NJ CENTER FOR TOURETTE SYNDROME & ASSOCIATED DISORDERS

2018 YEAR IN REVIEW













celebrating our TS community



ESTABLISHED IN 2004 AS THE NATION'S FIRST CENTER OF EXCELLENCE FOR TOURETTE

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OUR MISSION

The New Jersey Center for Tourette Syndrome is a not-for-profit organization committed to the advocacy of children and families with Tourette Syndrome and its associated disorders. Dedicated to delivering high quality services to these individuals, the Center recognizes the importance of educating the public, medical professionals, and teachers about this disorder through programs and affiliations with public schools, health centers, and universities. To ensure that individuals with Tourette Syndrome are contributing members of their communities and society at large, the Center is committed to leading the promotion and development of diagnostic and treatment therapies and actively supporting research for a cure.

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DEAR FAMILIES & FRIENDS.



This year we saw many positive education outreach, youth development, and research advances in our programs.

First, we added a law enforcment and first responder presentation to our outreach. We conducted 17 Grand Rounds presentations in hospitals throughout the state. More than 3,000 educators attended our in-service trainings, 20 of which were in urban and underserved areas.

Our Youth Advocates accomplished amazing things, from speaking in front of thousands at Great Adventure, to working and studying on a ship sailing the Atlantic.

Finally, our collaboration with TIC Genetics researchers yielded yet another critical breakthrough, identifying more genes that may cause Tourette Syndrome.

I could not be more grateful for the support we receive from our families, partners and donors. Your support will allow NJCTS to continue to change minds and change lives well into the future!

Gratefully,

Faith W. Rice

Founder & Executive Director



WHAT IS

TOURETTE SYNDROME:

Tourette Syndrome (TS) is an inherited neurobiological disorder characterized by the childhood onset of uncontrollable vocal and physical tics. It is estimated that about 1 in 100 individuals exhibit symptoms of TS. Kids with TS frequently report feelings of isolation from being ostracized or bullied.

Tics can include head jerking, eye blinking, facial grimaces, jumping, spinning, sniffing, throat clearing, squealing, barking, and more.

Vocal tics can also include echolalia, involuntary repetition of what someone else has just said, the involuntary repetition of one's own words and the most infamous and problematic vocal tic: coprolalia, which is the involuntary utterance of curse words, ethnic or racial slurs. This symptom is present in only 10 percent of cases.

HERE ARE SOME OTHER FACTS ABOUT TS:

- Usually appears when a child is 6 or 7 years old
- Affects all ethnic groups
- Boys are affected 3 4 times more often than girls
- Lifelong condition course unknown –no cure
- No standard treatment protocol
- Average time from onset to diagnosis is still 7 years
- Psychological, social, educational, physical impact
- Associated Disorders: Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder, learning disabilities, panic attacks, depression, generalized anxiety disorder, sleep disorders
- Misunderstood by the public and educators
- Underdiagnosed by medical professionals



OUR IMPACT

LOCAL CONNECTIONS, GLOBAL REACH

From the moment they make contact with our organization, families are immediately supported through information and referral, access to training through webinars, and connections to other TS families.

6800

Nearly 6800 families, educators and healthcare professionals viewed our educational webinars

20



20 trainings were conducted in urban and underserved communities



More than 40,000 copies of literature and research updates were distributed to medical and mental health professionals, educators and other school personnel

40,000

NJCTS advocated at 11 professional conferences reaching more than 15,000 people

15,000



11



NJCTS and TIC Genetics have been partnering for 11 years to advance TS research.



NJCTS responded to 1558 calls for support

1558

3321 educators attended 66 training sessions throughout the state

3321





2855 clinicians attended 17 NJCTS medical trainings

2855

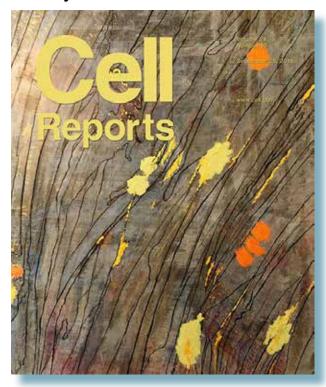
For support, please reach out to NJCTS at 908.575.7350 or info@njcts.org. Learn more at www.njcts.org.

NJCTS and Rutgers Scientists Contribute to Worldwide Study Uncovering Possible New Causes of Tourette Syndrome

In a study published in the journal Cell Reports on September 25, 2018, scientists identify a new high-confidence Tourette risk gene as well as two probable risk genes. The revelations from this ongoing research – a collaborative effort among NJ Center for Tourette Syndrome (NJCTS), Rutgers University and scientists around the world – will help to unravel causes of Tourette Syndrome (TS) which could help guide effective treatment options. For the past 11 years, NJCTS families have been donating DNA samples to the study in hopes of advancing the cause for treatments and a cure.

In the new study, scientists and clinicians from the United States, Europe and South Korea, report two significant findings: TS is sometimes caused by new and rare damaging mutations in specific genes or through structural mutations, known as copy number variants (CNVs), spanning multiple genes. In addition to "likely" TS risk genes, they found another "high confidence" risk gene called CELSR3.

According to Dr. Jay Tischfield, MacMillan Distinguished Professor of Genetics at Rutgers University, CNVs change the structure of segments of DNA, either through duplication or deletion. "We discovered that CNVs occur two to three times more often in children with TS compared to those without," he said.



Additionally, the reoccurring damaging mutations in CELSR3 in different families, as well as observation of new mutations in other genes involved in cell polarity, provide additional evidence for how brain development is disrupted in TS.

"These two significant findings provide a framework for future research into the causes and treatment of this remarkable and peculiar disorder," said Tischfield.

Tourette Syndrome – a neurological disorder linked to problems in the basal ganglia, the part of the brain responsible for voluntary motor control, procedural learning and eye movement, as well as cognitive and emotional function -- is characterized by uncontrolled vocal and motor tics. It is often accompanied by co-occurring conditions, such as anxiety, obsessive-compulsive disorder or attention deficit disorder.

Tischfield and Dr. Gary Heiman, associate professor in the Department of Genetics in the School of Arts and Sciences, lead the Tourette International Collaborative Genetics (TIC Genetics) study - the largest and most comprehensive genomic analysis conducted - that includes scientists and clinicians from the United States, Europe and South Korea.

The research began in 2007 when Rutgers collaborated with NJCTS to establish the NJCTS Cell and DNA Repository – the world's first sharing repository for Tourette Syndrome making samples available for collaborative research on TS.

"More than 200 families at NJCTS were instrumental in launching the pilot study," said Heiman. "Through the initial families who participated, we were able to collect samples and data to start the study and establish the first sharing repository for researchers from all over the world interested in studying Tourette syndrome."

The new results are the second major set to come out of the 11-year-old study, following last year's findings that four damaged, high-risk genes may disrupt the normal brain development. That study was published in Neuron in May of 2017. Researchers identified one damaged, or mutant, "high confidence" risk gene for Tourette's as well as three others they believe are genes whose mutation is a probable risk for the disorder. The findings were the first to establish Tourette as a genetic disease similar to other neuropsychiatric disorders like autism, where multiple genes have been identified as the cause.

RESEARCH

NJCTS continues to lead the way in research to find better treatments and a cure for Tourette Syndrome. Nearly a decade ago, NJCTS began its research partnership with Rutgers University and established the NJCTS Tourette Syndrome Sharing Repository. By 2011, the National Institutes of Health recognized this extraordinary accomplishment and declared it a federal asset, designating it as the federal repository for Tourette Syndrome and awarded funding to establish 26 collection sites around the world.

This worldwide "sharing repository" for cell and DNA samples was now available to researchers across the globe to study the genetics of TS. This was the first program of its kind and changed the direction of TS research. Prior to establishing the repository, which contains over 2,800 genetic samples of individuals with TS and their relatives, there was nowhere for independent scientists and institutions to request TS samples.

Rutgers researchers and their colleagues estimate that there are approximately 400 mutated genes that could pose a risk for Tourette Syndrome, which affects one out of 100 people, suggesting the disorder is as complex as autism, epilepsy, and intellectual disability.

In 2018, the National Institute of Mental Health (NIMH) awarded the TIC Genetics study a grant of more than \$10 million to continue their research for the next five years.

Rutgers scientists say more samples from families are needed to better understand how these and other damaging mutations lead to Tourette disorder.





RUTGERS & NJCTS

"COLLABORATIVE EFFORTS
BY OUR RESEARCH TEAM
AND CONTINUED SUPPORT
FROM FAMILIES LIVING WITH
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FUTURE BREAKTHROUGHS
BRINGING US BETTER
TREATMENTS AND CLOSER
TO A CURE FOR TS."
— FAITH RICE



HARINĞ REPOSI

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

EUROPE

Denmark University of Copenhagen

University of Lübeck Germany

Germany **University 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

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







NJCTS, Rutgers University, and participating families have forever changed the direction for Tourette Syndrome research.

NJCTS, in partnership with Rutgers University's RUCDR Infinite Biologics, established the NJCTS Cell & DNA Sharing Repository in 2007 as a resource of clinical and genetic data for Tourette Syndrome. A collaboration with Yale University and other partners helped to develop a set of uniform methods and collection tools. After four successful years into the pilot, the National Institute of Mental Health recognized the repository as a federal asset and funded its expansion. Through the establishment of the Tourette International Collaborative Genetics (TIC Genetics) study, the repository now includes more than 25 collection sites around the world.

NJCTS-affiliated experts are bringing the latest information to New Jersey families through Tourette Syndrome workshops led by Dr. Gary Heiman, Director of TIC Genetics. In 2018, Dr. Robert King, professor of child psychiatry at the Yale University Medical School and medical director of the TS/OCD Clinic at the Yale University Child Study Center, traveled to New Jersey monthly to conduct screening interviews and information sessions for individuals and families interested in participating in the TS study.

Every day, scientists are working to find a cure for TS. This work would not be possible without the continued support of families participating in the study through interviews and tissue samples.

TS Clinic and Practicum at Rutgers University Graduate School of Applied and Professional Psychology

Created in 2000, the NJCTS Tourette Syndrome Clinic and Practicum at Rutgers University continues to further our mission in the areas of family support, treatment, and research. The Clinic's approach is to focus not only on the child living with TS but also his/her family. Families who come to the Clinic become part of a community, overcoming the isolation that accompanies the stigma of TS. The Clinic works with NJCTS to perform peer and faculty in-service trainings, parent groups and skills groups for children, and the clinic staff participates in NJCTS Family Retreat Weekends.

The NJCTS Tourette Syndrome Clinic and Practicum provides a unique, hands-on learning experience for advanced graduate students striving to increase awareness of TS in the professional community. The students are the future practitioners for individuals with TS, a specialized area of psychological care that has alarmingly few specialists nationwide. Their consistent ability to provide relief and assistance to families in need has built the reputation of the Practicum, allowing it to become the premier place for the behavioral treatment of TS-related issues.

This is the only such program in the nation providing a university-based, stand-alone teaching practicum and psychological clinic. The TS Clinic represents accessible, affordable care for individuals from New Jersey and surrounding areas. Since its inception, the Clinic has

treated more than 1,200 patients and families with



TS in New Jersey as well as from the surrounding New York and Pennsylvania area and has trained more than 50 new psychologists who are now in practice across the country.

The clinic offers evaluation and treatment services according to a sliding scale based on family income, with session fees as low as \$5 when need is demonstrated. A central tenet to the mission is that individuals will not be turned away from needed psychological services due to inability to pay standard fees. GSAPP therapists are all clinical and school psychology doctoral students.

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
- · Services available on a sliding scale

YOUTH DEVELOPMENT

Offering a Continuum of Services for Youth at all Stages of Life



The objective of the NJCTS Youth Development Program is to provide youth diagnosed with TS opportunities to develop their strength, courage and confidence while embracing their differences and advocating for themselves and others as an NJCTS Youth Advocate.

Our wide variety of Youth Development programs discussed below put kids with this often misunderstood disorder on a positive path to becoming leaders and productive citizens.

School and Community Presentations

The NJCTS Youth Advocate Program trains children and teens, ages 10 to 18, to lead presentations to students and community groups about Tourette Syndrome and its associated disorders. Advocates are empowered by sharing their experiences in front of audiences of all sizes and attendees receive a strong anti-bullying message that promotes acceptance, tolerance, and self-advocacy for all.

In 2018, our NJCTS Youth Advocates reached more than 3,600 students at public and private schools in New Jersey. In addition, our educational outreach professionals reached 3,321 teachers through in-service trainings providing information on the disorder as well as techniques for dealing with TS in the classroom.

Hospital Grand Rounds Presentations

A TS medical expert shares the podium with a youth advocate and together they present to a team of attending physicians and residents. The medical expert discusses the signs and symptoms, characteristics, diagnosis and treatment of TS. Following this the youth advocate presents for 20-30 minutes including questions and answers. This allows those in attendance to hear first-hand the impact and challenges of TS in a person's daily life.

Patient Centered Medical Education

In PCME presentations, two Youth Advocates, along with their families, present to a group of residents. Both families share the presentation responsibilities and discuss their experience around diagnosis, treatment and developing coping strategies.

Legislative Testimony

Throughout the year, representatives from NJCTS will meet with legislators in New Jersey regarding a number of issues of concern to the TS community. Often, a Youth Advocate will accompany the Executive Director to meet and speak with the legislators and share their story.

Family Retreat Mentor Panel

Each year, NJCTS comes together at YMCA Camp Bernie for some family fun. Included in our activities is a mentor panel, where camp attendees (both kids and parents) have the opportunity to ask questions of our seasoned advocates. Mentors range in age from teenagers still in high school to young adults making their way in the world. It is a unique opportunity for kids and families to ask questions of those going through similar experiences.

June 4th-Proclamation

We encourage our advocates to spread awareness through the promotion of TS Awareness Day. We ask them to request that their mayor, county or state official make a TS Awareness Day proclamation. This involves contacting their office, explaining what Tourette Syndrome is and specifically what they are requesting. Often when someone succeeds in getting a proclamation declared, there is the chance to meet the official and have photos taken.

Event Involvement

One of our main fundraisers is our annual walk. NJ Walks for TS promotes awareness, acceptance, action, and advocacy of Tourette Syndrome and its associated disorders. This event is about fun and empowerment for kids, by kids, and about kids.

The NJ Walks for TS virtual walk spans the months of March through May, and is a great opportunity for Youth Advocates to spread their wings as leaders by organizing a team, serving as a team captain, creating awareness and raising funds for NJCTS programs and services.



THE NJCTS TIM HOWARD LEADERSHIP ACADEMY

The 5th annual NJCTS Tim Howard Leadership Academy took place at Rutgers University from August 2-5. The intensive four-day training promoted self-advocacy, self-leadership, resilience and grit—all important skills to succeed while living with Tourette Syndrome.

Created in 2014 in partnership with Colorado Rapids goalkeeper and TS advocate Tim Howard, the Academy is the only leadership program for teens diagnosed with TS in the nation. The teens who participated in 2018 represented New Jersey, New York, Pennsylvania, Florida, Texas, Minnesota, California, Canada and Australia.

Tim Howard, who was diagnosed with TS as a teen himself, surprised the teens by calling in to video chat with the group. During the 30 minute conversation, he fielded questions about everything from disclosing his TS publicly to his plans after retirement. He told them that in his mind, TS "chose me," so he has always accepted the disorder as a part of who he is.

Academy participant Sam Regen of Robbinsville asked Howard for advice on how to handle TS as you grow up. "The world is an awesome place. It can be good, but it can be scary. There can be some bad people out there," Howard answered. "Surround yourself with people that are compassionate and understand who YOU are. The rest of them don't matter."

Throughout the four days, participants had the opportunity to learn from neurologists, psychologists, social workers, and others about their diagnoses. In addition, sessions were conducted on asking for and receiving accommodations at college and in the workplace. During their downtime, the teens formed connections with new friends through small group activities or a friendly game of kickball.

"We want them to leave as experts with the ability to advocate for themselves and be ready to face an often misinformed public," explained Academy Director Melissa Fowler. "With the lessons and skills they gained, and the

goals they've set for themselves, this class will step up to be the voice of awareness in their own communities."



njcts.org/academy

EDUCATION OUTREACH

Youth Advocates Spread TS Education, Awareness and Anti-Bullying Message to All Corners of the State

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 400 presentations to individual audiences as large as 800 students, raising awareness, standing up to bullying, and increasing understanding of this often-misunderstood disorder. In 2018, Youth Advocates led 52 presentations, reaching thousands of students, teachers, first responders and health professionals across the state.

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.





Youth Advocate Presentations were conducted at the following schools:

Bradley Gardens Elementary School
Bloomsbury Elementary School
Rumson-Fair Haven Regional High School
Madison Park Elementary School
Montclair Kimberley Academy
Rockaway Valley School
Ethel Hoppock Middle School
Memorial Middle School
Voorhees Middle School
Roosevelt Elementary School
Westmoreland School
West Deptford Middle School

Cordero School
Heywood Avenue School
Jersey City Community Charter School--Middle School
Jefferson Elementary School
Smalley School
Frenchtown Elementary School
Drum Point Road Elementary School
Rosa International Middle School
YCS Davis House
Jersey City Community Charter School - Elementary School

YOUTH ADVOCATES WHO PRESENTED IN 2018

Brennan Skirzenski Charles Griebell Sam Regen Ethan Lederman Lia Sturrock Jonah Grossman Kyle Swords Dominic Dominguez Eric Baldwin Rachel Flynn Jenna Smith Jonah Grossman Ben Mars Tara Barr Paige Kowalski Jatin Nayyar Hallie Hoffman Jeff DeCicco Victoria Franco













EDUCATION OUTREACH

Providing Tools & Strategies for Education Professionals and School Nurses

FACULTY IN-SERVICE PROGRAM

The NJCTS School In-service Program provides tools and strategies for educators, guidance counselors, child study teams, administrators, school nurses, and support staff for assisting students with TS and associated disorders in elementary and secondary schools across New Jersey. These programs are also presented at professional conferences like the NJEA and NJCEC.

In-service presentations and workshops inform and enlighten professionals about Tourette Syndrome and co-occurring disorders such as OCD, ADHD, learning disabilities, depression, anxiety and the impact they can have on a child's school performance. They also provide educators with specific classroom strategies and accommodations that can have a positive impact on a student's academic success. NJCTS presenters are teachers, psychologists, or other professionals with education or medical backgrounds and have first-hand knowledge of TS. The presentations promote more positive, inclusive, and successful classroom environments for all students.









IN-SERVICE PRESENTERS:

Barbara Chabner, Psy.D.
Patricia Phillips, MBA
Lisa E. Cox, PhD, LCSW, MSW
Michelle Miller, Psy.D.
Jeremy Lichtman, Psy.D.
Graham Hartke, Psy.D.
Diana Antinoro Burke, Psy. D., BCBA-D
Lori Rockmore, Psy.D.
Michelle Lubonski, M.S. Ed.
Steven Lindenbaum, M.A., Special Ed.
Tracy Lederman, M.S., Ed. D.
Joseph Buonadonna, Sr., PhD
Carolyn Baldwin, B.A, English
Cheryl Ludwig, M.A., CCC-SLP
Nicole Janiec, M.A., NCSP

Faculty In-service Schools in 2018

Salem County School Nurses
Association
Warren H. Wolf Elementary School
Hunterdon County School Nurses
Association
Black River Middle School
Hudson County School Nurses
Association
Collingswood Public School
Gloucester County Administrators of
Special Education
Radburn School
Monmouth County Association of
Directors of Special Education
Midtown Community School

Mercer County School Nurses Association Montclair Kimberley Academy Warren County School Nurses Association Bound Brook School District Mount Olive Middle School Mountain View Elementary School Rockaway Valley School Frenchtown Elementary School Bergen County School Nurses Association Hightstown High School Hudson County Social Emotional Character Development Consortium Ethel Hoppock Middle School

Department of Children & Families-Office of Education
Mt. Pleasant Middle School
Rosa International Middle School
Drum Point Road Elementary School
NJ Ahead
Roosevelt Elementary School
Evesham Township School District
Atlantic County Office
Oakland Public Schools
Smalley School
New Jersey Principals & Supervisors
Association
William Paterson University

Briarcliff Middle School

MEDICAL OUTREACH

Educating the Medical Community and the Next Generation of Doctors

GRAND ROUNDS PRESENTATIONS

NJCTS works with hospitals throughout New Jersey to present Grand Rounds trainings for doctors, nurses, and other healthcare providers.

Grand Rounds are presented by Tourette Syndrome experts and a teenager or young adult to groups of between 25 and 100 physicians and/or students. The NJCTS Youth Advocate or family describe their experience with TS at school, at home, and in the community, and focus on initial diagnosis, quality of life, and encounters with physicians and the healthcare system. The goal of this medical education program is to help physicians enhance their understanding of the perspectives, stresses, and needs of patients with neurological disorders and their families and to improve interpersonal and communication skills in patient encounters.

In 2018, NJCTS reached more than 2,800 medical professionals through Grand Rounds at hospitals throughout the state, in addition to the hundreds that receive our regular distribution of the latest TS-related research articles.



HOSPITAL GRAND ROUNDS

Riverview Medical Center
Bayshore Medical Center
Raritan Bay Medical Center
Rutgers-NJ Medical School
Saint Barnabas Medical Center
Jersey Shore University Medical Center
Hackensack University Medical Center
Hunterdon Medical Center
Saint Clare's Health
Hackensack Meridian Health - Palisades Medical Center
Hoboken University Medical Center
Riverview Medical Center
Saint Peter's Hospital



GRAND ROUNDS PRESENTERS:

Harvey Bennett, MD Rob Zambrano, Psy.D. Jeremy Lichtman, Psy.D. Michelle Miller, Psy.D. Justin Misurell, PhD Roger Kurlan, MD

COMMUNITY OUTREACH

Informing the Community about Tourette Syndrome and Associated Disorders

& CONFERENCES

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 2018, NJCTS continued to emphasize an expanded focus to underserved communities, developing relationships with a wide range of local organizations who can, in turn, reach families in need.

This outreach has provided NJCTS with the opportunity to collaborate with representatives of Care Management Organizations, Family Support Organizations, Family Success Centers, child welfare, schools, hospitals, mental health organizations, and a wide range of county-based social and human service agencies. The goal of such partnerships is to connect families in need with the support and services available through NJCTS and its partners.

In addition to 22 community presentations, NJCTS was present at 11 professio nal conferences in 2018, including the NJEA Conference in Atlantic City.

CONFERENCES

The Center for Neurological & Neurodevelopmental Health (CNNH)

NAMI

NJ Council for Exceptional Children

NJEA Conference

Latino Mental Health Association

Parents, Inc.

OCD NJ Annual Conference

NJ School Nurse Association

NJ Association of School Social Workers

Tri County CMO

Children's Mobile Response Services

NJ Coalition for Inclusive Education

COMMUNITY GROUPS

Healthier Somerset

Mercer County FSO

Division of Vocational Rehabilitation

Pioneer Family Success Center

Partnership for Maternal and Child Health (FSC)

Circle of Care for Families & Children of Passaic

County

Arc of Hunterdon County

Congressman Norcross Constituent Services Fair Workforce Development Board of Passaic County

Faith Based Committee

Workforce Development Board of Passaic County

Disability Committee

Cumberland County CIACC

Middlesex CIACC - Education Partnership

Traumatic Loss Coalition

New Brunswick Public Schools

Coordinated Family Care (CMO)

Straight and Narrow Inc.

Family Support Organization Passaic County

Family Service Association

Highlands Family Success Center

National Association of Social Workers

Bernards Township Health Department



FIRST RESPONDER IN-SERVICE

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.

Another component of the program is a medical ID card for those with TS to keep in their wallet or car so they can provide it to first responders and law enforcement.

In response to one training, Middlesex County Prosecutor Andrew C. Carey said, "I sincerely thank you for all of your efforts in making our Crisis Intervention Training held at our police training center a great success. It is only through cooperation between law enforcement, health care professionals, and our community partners that we will continue to make strides towards protecting the rights, dignity, and safety of every one of our citizens, as well as our first responders. The feedback from the participants has been excellent."



AGENCIES

Middlesex County Office of Human Admin Services Somerset County Police Academy Essex County College Public Safety Academy Morris County Public Safety Training Academy Gloucester County Police Academy Bergen County Law & Public Safety Institute Mercer County Police Academy Middlesex County Office of Human Admin Services North Plainfield Police Department Sussex County CIT



Tourette Syndrome ID Card

A component of our new first responders outreach initiative are these ID cards for individuals with TS. Sign the plastic card and keep it in your wallet with your ID and use it when communicating with first responders including police or EMTs. These situations can be stressful enough without having to try to explain your tics. The cards are available at our Somerville office. Please swing by to grab one. Live too far away? Request one my email at info@njcts.org and we'll pop one in the mail to you!

WEBINARS

Global Reach with More Than 6,500 views in 2018.

The need has never been greater for practical and accurate information about TS and associated disorders for parents, educators, and healthcare professionals. In an effort to bridge that knowledge gap, NJCTS provides valuable education for the benefit of all through the Wednesday Webinar series. Since 2008, more than 30,000 parents and professionals have attended webinars delivered by NJCTS experts in neurology, psychiatry, psychology, education, and law. As a recognized and trusted source, NJCTS welcomes participants from across the country and around the world.

What makes Wednesday Webinars so powerful is that attendees have the opportunity to ask questions during the live presentation. This allows families who do not have regular access to professionals with experience in TS the chance to connect with an expert. Credits are offered to qualified professionals, making this an important learning tool for educators as well. All presentations are archived at NJCTS.org for continued viewing.

2018

WEDNESDAY WEBINARS

What a Difference a School Nurse Can Make! A Tourette Syndrome Guide for School Nurses

Presenter: Dr. Graham Hartke

School Nurses play an essential and invaluable role in the lives of children and their families. Dr. Hartke provides an overview of TS and associated disorders along with specific tips and strategies for school nurses, families, and educators to best help students living with TS.

Learning Systems – How to Improve, Build, and Develop Compensatory Strategies

Presenter: Dr. Sarah Levin Allen

Dr. Allen reviewed the essential systems for learning including those related to the cognitive, executive, emotional, and behavioral aspects of functioning in a classroom. She made recommendations for how to improve children's functioning, build skills, and develop strategies to promote learning.

How Anxiety and Repetitive Behaviors Interact to Complicate Your Child's Life

Presenter: Dr. Kathryn Roberts Individuals with anxiety and related repetitive behaviors often qualify for more than one diagnosis, or may present with a singular set of symptoms that does not fall into any one category. This presentation will increase understanding of the commonalities in diagnosis and treatment among anxiety, obsessions/compulsions, tics, hairpulling, skin-picking, and autism.

STOP: An Anti-Bullying Guide for Families Schools, and Others Working with Children

Presenter: Dr. Graham Hartke

Effective intervention and prevention of bullying is essential to protect our kids, quickly stop unwanted aggressive behavior, and promote prosocial skills in all environments. This webinar provides an overview of bullying, why it occurs, and strategies for how it can be prevented and responded to in school, at home, and online.

The TS Puzzle: How Do the Pieces Fit Together?

Presenter: Dr. Martin Franklin

This webinar presents the underlying neurology, development and treatment for TS along with strategies for the management of its typical co-occurring disorders anxiety, OCD and ADHD.

Usually Messy and Always Late: Understanding Executive Functioning and Organizational Skills

Presenter: Dr. Lisa Ahern

Late homework, missing materials, procrastination, and daydreaming are the frustrating hallmarks of executive functioning weaknesses for many students. Understand these challenges and learn concrete ways to support students in building these skills.

The Relationship Between TS and Autism

Presenter: Dr. Roger Kurlan

The relationshiop between ASD and TS has received little clinical or research attention so the information in this webinar should be considered preliminary. Much more research is needed to answer the key question: Is TS part of the Autism Spectrum Disorder.

Cognitive, Executive, Emotional, and Behavioral Interventions for Students. Designing Interventions That Work!

Presenter: Dr. Sarah Allen

A whole-child centered approach is needed to improve children's functioning, build skills, and develop strategies to promote learning and independence. This webinar reviews the essential systems for learning including cognitive, executive, emotional, and behavioral aspects of students' functioning.

FAMILY SUPPORT

In addition to our Education Outreach, TS Clinic and Youth Development Opportunities, NJCTS provides a myriad of programs to our families.

PHYSICIAN REFERRAL NETWORK

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

The Physician Referral Network is a critical aspect of the work at NJCTS, and it is reviewed and revised to provide the best, most up-to-date information on clinicians with understanding of TS and its co-occurring disorders.

Medical professionals in the NJCTS Physicians Referral Network include:

- Neurologists
- Psychiatrists
- Psychologists
- Social Workers

For more information about accessing a professional in the network, or if you are a professional interested in working with the TS community, please call 908-575-7350 or email info@njcts.org.







FAMILY PICNIC

In 2018, NJCTS held our first Family Picnic at Johnson Park in Piscataway. The families that attended enjoyed a potluck that included hot dogs, salads and dessert! Kids enjoyed the playground and animals while parents had the opportunity to relax and connect.

YOUTH SCHOLARSHIP

Since 2001, the NJCTS Youth Scholarship Award has been given to more than 200 outstanding high school seniors in New Jersey who have excelled in their schools and communities. In 2018, 12 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing themselves as outstanding advocates for Tourette Syndrome.



First Place Winners

HALLIE HOFFMAN BELLE MEAD

Hallie is a graduate of Princeton Day School where she served as editor-in-chief of her school newspaper, the co-head of the service learning committee, co-head of the school's chapter of the National Organization for Women, a student mentor and a tour guide and ambassador for prospective students. Outside of school, when she wasn't singing or playing piano, she volunteered as a Youth Advocate for NJCTS, where she has given presentations to thousands of students throughout the state.

CHARLES GRIEBELL MONTGOMERY

Charles is a graduate of Princeton High School and wants to study something that has become his passion: Agriculture and Food Systems. It is a career he hopes may even result in creating holistic treatments for Tourette Syndrome. Charles spent his high school career advocating for acceptance and anti-bullying, working with local non-profits as well as NJCTS, where he served as a Youth Advocate speaking to school children, fundraising and meeting with his local legislators.



Second Place Winner



MICHAEL HAYDEN RIVER VALE

Michael is a graduate of Pascack Valley High School where he captained the cross country, winter track and spring track teams as well as the local Club Ultimate Frisbee Team. He's a member of the National Honor Society, the Science National Honor Society and the Italian National Honor Society. He has volunteered as an NJCTS Youth Advocate, presenting to thousands of students, teachers and medical professionals.

Honorable Mention Winners



SARAH BALDWIN MANTUA



GREGORY BRISTOL FLEMINGTON



ALEXIS CARIDDI FRANKLIN LAKES



VENKATA DUDI PINE BROOK



CRYSTAL FLAX BRIDGEWATER



GREGORY HOULDSWORTH WYCKOFF



BENNETT MILLER CHESTER



MATTHEW MULLER LITTLE EGG HARBOR



LIANE STURROCK FORT LEE

FAMILY RETREAT

The "best weekend of the year" returned in 2018 after a one year hiatus.



Since 2004, NJCTS has welcomed families to enjoy some time away from it all at the NJCTS Family Retreat Weekend at YMCA Camp Bernie in beautiful Hunterdon County. The weekend allows children and their families to meet others with Tourette Syndrome (TS), learn more about their diagnosis, and engage with peer mentors in a fun, safe environment.

Kids enjoy canoeing, swimming, wall climbing, arts & crafts, participating in a talent show, rekindling old friendships, and cultivating new ones. Parents join in many activities with their children but also connect with other parents and share their stories. Powerful workshops provide a safe place for both youth and parents to ask questions about TS and learn from peer mentors.

The NJCTS Family Retreat Weekend is popularly known as "the best weekend of the year" to the many families who attend looking for camaraderie, a relaxing getaway from the stress of everyday life, and a chance to learn more about TS and self-advocacy.









AWARENESS & ADVOCACY

NJ WALKS FOR TS

When NJ Walks for TS was founded in 2010 as the first and only advocacy walk/run for kids, by kids, to benefit children with Tourette Syndrome, it was made clear to NJCTS that families and friends enjoy stepping out in support of their loved one with TS.

To meet the needs of our on-the-go families and to ensure the greatest impact, NJCTS expanded NJ Walks for TS in 2018 to encompass the entire state throughout the spring. The NJ Walks for TS Virtual Walk allows families and friends to show support wherever they choose anytime in March, April or May.

Our top teams organized local walks, held family fun days, organized beach clean-ups, and even planted trees to celebrate Tourette Syndrome Awareness. They garnered support from classmates, teachers, family from near and far, neighbors and teammates.

These great advocates raised thousands of dollars to support NJCTS.





TOP FUNDRAISING TEAMS

Team Jatin
Nicholas' Trek with Tourette
Team Reyner & Charles
Team Jamo
Tim's NB Raiders













AWARENESS & ADVOCACY

TS ROCKS

NJCTS hosted the second annual TS Rocks at Indian Acres Tree Farm in Medford. Guests enjoyed live music, vendors, a beer garden and access to all of the Indian Acres Fall activities including a corn maze and a hay ride to the pumpkin patch.

Guests enjoyed performances by the GoodWorks Band, Pointless, The Bad Bees and Sara Henya.

The name, TS Rocks, was first coined by a young member of NJCTS in gratitude for the skills she learned at a self-advocacy training.

TS Rocks Sponsors:

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The Wawa Foundation.











ADVOCATES IN ACTION



In August, NJCTS Youth Advocate **Sam Regen** spoke before the Jacob Sartorius concert at Six Flags Great Adventure. Jacob is a singer and YouTube sensation. Sam addressed more than 3,000 people, mostly teenagers, and spoke about his Tourette Syndrome diagnosis, his struggles, and how he is overcoming them with positivitity.

In May, NJCTS Youth Advocates Amanda Silvers, Charles Griebell and Ethan Lederman, spoke to the New Jersey Senate and Assembly Health Committees to advocate for continued support of NJCTS and the passage of the joint resolution that would designate June 4 as Tourette Syndrome Awareness Day in New Jersey.





In October, NJCTS Youth Advocate **Ally Abad** set sail for a month-long adventure at sea. She sailed down the middle of the Atlantic to the island of Grenada aboard the Corwith Cramer as part of the SEA Semester program. Ally and her shipmates did marine research while on board. TS is not stopping her from persuing a career in Marine Biology!

AWARENESS & ADVOCACY

JUNE 4TH IS OFFICIALLY TOURETTE SYNDROME

AWARENESS DAY IN NEW JERSEY

Governor Phil Murphy signed legislation designating June 4 of each year as "Tourette Syndrome Awareness Day" in New Jersey.

"One in 100 children are impacted by Tourette syndrome in New Jersey," Senator Bateman (R-16,) a longtime advocate for those with Tourette syndrome, stated. "People who cope with this syndrome often face significant challenges. By designating June 4 as 'Tourette Syndrome Awareness Day,' we can raise awareness, support research, and decrease the stigma surrounding this condition."

The legislation, SJR-16/AJR-44, aims to raise public awareness of Tourette Syndrome (TS) and help improve the quality of life of all people touched by TS. The bill was signed into law by Governor Murphy on July 20, 2018.

The joint resolution, which officially designates June 4 of each year as "Tourette Syndrome Awareness Day," passed the General Assembly on May 24 and the Senate on June 7.

"Raising public awareness of Tourette Syndrome is a critical step in encouraging the medical research needed to discover effective treatments, or even a cure, for those affected by this condition," said Senator Singleton. "There are more than 20,000 children in New Jersey alone facing this neurological disorder. By dedicating June 4th as 'Tourette Syndrome Awareness Day,' those living with this condition are brought to the forefront of our hearts and minds."







Primary Sponsors

Senator Christopher Bateman Senator Troy Singleton Assemblywoman Valerie Vainieri Huttle Assemblyman Nicholas Chiaravalloti Assemblywoman Angela V. McNight

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To mark the occasion of Tourette Syndrome Awareness Day being instituted in New Jersey, the NJ Center for Tourette Syndrome and Associated Disorders, Inc. (NJCTS) celebrated with an awards ceremony at the New Jersey State House in Trenton on Thursday, June 7. During the ceremony, NJCTS presented twelve scholarships, recognized the top fundraising teams of their virtual walk event, and awarded the Youth Advocates of the Year.

Scholarships were given by NJCTS to accomplished high school seniors who live with Tourette Syndrome. These awards were all presented by Senator Christopher "Kip" Bateman. The top scholarship award was presented to Charles Griebell of Princeton and Hallie Hoffman of Belle Mead. The second place award was presented to Michael Hayden of River Vale. Finalists included Sarah Baldwin of Mantua, Gregory Bristol of Flemington, Alexis Cariddi of Franklin Lakes, Venkata Dudi of Pine Brook, Crystal Flax of Bridgewater, Gregory Houldsworth of Wyckoff, Bennet Miller of Chester, Matthew Muller of Little Egg Harbor, and Liane Sturrock of Fort Lee.

"We could not be more proud of these young men and woman and all that they have accomplished during their high school career," said Faith Rice, Executive Director of NJCTS. "They have shown that TS does not have to hold you back. We wish them well in college and in all of their future endeavors."



Earlier in the year, NJCTS conducted a virtual event: NJ Walks for TS. Several families participated by creating their own event to raise awareness and funds for TS. The top fundraising teams were awarded certificates of achievement at the State House by Senator Troy Singleton, including Jatin Nayyar, 15, of Morganville who was the top fundraiser in the state. Other top fundraising teams included: Team Charles & Reyner, led by Charles Griebell and Reyner Allen of Princeton; Team Nicholas' Trek with Tourette, led by Nicholas DeLieto of Spotswood; Team Jamo, led by Jameson Dougherty of Newfoundland; Team Aiden, led by Aiden Storer of Trenton; and Team Tim's NB Raiders, led by Ally Abad of North Brunswick.

Youth Advocate of the Year awards were presented by Assemblywoman Patricia Egan Jones to the graduating advocates in recognition of their contribution to making a difference in New Jersey's Tourette Syndrome Community. NJCTS Youth Advocates are dedicated to improving awareness and breaking the stigma of TS by educating the public, medical professionals, and educators, and by supporting kids and families living with TS. Youth Advocates receiving the award this year were Ally Abad, Sarah Baldwin, Charles Griebell, Michael Hayden, Hallie Hoffman and Liane Sturrock.

AWARENESS & ADVOCACY

NJ DEPARTMENT OF EDUCATION SELECTS NJCTS YOUTH ADVOCATES TO DELIVER DARE TO DREAM KEYNOTES

In 2018, seven NJCTS Youth Advocates were selected to deliver keynote presentations at Dare to Dream High School Student Leadership Conferences.

Dare to Dream is sponsored by the New Jersey Department of Education Office of Special Education Programs and highlights strategies and knowledge to prepare high school students with disabilities for college and career readiness. Each conference features keynote presentations from accomplished students and young adults with disabilities who have demonstrated exemplary self-advocacy and leadership skills.

As teens and young adults living with Tourette Syndrome, NJCTS Youth Advocates are uniquely positioned to speak to and inspire others who are overcoming obstacles.

More than 200 students attend each conferece which includes a variety of workshop sessions that provide opportunities to gain insight into the transition from school to adult life. The conferences give students the opportunity to participate in workshops led by their peers on topics such as self-discovery, self-advocacy, learning styles, developing career paths, and understanding rights and responsibilities in college. Dare to Dream has

long been a positive and empowering experience for thousands of New Jersey's students and NJCTS is proud to be

involved in this program.







NJCTS Youth Advocates presented at the following 2018 Dare to Dream Conferences:

- Rider University Ethan Lederman
- Raritan Valley Community College Jatin Nayyar
- William Paterson University Brennan Skirzenski
- Middlesex County College Jeffrey DeCicco
- Montclair University Jenna Smith
- Cumberland County College Sarah & Eric Baldwin
- St. Joseph's School for the Blind Liane Sturrock
- Rowan College at Burlington Sarah Baldwin

INTRODUCING.....TWITCHA!

Coming in 2019



Twitcha was created by three participants of the 2017 NJ Center for Tourette Syndrome Tim Howard Leadership Academy - Sarah Baldwin, Mary Gregorian and Julie Nemerson. The three high school students dreamed up a superhero that would be living with the same disorder they faced every day, Tourette Syndrome. During late night brainstorming sessions about their final Academy project, Twitcha became a story about struggle, overcoming stigma and, finally, acceptance.

In 2018 Sarah Baldwin took the project to the next level by working with a mentor, Ryan Brady, who publishes his own comic books. With Ryan's help, Sarah illustrated Twitcha with vibrant color and brought her vision to life.

Twitcha will be available on Amazon to download and printed versions will be made available to schools and communities to spread the messages of empathy, self-advocacy and stepping into your power.





Illustrations by Sarah Baldwin
Story by Sarah Baldwin, Mary Gregorian and
Julie Nemerson.

TIM HOWARD RENEWS BOARD COMMITMENT



World-renowned goalkeeper Tim Howard reaffirms his commitment to improving the lives of individuals with Tourette Syndrome by continuing his appointment as a member of the Board of Directors for the NJ Center for Tourette Syndrome and Associated Disorders.

The North Brunswick native was diagnosed in middle school and over the years has shared his personal experience with Tourette Syndrome. Tim has had a stellar career, making his Major League Soccer debut in 1998 and starred on the US Men's National Team. He has served in goal for the Colorado Rapids since 2016. As his star rose, he worked with NJCTS to bring Tourette Syndrome awareness to the global stage. He has announced his plan to retire from the sport in 2019.

"Tim Howard's partnership with NJCTS was formed when he publicly announced his TS diagnosis in 2000," said NJCTS Executive Director Faith W. Rice. "We are delighted to have Tim's continued support and inspiration as we work toward making lives better for individuals and families living with Tourette Syndrome."

SUPPORT

FAMILIES GIVE BACK

We love it when our families initiate fundraising events in their community and schools. They bring awareness to TS while supporting the programs of NJCTS. You can do it, too! Organize a family fun night in your community. Gather your friends for a "Paint-and-Sip" fundraiser or organize a bowling night. The possibilities are endless!

2018 Family Initiated Fundraisers

- Maddie Golden's "Leggings for a Cause" Maddie raised money selling specially designed leggings for her Mitzvah project
- Steve Lindenbaum's Paint Party and Facebook Birthday Fundraiser
- Jaiden Mendez in honor of her Grandmother Dolores' birthday
- · Portia and Bond Roncati's birthday fundraiser
- Sarah Casamalhuapa and Amanda Silvers Facebook Birthday Fundraisers
- · Sarah, Kimi and Tanya Freeman's Birthday Fundraisers





JEFF VITEK MEMORIAL FUND FOR YOUTH DEVELOPMENT

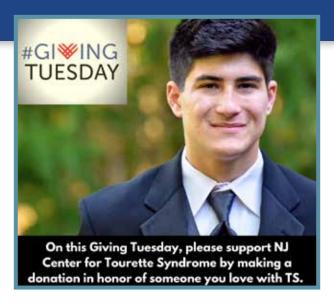
In the fall of 2015, Susan and Patrick Vitek established the Jeff Vitek Memorial Fund for Youth Development at NJCTS in honor of the cherished son they loved and lost. Jeff struggled with Tourette Syndrome throughout his school years and the Viteks sought to get him the support and services he needed. 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.

ONLINE GIVING

In 2018, 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. We even saw our first handful of Facebook birthday fundraisers. 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!



WAYS TO GIVE BACK

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

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

<u>Volunteer opportunities:</u>

- Become a community presenter
- Train to be a Youth Advocate
- Contribute to our TSParentsOnline or Teens4TS blog
- Help us with mailings
- Assist with mission-critical grant proposals
- Work with our development team on on-going fundraising initiatives
- · Help our staff organize, set up, and run an event
- Serve on a NJ Walks for TS or Family Retreat Weekend committee

WE ARE NJCTS

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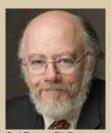


Tim Yingling Giddyup Bronco Productions



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NJCTS SUPPORTERS

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Ruth D. Eni 1925 - 2019

IN MEMORIAM

Ruth was born and raised in Philadelphia, where she received a bachelors and Master's degree from the University of Pennsylvania. Post-graduation Ruth taught English at Upper Darby High. After a few years of teaching, Ruth's father Gottlieb Dietz, asked her to join him and help run his company, Dietz & Watson. She would spend the rest of her life as a leader of the company, eventually becoming the face of the company's ad campaign as 'Momma Dietz'.

Ruth was a generous supporter of NJCTS and our mission, a tradition her family continues.

NJCTS VOLUNTEERS

Jackson Angermeier Baldwin Anna Carol Baldwin Eric Baldwin Sarah Baldwin Tara Barr Rilev Burke Daniel Callahan Marian Carew Patrick Carew **Christian Concepcion** Michael Condon Sophia Cristaldi Grace Dalsev Jeff DeCicco Nicholas DeLieto Rob Dicenzo Gino DiGiovanni Laura DiGiovanni **Dominic Dominguez** Jameson Dougherty Ken Ellis Maggie Esposito Susan Everett Jillian Firenze Rachel Flynn Victoria Franco Drew Friedrich Krystal Geese Tracey Geiger Monica Gilbert Evan Gilman Jarod Gilman Jonathan Glick Mike Gownley Wyatt Gray Charles Griebell Jonah Grossman Vanessa Hailey Mike Hayden Andrew Hendry

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