



Faith W. Rice
1943 - 2021

2021

YEAR IN
REVIEW



YEAR IN REVIEW 2021

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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.

Welcome

As we moved through the challenges of the health crisis last year, we remained strong and steadfast in serving the Tourette Syndrome community to provide high quality programs and services. We were able to engage with many families and supported them as they navigated various stages of their TS journey, and we learned from them the essence of true grit and resilience as they jumped over many hurdles. It is truly the strength of this community that inspires us all at NJCTS to do the work we do.

Last year also brought many exciting changes, as we created new programming, including a new parent support group, Today's Challenge, Tomorrow's Strength, facilitated by Dr. Jeremy Lichtman, and for the first time, adult programming for ages 18-35. Community Connections for Young Adults with TS gives young adults an opportunity to share information and ideas and creates a space for open dialogue in an environment that is friendly and inclusive. Also important to this adult network, is the recently formed Facebook group, Tackling TS, which allows conversations to continue long after online sessions end.

Not only was NJCTS busy creating new programs but we also embarked on a new partnership with NYU Langone Child Study Center in Hackensack, NJ. Staffed by a team of advanced graduate students and supervised by physicians at NYU Langone, this collaboration gives NJCTS families another option for receiving comprehensive treatment at a significantly reduced rate.



Despite the prolonged pandemic, our outreach to schools, hospitals, law enforcement, and various communities across the state made a great impact touching over 800 professionals. We were also able to offer 40 different virtual events for families so everyone could stay informed and connected, and through our webinars, support groups, teen workshops and summits reached almost 3,000 attendees.

Many thanks to our youth advocates who used their voices in our compelling public service announcement to increase awareness and put a stop to TS stereotypes. (If you haven't viewed them yet, please take a moment to do so!) The year 2022 looks bright and the possibilities are infinite. We are thankful for all of our families and friends, and their ongoing support. NJCTS continues to grow and remains strong even in the time of uncertainty. You can count on us to be there for you today, tomorrow and into the future.

Patricia Phillips

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

2021 Impact

More than 4,000 in attendance at 70 live virtual events, support groups and presentations

13,400 Reached via Webinars

97% Satisfaction Rate of Webinars

More than 190,000 Website Page Views

Nearly 250,000 Social Media Impressions

11,000 views on YouTube

Remembering Faith

Faith W. Rice, founder and past executive director of NJ Center for Tourette Syndrome and Associated Disorders, passed away on March 22, 2021.

Faith became a Tourette Syndrome advocate when her son Kim began exhibiting signs of the disorder as a child. It took 10 years to get a diagnosis but even with that information she found that there were no resources for her son – few knowledgeable doctors, no family support and no network. Leaving her full time job at IBM, she set out to bring about change for her son, and for others facing a TS diagnosis.

Her journey to create quality programming for families living with TS and to bring awareness to the disorder led to the state of New Jersey funding her vision and, in 2004, establishing NJCTS – the nation's first Center of Excellence for Tourette Syndrome.

Under Faith's leadership, NJCTS trained tens of thousands of educators and medical professionals about Tourette Syndrome and its common associated disorders. She created a Youth Advocate program so children and teens with TS could learn how to advocate for themselves and others. In partnership with Rutgers, she created the NJCTS Tourette Syndrome Clinic and, perhaps her greatest legacy, the NJCTS Cell & DNA Sharing Repository which has propelled TS research forward in remarkable ways.

With as many as 1 in 100 individuals living with a TS or a chronic tic disorder, there is still much work to be done to raise awareness and decrease the stigma associated with TS. But from recruiting clinicians to go into schools and hospitals to educate professionals 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 led the way.

What families will remember the most about Faith will be the empathetic voice on the other end of the phone, her passion to advocate for them or their kids, and the unwavering support she gave them that she couldn't find all those years ago.

Faith is survived by husband Mike, her son Kim, and an army of Tourette Syndrome advocates around the world.



Looking Forward

Our Vision:

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

Our Values:

*F*orward Thinking

An innovative approach to managing all areas of the business

*A*ccepting

Creating a community where people with TS are accepted

*I*nspiring

Empowering those with TS to self-advocate

*T*ransformative

Changing the lives of those affected by the disorder

*H*olistic

Looking beyond the TS and seeing the whole person

"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."

Faith Rice

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 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 2021, 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.



NJCTS

Family Support

Physician Referral List

NJCTS maintains a Physician Referral List comprised of more than 200 medical professionals who have expertise in treating Tourette Syndrome and associated disorders. The list is compiled from interviews with clinicians and recommendations from our members as well as other clinicians. It is a direct link for families to medical professionals across the region with expertise in TS, ADHD, OCD, anxiety, and depression.

Medical professionals in the NJCTS Physicians Referral List include:

- Neurologists
- Psychiatrists
- Psychologists
- Social Workers



New Collaboration Creates More Opportunities for Families

NJCTS and NYU Langone Health's Child Study Center designed a program to provide increased education, support, and treatment options to families affected by TS in New Jersey.

This collaboration allows families to receive services provided through a graduate student training externship located at the Child Study Center's Hackensack, NJ office. Services, including CBIT, treatment for associated disorders, and neuropsychological evaluations, are offered at a significantly reduced rate. Learn more: www.njcts.org/nyu

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 2021, NJCTS continued to increase family engagement through online programming including two Parent Summits and a new parent support group called Today's Challenge, Tomorrow's Strength featuring Dr. Jeremy Lichtman.



Camp FantastIC Provides Laughs

The 2021 Camp FantastIC was a fun-filled day of exploring the creative arts, games, parent sessions, entertainment and a variety of activities including baking with Kelley, crafts with Arts Horizon, and learning magic with Jason Michaels. In the evening families had the opportunity to try their luck in one of our escape rooms.

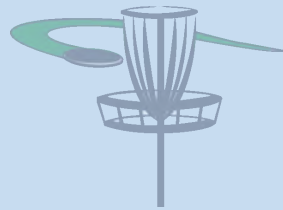
Special guest Pamela Schuller, a comedian, motivational speaker, and advocate, told stories of growing up in a body she had no control over and fun accounts of her life living in New York City.

As much fun as we had online, NJCTS is looking forward to an in-person camp in 2022!



New Fun and Games

In the fall, NJCTS families took part in a little friendly competition at Mercer County Park. The first annual **Disc Golf Tournament** was a wonderful opportunity to get together in-person, catch-up, and meet new friends. No Disc Golf experience was necessary but volunteers from Two Johns Productions were on hand to help run the tournament and give us some pointers. Be on the lookout for another tournament in 2022!



2021 Family Support Groups

- Ask the Doc: Tourette Syndrome and the COVID Vaccine
- Executive Function Skills: An Overview and Strategies for Success
- Stop Making that Noise: A Discussion of Misophonia
- Overcoming the Challenges of Living with TS as an Adult
- Transitioning Back To School In the Era of COVID 19
- Trichotillomania: What is it and how is it Treated?
- Understanding Selective Mutism as a Social Communication Anxiety Disorder
- The Genetics of TS and Saying "I Do"
- How can DVRS Work for You
- What's Going to Happen THIS Year? Easing the Anxiety
- Music Therapy

Youth Scholarship

Since 2001, the NJCTS Youth Scholarship Award has been given to more than 220 outstanding high school seniors in New Jersey who have excelled in their schools and communities. In 2021, 16 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing themselves as outstanding advocates for Tourette Syndrome.

FIRST PLACE



Jenna Smith – Scotch Plains

One of her teachers at Kent Place School once commented “I envision casting a ballot for her one day.” Jenna interned and volunteered at Congressman Tom Malinkowski’s office since 2018 and sat on his Youth Advisory Council. An incredibly accomplished student, Jenna has numerous writing awards under her belt, has competed in the Ethics Bowl and Mock Trial, and also competed in the American Legion Oratorical Scholarship Contest.

But it’s Jenna’s public service and advocacy that makes her stand out. She created an online community for youth with Tourette called “Talking TS.” She has spoken to numerous school-aged kids and adults as an NJCTS Youth Advocate and participated in videos about bullying, suicide prevention and TS awareness. As president of her school’s Community Service Committee, Jenna put together a list of resources for her fellow students to help them understand the Black Lives Matter movement and ways they could lend their support to the cause. Then three weeks into her senior year, she organized a voter registration push at school. Jenna is off to North Carolina where she will attend classes at both Duke and UNC.



Sam Regen – Robbinsville

The first recipient of the **Faith W. Rice Memorial Scholarship** is Sam Regen. A graduate of Robbinsville High School, Sam loves to advocate. If there was an opportunity to speak on behalf of NJCTS at a hospital or school, Sam would find a way to make it work and be there. He even jumped at the opportunity to address 3,000 at a concert at Six Flags Great Adventure. His involvement with NJCTS goes beyond presentations. He counted down the days until he could be part of the Tim Howard Leadership Academy. He frequently participates as a mentor for younger kids and volunteers at camp. In 2019, he won the Youth Achievement Award from the New Jersey Chapter of the American Academy of Pediatrics. He parlayed that into a spot on the Academy’s Youth Advisory Committee. Sam is also an accomplished musician. He is a percussionist for the Youth Orchestra of Central Jersey, was a member of the Music Honor Society, and participated in the school’s musical productions. Sam wants to be a teacher and began that new journey at The College of New Jersey. Sam’s school counselor sums it up best when she says, “Sam represents what is positive in this world and will make this world a brighter place.”

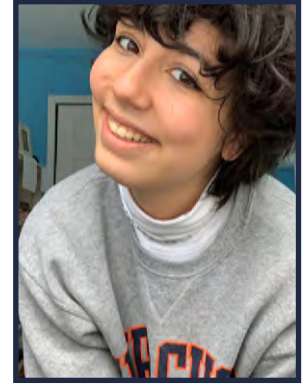
SECOND PLACE



Eric Jones
Millburn

Eric was described by one teacher as “a bright light” and by another as “a man with exceptional character.” His high school career included becoming varsity Tennis captain, volunteering at the food pantry, and working as a camp counselor, head umpire and tutor. He even started a Senior Citizen Support Club, matching volunteers to seniors that needed help with getting their driveway shoveled or solving technology problems.

Grace spent hundreds of hours volunteering during her time at Jefferson High School, where she finished fourth in her class. She is a Girl Scout Gold Award recipient, was a member of National Honor Society and the National Spanish, Social Studies, Math and Science Honor Societies. Her passion is filmmaking.



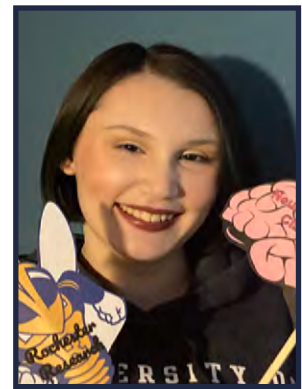
Grace Reed
Oak Ridge



Jordan Rullo
East Brunswick

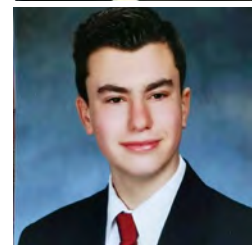
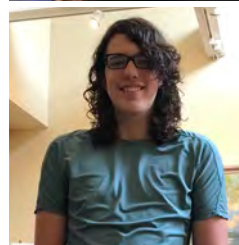
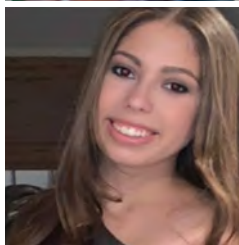
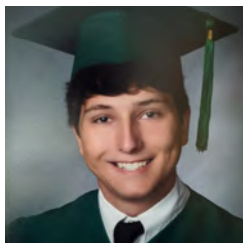
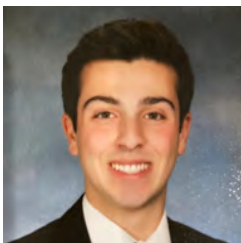
Jordan has a way with numbers, taking Honors Calculus and Honors Statistics his senior year with a plan of pursuing a career in Information Sciences, Statistics, or Business Analytics. His course load did not prevent him from volunteering with his high school Youth Council or being a member of the National Honor Society, Concert Band and the Track & Field team.

Natasha, the Valedictorian of her Middlesex High School Class, is also an accomplished musician, making first chair in the high school band with multiple instruments. She was a member of National Honor Society and Girls Who Code, and volunteered through the Key Club. Even before her TS diagnosis, her goal was to pursue a career in the field of Neuroscience.



Natasha Vacca
Middlesex

HONORABLE MENTIONS



Daniel Albanese
Eric Baldwin
Erin Gass
Julianna Gentilucci
Gavin Jackson

Paige Kowalski
Ethan Lehr
Emma Miller
Ryan Perrone
Matthew Stein



NJCTS | Youth Development

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 schools across the state to bring awareness to Tourette Syndrome with the hope of destigmatizing the disorder and prevent 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 events including advocacy trainings.

Blogging

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

June 4th Proclamation

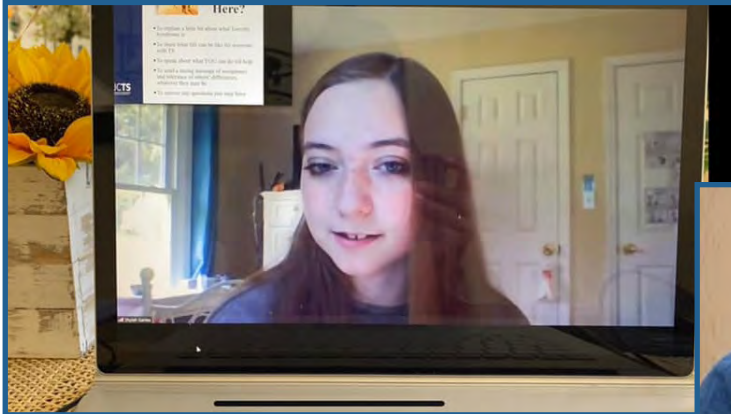
One of the ways we encourage our advocates to spread awareness is to request that their mayor make a TS Awareness Day proclamation. This will involve sending an email and/or making a phone call to the Mayor's office. Often when someone succeeds in getting a proclamation declared, there is the chance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

Event Involvement

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

Tim Howard Leadership Academy

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



Scholarship

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



Tim Howard Leadership Academy & Global Teen Summit

NJCTS hosted their second Global TS Teen Summit in January of 2021. The first session was “Navigating the Ups & Downs of COVID 19 & TS” and was followed by “Advocating for the Best in Your Relationships.” Both sessions featured discussions with a panel of young adults who shared their personal experiences with both topics.

We were grateful to have TS Advocate Britney Wolf for the final session about getting in high gear and ready to take charge, set goals and break through barriers in 2021.

The NJCTS Tim Howard Leadership Academy is designed to develop self-leadership, advocacy skills, and resilience in teens with Tourette Syndrome and its associated disorders.

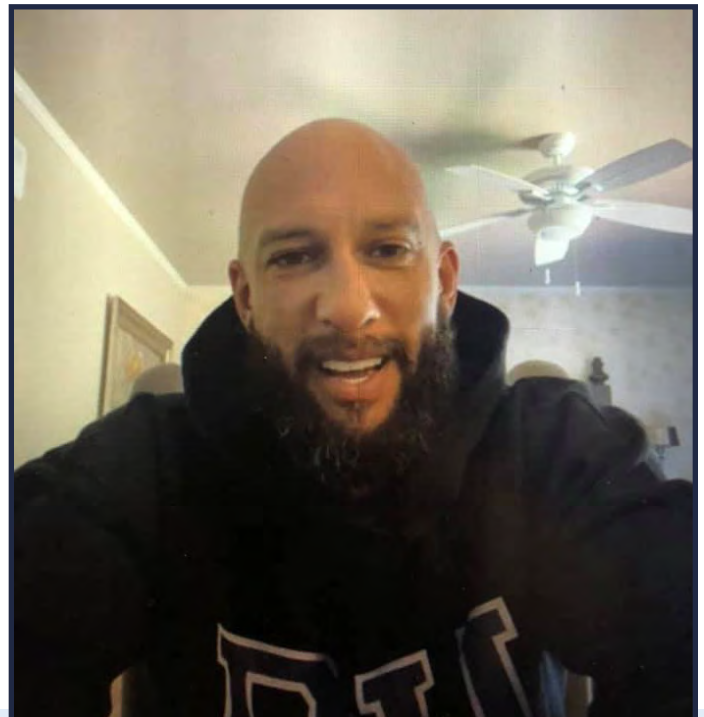
In its second year of being virtual, the Academy welcomed participants from seven states and the United Kingdom.

In addition to the presenters of each session, the teens heard from young adult mentors, or coaches, throughout the two days. Topics covered:

- TS and co-morbidities
- How tics impact one’s life
- Educating others and sharing your story
- Self-advocacy in school/ college
- How to deliver your message

Camp FantastTIC guest Pamela Schuller returned to tell her story, share some laughs, and lead a workshop on crafting your advocacy message. Motivational speaker Chad Juros told his story of survival and strength, wrapped into the entertainment of a virtual magic show.

US Soccer legend and broadcaster Tim Howard made his traditional appearance to speak to the participants about his journey and answer their questions.



Spotlight on Youth

Spotlight on Youth gave teens a chance to connect with new people, engage in conversation, and build their TS community! The sessions were meant to be fun and educational.

Sessions included:

- College Preparation
- Creating a TS Awareness Mural
- Back to the Books
- My TS is Not Your Excuse for Bad Behavior
- What Would YOU Do?
- Name That Tune!
- Vision Boards



Young Adult Support Group

Young adults with TS, age 18-35 were invited to come together to build community and connect with others navigating both the TS journey and adulthood. At the Community Connections for Young Adults Support Group, participants can comfortably discuss experiences, share advice, and build relationships with those who understand their unique challenges. The new group meets once a

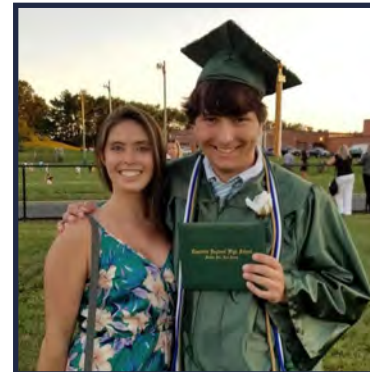


Graduating Youth Advocates

CONGRATULATIONS to our NJCTS Youth Advocates who graduated in 2021.

Eric Baldwin
Eric Jones
Paige Kowalski
Eliza Lederman

Grace Reed
Sam Regen
Jenna Smith





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.

2021 Faculty In-Services were conducted at the following schools:

- J. Mason Tomlin School
- Gloucester Board Of Education
- Hightstown High School
- Clarendon Elementary School
- Elisabeth Morrow School
- Hatikvah International Academy Charter School
- Livingston High School
- Morristown High School
- Mt. Olive Middle School
- Lincoln Elementary School
- Rutgers - NJ JCC
- Central Elementary School

Presenters for Faculty In-Services:

- Dr. Michelle Miller
- Tracy Lederman
- Carolyn Baldwin
- Dr. Marla Deibler
- Anton Shcherbakov
- Tracy Lederman
- Debra Park
- Karen Benjamin

YA Presenters for Faculty In-Services:

- Hallie Hoffman
- Eric Baldwin
- Mateo Acevedo
- Colin Deibler
- Kyle Swords



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 2021, 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.

2021 Community Presentations & Conferences

	Presenters for Community/ Workshops	Youth Advocates for Community/ Workshops
• “Straight Talk” Network Group		• Demetrio Loukaitis
• Unwine	• Dr. Barbara Chabner	• Jenna Smith
• NJCEC Council for Exceptional Children	• Patricia Phillips	• Mateo Acevedo
• Statewide Hispanic Chamber of Commerce	• Dr. Jeremy Litchman	
• Bergen Family Center	• Claudia Lijo	
	• Carolyn Balwin	

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 2021:

- Mantua Township Public Schools
- Glassboro School District
- Hatikvah International Academy Charter School
- Lincoln Elementary School

Youth Advocate Presenters:

- Sam Regen
- Eric Baldwin
- Shylah Gahles



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.

Grand Round Presenters:

Dr. Meir Flancbaum
Dr. Jeremy Lichtman
Dr. Michelle Miller
Dr. Rob Zambrano
Dr. Marla Deibler



2021 Grand Rounds Presentations

- SBMC -Pediatrics
- Children's Specialized Hospital
- Cooper University Hospital
- Rutgers - New Jersey Medical School
- St. Peter's University Hospital – Pediatrics

Training the Next Generation

Rutgers Graduate School of Applied and Professional Psychology In-Service

- Dr. Robert Zambrano
- Youth Advocate Kyle Swords

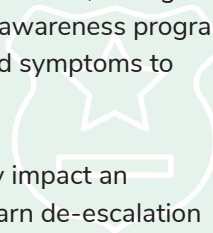
Rutgers - New Jersey Medical School In-Service

- Patricia Phillips
- Youth Advocate Colin 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.



2021 Law Enforcement In-Services

- Middlesex County Prosecutor's Office Police Training Center CIT

Presenters:

- Patricia Phillips
- Dr. Anton Shcherbakov
- Youth Advocate Kyla Butler
- Youth Advocate Colin Deibler

Webinars

In 2021, NJCTS presented eleven webinars that covered everything from mindfulness to the important work of play. This is in addition to the more than 130 webinars that are available in our online archive.

IEPs and 504 Plans: Navigating Special Education

Presented by Andrew Meltzer, Esq.

Special education attorney Andrew Meltzer will provide a comprehensive overview of special education in New Jersey. He will discuss the structure of the Individuals with Disabilities Education Act ("IDEA"), who is eligible, and how to go about securing an appropriate educational program for your child. Section 504 of the Rehabilitation Act.

Explosive Outbursts in Tourette Syndrome

Facilitated by: Cathy L. Budman, MD for NJCTS and the NJ Chapter of American Academy of Pediatrics

Explosive outbursts are common symptoms in both youth and adults with Tourette Syndrome (TS) and cause significant morbidity. This webinar will provide an updated overview for the participant.

A Neuroplasticity-Based Approach to Tics

Presented by Betsy Stroeber

It's well understood that tic disorders are neurological in nature and usually follow a common developmental course. Most often, this course leads to abatement of symptoms in adulthood, even in relatively severe childhood cases. What's behind the common course of tic disorders and what if we could speed the process up?

Mental Health in Media: Its Stigma and Stereotypes

Presented by Meg Isbitski, LCSW

We will discuss the inaccurate and harmful depictions of mental health in the media. There will be an explanation of how these depictions relate to stigma and perpetuating stereotypes from a personal and societal perspective and how this affects our ideas of experiences with mental health and how this can desensitize us to empathy, treatment, and reaching out. TS is generally misrepresented in the media, especially Coprolalia, the typical portrayal of TS. Also considered is the opposite end of the spectrum, the dangerous romanticization of mental health conditions.

Getting into the Weeds with Medical Marijuana

Presented by Svetlana (Lana) Ros, Esq.

Medical marijuana has been approved for the treatment of Tourette Syndrome. However, it is not always easy to understand how to navigate the process for acquiring medical marijuana or what to expect. Join this session as we discuss how the process works and what you need to know.

Trauma Informed Classroom

Presented by Bobbie Downs, Ed.D.

During this presentation, we will recognize the prevalence and realize the impact of Adverse

Childhood Experiences (ACEs) so that we can respond in a trauma-informed way and resist re-traumatization. We will explore the way that trauma can shape learning and behavior while also discussing strategies for mitigating the potential impact.

Nature Connection for Children's Mental Health

Presented by Cathy Jordan, Ph.D.

Over the last couple of generations, children have become increasingly disconnected from nature, with worrisome implications for their physical and mental health, cognitive development and educational outcomes. In this webinar we will take a deeper dive into how nature supports children's mental wellbeing including strengthened self-esteem and confidence, enhanced positive emotion and reduced negative emotion, stress reduction, restoration, social benefits, and resilience.

Important Work of Play

Presented by Colleen Daly Martinez, Ph.D., LCSW

Play is a necessary and valuable contributor to children's development. Unfortunately, in an atmosphere that prioritizes competition and achievement, play can become less of a priority.

When to Worry About Your Child's Worries

Presented by Jerry Bubrick, Ph.D.

Dr. Jerry Bubrick, Senior Psychologist, from the Child Mind Institute speaks about children's mental health, signs to look out for, what anxiety looks like in school, what parents can do, and when to get help.

Outgrowing the Child Neurologist: Transition in Tourette Syndrome

Presented by Lawrence W. Brown, MD

Adulthood may come naturally, but it takes years of preparation. There are many challenges and barriers facing adolescents with any neuropsychiatric disorder. But there are also practical solutions that can lead to optimal success for youth with Tourette syndrome.

Using Positive Psychology to Find More Happiness Everyday

Presented by Anton Shcherbakov, Psy.D, BCBA

Historically, the science of clinical psychology has focused on the treatment of mental illness. However, in the 1990s, psychologists began to study more deeply what actually makes us happy. They found that happiness is not the absence of depression or anxiety, but the cultivation of experiences that make life worth living. In this webinar, you will learn about the basic principles of positive psychology, foundational research in the field, and simple strategies you can apply to your everyday life to enhance feelings of well-being.

NJ Walks for TS

TS Awareness Day

Advocates in Action

Families Give Back



NJ Walks for TS

In Spring of 2021, NJCTS conducted the virtual NJ Walks for TS. Brand new team and sponsor, Smile More Dentistry, led by Tim Howard Leadership Academy Coach Amanda Silvers hit their goal by conducting a dance-a-thon.

On board this year were sponsors Dietz & Watson, Black Bear Brand Deli Meat, The Wawa Foundation, The Creamer Family Foundation The Center for Emotional Health of Greater Philadelphia, and Smile More Dentistry.



2021 Top 5 Virtual Walk Teams

1. Trabilcy Tackles Tourette
2. Marching with Mia
3. Smile More Dentistry
4. Team Jamo
5. Team Oliver



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

Dr. Kim Buxenbaum, Director of the Office of Special Education at the NJ Department of Education recognized our graduating Youth Advocates and NJ Assemblyman Dan Benson awarded our top scholarships. Senator Troy Singleton sent a pre-recorded message to our honorees.

Advocates in Action

NJCTS Advocates Call for a Stop to TS Stereotypes

It's not a joke. It's not a punchline. It's not an excuse. Those are the refrains from four Youth Advocates who live with Tourette Syndrome, a neurobiological disorder characterized by uncontrollable movements or vocalizations known as tics. The disorder is often portrayed in movies or TV as a joke, used by those with a platform as an excuse for misbehavior, or is faked on social media for attention.

"We felt it was time to make a statement about Tourette Syndrome and what it REALLY is," said NJ Center for Tourette Syndrome and Associated Disorders (NJCTS) Executive Director Patricia Phillips.



NJCTS created the series of PSAs with the help of production company Grey Sky Studios out of Rockaway. "In the last few years we have seen celebrities, politicians and even those in the news media use TS as a joke or an insult. Then there are those on social media who fake tics to get views and likes. Our kids and adults with TS deserve better than having people use a disorder they struggle with on a daily basis as fodder to gain laughs."

The participants in the PSAs have all been outspoken advocates for NJCTS who have given presentations to students, teachers, law enforcement, and medical professionals in the past as part of the organization's Youth Development program.

Jenna Smith of Scotch Plains believes more people need to be educated about TS. "One of the hardest things about having TS is feeling or being misunderstood," the Duke University freshman said. "If we can take the time to educate people, I think they would be more empathetic to the situation and less likely to use TS as the butt of a joke."

Jenna was joined by Dominic Dominguez of Bloomfield, Paige Kowalski of Plainsboro, and Mateo Acevedo of Belleville. The teens are aware of

the increased use of tics on platforms like TikTok. While some on TikTok use the social media channel to bring awareness to the disorder, others use it to fake tics for attention.

"It's not right to fake tics, bully others, or make fun of Tourette," said Acevedo, a high school student. "And it's not an excuse for someone else's bad behavior."

As many as 1 in 100 people show signs of TS or other tic disorder but many times go undiagnosed. Dominguez points out that it's not just tics. "Every person with TS is different and fight their own battles. I was so depressed that I couldn't get out of bed for months," he recounted. In fact, more than 86% of those with the disorder also struggle with associated disorders such as ADHD, OCD, anxiety, and depression.

The PSAs, four individual PSAs with each advocate and one compilation, can be seen on the NJCTS YouTube channel, Instagram, Facebook and website. The TS community and others are encouraged to share them to spread the word.

Families Give Back



Ryan Bassett reigned victorious in his charity wrestling match and brought in more than \$1,300 for NJCTS. The people of Wrightstown, NJ came out to support their local champion and NJCTS. Thank you to the entire Bassett family, Kelly's Bar, and the people of Wrightstown for their support. It was an awesome night!

Facebook Birthday Fundraisers

Timothy Gahles
Steven Ross
Nick Buckley

Michele Newman
Michael Piacente
Jacob Gerbman

Kim Jenness
Deanna Young



Success on the Slopes

Congratulations to NJCTS Youth Advocate Kyla Butler for making New Jersey Interscholastic Ski Racing Association's 1st Team All-State! Kyla also had an impressive showing at the Race of Champions, finishing fourth overall. Great job!!



Youth Advocate Dominic Dominguez Takes On Advocacy For the Planet

Last year I worked for three months as an Americorps Member with the Walker Basin Conservancy in Yerington, Nevada. The goal of this organization is to restore and maintain Walker Lake located in the Walker Basin while protecting the terrestrial environment throughout the Walker Basin. Walker Lake has decreased in volume and increased in salinity because water from the river that runs to it has been diverted to agricultural estates for decades. The organization acquires water rights from willing sellers and works with the surrounding communities, private landowners, and tribes to restore Walker Lake. In the process, WBC acquires large land estates which they have recruited Americorps workers (like myself) to "...restore native shrubs and forbs, improving and increasing habitat for wildlife. In addition to native plant restoration,

through riparian corridor enhancement activities, Walker Basin Conservancy improves water quality and riparian [adjacent to rivers and streams] habitat for aquatic species." (Walkerbasin.org) I was able to participate in a variety of projects including the construction of wildlife-safe fences to protect riparian habitats from cattle grazing, large scale planting projects, and I even got to use a flamethrower to control invasive tumbleweed species! The work wasn't glamorous, and it was very dirty: removing large piles of junk from the riverside, digging holes for hours, and crawling through thickets of branches and brush to cut down tamarisk. But I miss the 10 hours of sunshine a day, the thousands of stars at night, and the scenic mountains and desert of Nevada.

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The Center for Emotional Health of Greater Philadelphia

The Horizon Foundation



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

- Adam Regen
- Amanda Silvers
- Andrew Hendry
- Andrew Meltzer
- Andrew Travis
- Anna Urbaniak
- AnnaClaire Sems
- Betsy Stoeber
- Brennan Skirzenski
- Carolyn Baldwin
- Charlotte Regen
- Cheryl Ludwig
- Chris Markulic
- Christian Concepcion
- Christine Seymour
- Colin Deibler
- Conrad Roncati
- Debra Park
- Demetrio Lukaitis
- Dominic Dominguez
- Eliza Lederman
- Eric Baldwin
- Eric Deibler
- Eryn Travis
- Gary Heiman
- Gerri DeCicco
- Hallie Hoffman
- Helene Sims
- Jason Michaels
- Jenna Smith
- Jennifer Brittingham
- Jeremy Lichtman
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- Kyla Butler
- Kyle Swords
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- Tara Barr
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- Tim Kowalski
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- Tim Yingling
- Tracy Lederman
- Wilamena Dyer
- Yolanda Lawas

Thank you!



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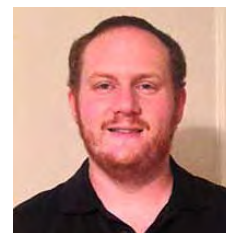
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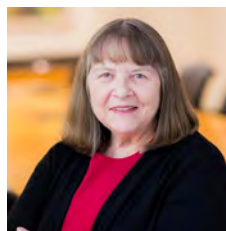
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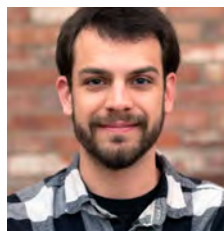
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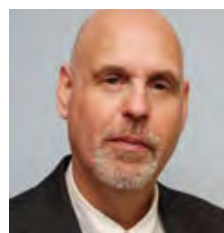
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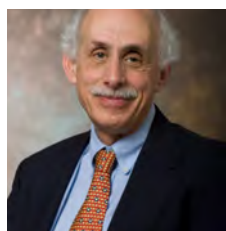
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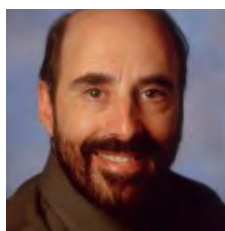
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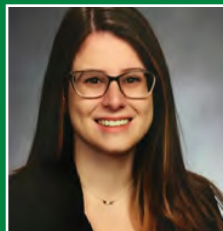
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LET'S NOT PRETEND TOURETTE SYNDROME (TS) DOESN'T MAKE US ANY DIFFERENT. IT DOES. IT HAS ITS IMMENSE CHALLENGES. ITS SETBACKS. BUT BECAUSE OF THESE DAILY HARD-FOUGHT BATTLES. WE'RE STRONGER. WE FEEL MORE. SENSE MORE. SEE MORE. IT'S WHEN WE STOP HIDING 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**.



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.




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