir Flanbaum, PsyD, Center for Cognitive Behavioral Therapy

Parenting Skills For The Mental Health Aspects of Tourette Syndrome

Presented by Eric Deibler, M.S.Ed., Psy.D., Director of Psychoeducational Services of the Center for Emotional Health of Greater Philadelphia, Taylor Wilmer, Ph.D., InStride Clinical Director, and Lindsay Henderson, Clinical Child Psychologist & Clinical Director of Fort Health.

Trichotillomania: Letting Go of Your Hair

Presented by Anna Urbaniak, PsyD, Stress & Anxiety Services of NJ





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 Faith W. Rice Legacy Award Winner at a special luncheon at Maggiano's Little Italy in Bridgewater, NJ on Friday, June 2.



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.

2023 Health Care Professional of the Year

Dr. Naomi Lubar
Pediatric Neurologist
Hackensack Meridian Health

2023 Educator of the Year

Jennifer Wishnick
Matawan-Aberdeen Regional School District



Jennifer Wishnick receives her award from her student, Noah Santiago. Noah's parents nominated Ms. Wishnick.



Callum deQuevedo accepted the award for Dr. Lubar. She was nominated by Callum's family.

2023 Youth Advocate of the Year

Kyle Swords

Kyle was diagnosed with Tourette Syndrome at just five years old. As he got older, the tics got worse and so did the stares and comments from kids at school. But at 13 Kyle chose to embrace his Tourette. He said, "If I couldn't cure it, I felt that the least I could do was accept it and help others understand."

Kyle has been a NJCTS Youth Advocate for several years, presenting to peers, doctors, and teachers about what it means to live with this disorder. When Kyle is not advocating for TS, he is also a member of the Morris Catholic High School's drama club and theater programs, a student ambassador, and tutor.

"There was a time where I saw my Tourette's as a handicap, but now I must give it credit for making me the person I am," Kyle writes in his scholarship essay. "I am now proud to say, I have Tourette's."



Kyle with Youth Development Coordinator Lisa Augliera.

Faith W. Rice Legacy Award Presented to Cheryl Ludwig

NJCTS created the Faith W. Rice Legacy Award to honor someone who has gone above and beyond in education, advocacy or research. Someone who has enriched the lives of those in the Tourette Syndrome community while bringing an awareness of TS to a wider circle of educators and healthcare providers. The 2023 award was presented to Cheryl Ludwig.



Cheryl Ludwig is a licensed speech and language pathologist with over 45 years of experience working with special needs children. She is also not a stranger to the struggles of TS families. Her three children were all diagnosed with the disorder. When she learned that a newly created Tourette Syndrome advocacy group was creating a team to educate teachers throughout New Jersey, she jumped on board to help.

“Cheryl was tasked with educating the educators about Tourette Syndrome,” explained Pat Phillips, NJCTS Executive Director. “At the time, in the late 90s, there was a great deal of stigma associated with having TS and educators were not equipped to support the students living with TS and the many associated disorders.”



Under the leadership of Faith Rice, this education outreach team presented 3-hour long workshops to teachers at community colleges across the state. Cheryl then helped develop faculty presentations so clinicians could go directly into Middle and Elementary schools. NJCTS uses many of the elements of her presentations when they go into schools today.

“There is not an NJCTS program that Cheryl or her influence has not touched,” said Pat. “Cheryl is a wealth of knowledge and resources, and we are grateful for her willingness to share.”

Cheryl has been involved in family retreats, the Tim Howard Leadership Academy, and Parent and Youth Summits giving practical advice to the teens about transitioning from high school to college and helping their parents to let them go.

“She has walked the walk and talked the talk, and she’s always happy to share any knowledge she’s gained from her own journey as a parent to three children with TS,” said Melissa Fowler, NJCTS Leadership Academy Director. “She has inspired in me commitment to ensuring children—and their parents—don’t merely survive the difficult years with TS, but grow and thrive. She is passionately committed to seeing every child succeed.”



Congratulations Cheryl!

NJ Walks for TS



Sarah Freeman with her mom at a Newark awareness event.

In Spring of 2023, 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.

The NJCTS Youth Council, led by Sarah Freeman, Peter Franz Pendell, and Hannah Horner, helped push the campaign past the \$50,000 goal!

Sponsors



Members of the Architectura team, led by Dean and Bond Roncati

2023 Top 5 Captains

1. Dean & Bond Roncati
2. Tim Yingling
3. Sarah Freeman
4. Sofia Trabilcy
5. Peter Frantz Pendell

Advocates in Action

Former NJCTS Youth Advocate and The George Washington University student Jatin Nayyar says boxing is “a liberating way to tackle the challenges of living with Tourette syndrome” as he continues his journey as a TS and mental health advocate. Jatin was featured in his university’s magazine and on Washington DC’s NBC affiliate evening news.



Fresno Grizzlies pitcher Connor Staine was selected by Minor League Baseball as the California League Pitcher of the Week for May 8 - 14. Connor was a high school and college stand-out in New Jersey. He was also a NJCTS advocate and scholarship winner. He was drafted by the Colorado Rockies of MLB in 2022.

He said his goal is to start a foundation to help others like him. He wants to show others like him that they can do things like become a professional pitcher and that just because they have Tourette doesn't mean they can't still go out and chase their dreams.

Youth Advocate Sarah Freeman shared her Tourette Syndrome journey during a very special TS awareness event at University Hospital in Newark. Presenting at the event were Dr. Onajovwe Fofah, Chair of Pediatrics at Rutgers New Jersey Medical School, Lisa Augliera of NJCTS, and Newark Council President LaMonica McIver, who officially designated the day for Tourette Syndrome Awareness in the city of Newark. A special thank you to University Hospital's Board Chair (and Sarah's amazing mom) Tanya Freeman for making this all possible!





Peter Frantz Pendell, a member of the NJCTS Youth Council, welcomed everyone to a special donor event at the Center for Contemporary Art in October. After a moving speech about living with TS, he mingled with the other guests to talk about the importance of NJCTS.



Families Participate in New Outreach Videos

Grey Sky Films has produced a new series of videos to promote the impact NJCTS has had on families. Three families – the Straley’s, the Ordonez-Coronado’s, and the Delaney’s – sat down with us to discuss their journey with Tourette Syndrome and how they found NJ Center for Tourette Syndrome.

From the family retreat and other special events to school presentations and advocacy training, NJCTS brings the TS community together and helps them navigate their social, educational, and medical challenges. As young Armani says, NJCTS is his “safe place.”

The videos are available on our website and YouTube channel.



NJCTS | Support

Our Corporate, Foundation, & Community Partners

\$5,000 +



The Willis and Nancy King Foundation

\$2,500 - \$4,999



BANK OF AMERICA

Johnson & Johnson

George W. Bauer
Family Foundation

\$1,000 - \$2,499



J. Fletcher Creamer Foundation

\$250 - \$999

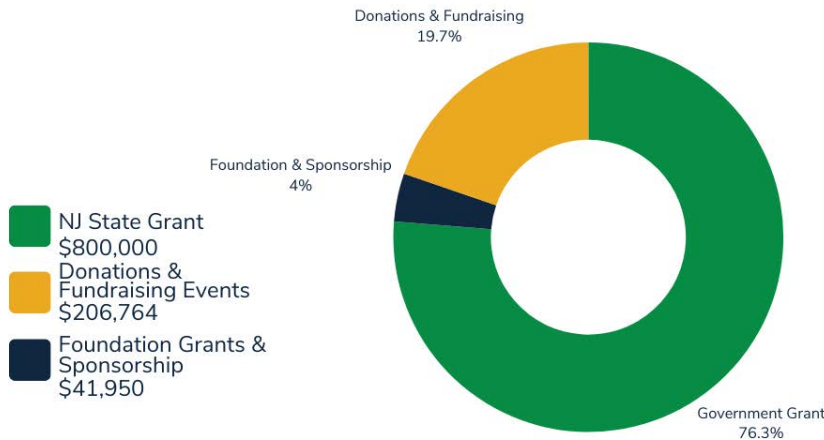
Unity Bank
New Jersey Education Association
Flounder Brewing Co.
Investors Bank
NJ Manufacturers Insurance
CNY Group LLC

The Center for Emotional Health
Citizens Philanthropic Foundation, Inc.
AmazonSmile Foundation
Medford Lakes Lions Charities, Inc.
Dear Out, LLC
Victory Insurance Agency, LLC
CPA Architecture, LLC

Financial Review

Fiscal Year July 2022 - June 2023

Revenue



Donations and fundraising increased year-over-year to bring revenue over the \$1 million mark.

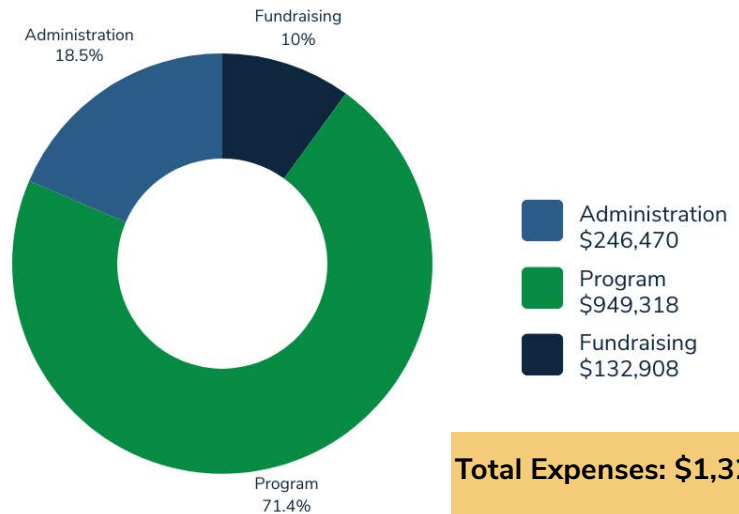
With the state of New Jersey's full support, NJCTS was able to maintain a strong financial position going into the second half of the year.

Total Revenue: \$1,048,714

Outreach to adults with Tourette Syndrome continued to be a priority as virtual and in-person networking opportunities grew. A new podcast was created for that demographic. Programs include awareness, medical and educational outreach, family programming, youth development, support of the TS clinic and the DNA repository, TIC Genetics research studies, and TS community support.

71% of every dollar spent during the 22/23 fiscal year went to the Tourette Syndrome community.

Expenses



Total Expenses: \$1,328,696



2023 GreaTS

Bonnie and Francis Costello
 Geri and Jeff Decicco
 The Deibler Family
 Lori DelVecchio
 Kelly and Arthur Femenella
 Alvin Garcia
 Deborah and Scott Gerbman
 Diana and Ken Griebell
 Andrew Hendry
 Mr. and Mrs. Wiliam Hoffman
 Linda and Wade Kirby
 Sarah and Jonathan Kiley
 Hilary and Victor Kruchowy
 Mr. and Mrs. Tim Omaggio
 The Frantz/Pendell Family
 Pat Phillips and Ardie Walser
 Tina and Brian Swords
 Cindy and Steve Yingling
 Caitee and Tim Yingling
 Justine Young

By contributing \$1,000 annually, you can join the ranks of The GreaTS and help sustain our programs, making them accessible to individuals with Tourette Syndrome. Your generosity can make a significant difference in ensuring children and adults with Tourette Syndrome and associated disorders are empowered and accepted through education, advocacy and research.

NJCTS shows gratitude to these generous donors through regular organizational and research updates and an annual reception.

Families Give Back

From online crowdfunding to matching gifts, our families find a way to support the efforts of NJCTS. Beyond financial support, they volunteer their time and skills, and are the number one cheerleaders for all that their kids do within the organization. And we cannot forget the families that volunteer to take part in research with our TIC Genetics partners. With you, there is no education, advocacy, or research.



Facebook Birthday Fundraisers

Heather Lynn
 John Dean
 Moriah Rosenblum
 James Rooney
 Arlene Murray

Michele Newman
 Lynn Persson
 Teri Neidich
 Viannie Glick
 Jamie Rivera

Jonathan Atwood
 Cristina Ordonez Coronado



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 RaiseRight to purchase gift cards

2023 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.

Anna Baldwin
Ari Bramson
Gerri DeCicco
Colin Deibler
Eric Deibler
Marla Deibler
Peyton Estabrook
Meir Flancbaum
Jordan Fleishman
Peter Frantz Pendell
Sarah Freeman
Caitlin Fritz
Shylah Gahles
Staci Greenwald
Andrew Hendry
Hannah Horner
Hui Jiang
Gavin Kiley
Paige Kowalski
Tim Kowalski
Sree Lakkamraju
Tracy Lederman
Jeffrey Lederman
Michael Leopold

Jeremy Lichtman
Steve Lindenbaum
Emily Liu
Cheryl Ludwig
Michelle Miller
Ray Nardella
Tim Omaggio
Ferdinando Palumbo
Savannah Porter
Katrina Reichenbach
Paul Romano
Conrad Roncati
AnnaClaire Sems
Reina Smith
Maria Sooy
Rebecca Spar
Lianne Sturrock
Kyle Swords
Azlen Theobald, PsyD
Sofia Trabilcy
Madaline Tarula
Donna Tischfield
Richard Gallagher
Ethan Winnegrad
Tim Yingling

Thank you!

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

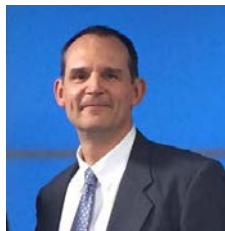
Board of Directors



Patricia Phillips
Executive Director



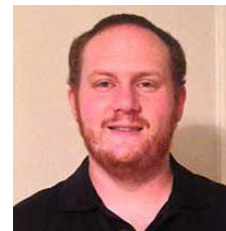
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Steven Lindenbaum
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Conrad Roncati



Tim Yingling



Tim Omaggio
Non-Officer
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Tim Howard
Honorary Member

Advisory Board



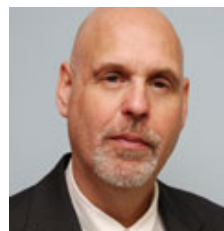
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Celgene Corporation
(retired)



Linda Brzustowicz, MD
Rutgers University
Dept. of Genetics



Lew Gantwerk, PhD
Former Executive
Director, Rutgers
GSAPP



Stuart Green, DMH
Director of NJ
Coalition for Bullying
Awareness &
Prevention



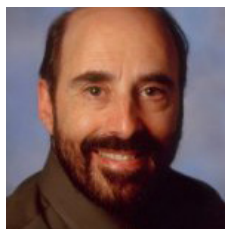
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Resource Director



Doreen Pustizzi
Communications
Manager



Hilary Kruchowy
Development Director



Lisa Augliera
Youth Development
Coordinator



Daryl Ball
Finance & Data
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Brianna Burkert
Communications &
Development Associate



Claudia Lijo
Education Outreach
Coordinator



Alina Lawas Osborn
Program Coordinator



Katie Delaney
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Outreach Coordinator



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



@njcts #njcts

Welcome to the UpTIC

The UpTIC is a podcast that provides an opportunity for the eclectic voices of the TS community to be heard. The topics covered will be as diverse as this neurodivergent population. You will hear personal stories, learn more about Tourette Syndrome, and be inspired to live fully. Wherever you are on your TS journey, this podcast will inform and engage listeners and offer new insights and perspectives for self-reflection and action.

By listening to the UpTIC, it is our hope listeners will feel empowered and be able to enhance their lives in meaningful ways. The conversations will be frank and offer a wide range of views and observations that may be common or uncommon in the TS community. Everyone has a voice and the UpTIC will provide that platform for discussion that opens up the door for further conversations with friends, family, colleagues and others, well after an episode has ended.

Be part of the experience and tune into the UpTIC, if you want to stretch the boundaries of what is possible in your life.



About our host:



Michael Leopold is a career coach, human resources consultant, and public speaker. As founder and president of Leopold Talent Consulting, he offers comprehensive career consulting services to individuals and training programs to organizations. As a professional with Tourette syndrome and ADHD, he leverages his lived experiences to help organizations hire and retain neurodivergent talent. Michael has held progressive HR and consulting roles at Deloitte, Xerox, Two Sigma Investments, and Mercer.

For 15+ years, Michael has been an outspoken advocate for tic conditions and mental health. Originally from Indiana, Michael now lives in NYC where he supports local initiatives around career development, neurodiversity, TS awareness, and mental health advocacy. Since 2016, he has been a coach at the NJCTS Tim Howard Leadership Academy. Michael holds a B.S. in Cognitive Science from Yale University and a M.S. in Human Capital Management from Columbia University.

Listen on your favorite podcast platform or visit

www.njcts.org/uptic

Supported by:

