

NJCTS

THE NATION'S FIRST
**CENTER OF
EXCELLENCE**
FOR TOURETTE SYNDROME

2015 Year in Review



**NJ Center for Tourette Syndrome
AND ASSOCIATED DISORDERS, INC.**

Collaborative Partnerships for the Tourette Syndrome Community

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NJCTS MISSION STATEMENT

NJ Center for Tourette Syndrome & Associated Disorders, Inc. is a not-for-profit organization committed to the advocacy of children and families with Tourette Syndrome and 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.





Dear Partners, Collaborators, Families, and Friends,

In 2015, NJCTS proudly introduced The GreatS movement in partnership with New Jersey native, soccer great, and TS advocate Tim Howard and New Jersey-based creative agency Baldwin & Obenauf (BNO).

The GreatS is a worldwide movement to help individuals with Tourette and associated mental health disorders—especially kids and teens—develop the confidence, leadership and self-advocacy skills

necessary to overcome their challenges and find their own paths to personal greatness.

The movement has roots in New Jersey and a global reach with people from around the world pledging their support. It is a movement dedicated to breaking down social stigmas, creating awareness and providing support resources. It is a call to action for kids and teens to rise above the challenges of their disorder and embrace personal greatness. It is an opportunity to stand with Tim Howard and other GreatS who have overcome their challenges and achieved personal greatness.

Never before have the TS and mental health communities stood together to inspire kids and families from around the world to step out from behind the shadow of their condition and rally others to support them.

Take action today—you can make a difference in the lives of kids everywhere. Visit www.standwiththegreats.org and sign up to be part of this global effort on behalf of the 1 in 100 kids living with TS.

Join me in pledging to Stand with The GreatS.

Best wishes,

Faith W. Rice
Executive Director

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What is Tourette Syndrome?

Tourette Syndrome (TS) is an inherited neuro-biological disorder characterized by the childhood onset of uncontrollable vocal and physical tics. It is estimated that 1 in 100 school-age children exhibit symptoms of TS. Kids and families 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

RESEARCH

NJCTS Cell & DNA Sharing Repository at Rutgers University

NJCTS, Rutgers University, and families are bringing researchers closer to identifying genetic factors that play a role in causing TS and associated disorders.

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 families through Tourette Syndrome workshops led by Dr. Gary Heiman, Director of TIC Genetics. In 2015, 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 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.

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
- Germany** University of Lübeck
- 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 voor Geestelijke Gezondheid, 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



RESEARCH

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

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

The NJCTS Tourette Syndrome 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 university-based, stand-alone program in the nation and, in 2007, received the Rutgers President's Award.

NJCTS has partnered with GSAPP for more than a dozen years to provide this model teaching practicum and psychological clinic to the TS community.

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



NJCTS presented to incoming graduate students at Rutgers University's Graduate School of Applied and Professional Psychology (GSAPP) for the 12th year in a row. Led by Dr. Robert Zambrano and NJCTS Youth Advocate Tommy Licato, this required lecture is an important part of NJCTS' relationship with Rutgers and a starting point for students who are interested in the TS practicum. Every doctoral candidate in the program for the past 12 years has heard a lecture from a doctor, a psychologist, a family with Tourette Syndrome, and NJCTS.

YOUTH DEVELOPMENT

NJCTS Tim Howard Leadership Academy Empowers a New Class of Teen Leaders

The NJCTS Tim Howard Leadership Academy welcomed a new class of leaders in 2015. Participants took part in an intensive four-day training promoting self-empowerment, self-leadership, and resilience—all important skills to succeed while living with Tourette Syndrome.

Created in 2014 in partnership with U.S. Men's Soccer goalkeeper and TS advocate Tim Howard, the Academy is a cutting-edge and innovative leadership program designed specifically for teens diagnosed with TS and associated disorders. During the opening ceremony, Howard's inspiring video message welcoming the Class of 2015 encouraged them to "learn as much as you can from the expert team we have assembled and enjoy the time together with others who will guide and inspire you."

The Academy took place at Rutgers University from August 6-9 and emphasized the biological, psychological, and social components surrounding a TS diagnosis.

"We want them to leave as experts, ready to face a public who is misinformed about TS," said Leadership Academy Director Melissa Fowler. "They have a unique opportunity to learn more about their diagnosis from our expert presenters."

Each of the 35 participants—who hailed from New Jersey, New York, Pennsylvania, Illinois, Maryland, Indiana, Washington, Virginia, and California—were eager to share life-skills tips with one another.

"It means so much to teens to engage with coaches and presenters who are the ideal role models," said Faith Rice. "Learning from others who are living successful lives with TS is invaluable."

2015 Leadership Academy Presenters:

Dr. Jay Tischfield, *Rutgers University, RUCDR*
Dr. Gary Heiman, *Rutgers University, RUCDR*
Dr. Robert King, *Yale University*
Dr. Lisa Cox, *Stockton University*
Dr. Daniela Colognori, *Rutgers University, GSAPP*
Jeremy Lichtman, *Rutgers University, GSAPP*
Dr. Matt Singer, *Chiropractic Wellness Solutions*
Dr. Michael Rubenstein, *University of Pennsylvania*
Dr. Steven Kugler, *Children's Hospital of Philadelphia*
Dr. Jamye Pelosi, *Union Square Practice*



WEDNESDAY WEBINARS

Since 2008, the NJCTS educational webinar series explores the details of living well and learning with TS and Associated Disorders

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 at no cost 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.

Wednesday Webinar presentations in 2015 included:

Creative Applications of Exposure Therapy and Habit Reversal Therapy

Joelle Beecher-McGovern, Ph.D.

University of Pennsylvania School of Medicine

Making Sense of Sensory Issues – How to Manage Heightened Senses at Home and in the Classroom

Michelle Miller, Psy.D.

NYU Langone Medical Center

Outgrowing the Child Neurologist: Medical Transition in OCD, ADHD & Tourette Syndrome

Lawrence W. Brown, MD

Children's Hospital of Philadelphia and the University of Pennsylvania School of Medicine

OCD and Teens/Young Adults: How to Keep them Engaged in their own Treatment, Symptoms, and Lives

Martin E. Franklin, Ph.D.

University of Pennsylvania, Perelman School of Medicine

Tourette Syndrome and Autism: Similarities and Differences

Mark Mintz, MD

Center for Neurological and Neurodevelopmental Health

Tourette Syndrome: A Psychiatric or Neurological Disorder

Harvey Bennett, MD and Joshua Braun, MD

Atlantic Health System

Anxiety and Test Taking

Colleen Daly Martinez, Ph.D. LCSW, RPT-S

Rutgers University, School of Social Work

Self-Injury in Adolescents and Adults

Edward A. Selby, Ph.D.

Rutgers University, Department of Psychology

Outgrowing the Child Neurologist, Part 2: Medical Transition in OCD, ADHD & Tourette Syndrome

Lawrence W. Brown, MD

Children's Hospital of Philadelphia and the University of Pennsylvania School of Medicine

Raising Emotionally Intelligent Teens

Steven E. Tobias, Psy.D.

Center for Child & Family Development

STAND WITH “The GreatS”

Tim Howard Adds One More Save Launches Global Tourette Syndrome Platform

In the summer of 2015, NJCTS partnered with Tim Howard and creative agency Baldwin & Obenauf (BNO) to develop a global Tourette Syndrome platform to change the world for people living with TS and associated disorders.

The GreatS platform builds awareness and sparks conversations around a disorder that is frequently misunderstood and misrepresented. More importantly, it serves as a call to arms for the TS community—inspiring those with Tourette to step out from behind the shadow of their condition and rallying others to support them in doing so.

Leading up to the official launch, The GreatS kicked off during the “Team Up with Tim Howard” event which was held on June 4 at Rutgers University. Howard reconnected with his New Jersey roots amid hundreds of fans and friends—all gathered to celebrate and strengthen the TS community.

Speaking candidly, the World Cup star described The GreatS not as an ordinary awareness campaign, but as a platform allowing people to see TS in a new light. With The GreatS campaign, said Howard, “for the first time...TS seemed cool; it seemed aggressive, and bold, and in your face.” Shortly after the launch of campaign, The GreatS appeared on a billboard in Times Square, gaining worldwide exposure.

The GreatS focuses on helping individuals with Tourette and associated disorders—especially kids and teens—develop the confidence, leadership, and self-advocacy skills necessary to overcome the challenges of TS and find their own paths to personal greatness.



BNO President Trista Walker noted, “We consider it a gift and a privilege to work with Tim and NJCTS to create this important platform, a movement, for Tourette Syndrome.”

Learn more at www.standwiththegreats.org

BNO

A CREATIVE AGENCY



TEAM UP WITH TIM HOWARD

Soccer star and TS advocate returns to his Jersey roots to give back

Hundreds of fans joined NJCTS and Rutgers Men's Soccer in welcoming home world renowned goalkeeper and New Jersey native Tim Howard at the Team Up with Tim Howard event on June 4 at Rutgers University.

For many, the event was a chance to meet a world famous athlete. For others it was a chance to meet a hero, a Tourette Syndrome champion—proof that people facing challenges can be and do anything. To others like Ethan Lederman, a 14-year-old from Howell, NJ, it was the “best day of my life.”

NJCTS Youth Advocate Tess Kowalski opened the afternoon by singing the national anthem. State Senators Christopher “Kip” Bateman, James Beach, and Bob Smith represented more than 26 towns across the state recognizing June 4th as Tourette Syndrome Awareness Day. Senator Bateman presented Esther Howard, Tim Howard’s mother, with Governor Chris Christie’s proclamation recognizing May 15 through June 15 as Tourette Syndrome Awareness Month. North Brunswick Township Councilman Ralph Andrews, on behalf of Mayor Francis “Mac” Womack, welcomed home North Brunswick native Tim Howard.

Coach Dan Donigan and Rutgers Men's Soccer led a clinic for kids while DJ Yoshi and the Rutgers University Dance Team entertained the crowd. Danny Breslauer, a long-time play-by-play analyst for Rutgers sports, served as emcee for the day.

Tim Howard posed for photos with fans of all ages and signed copies of his book, *The Keeper*, before addressing the crowd on the field. An integral partner of NJCTS since its founding, Howard spoke about soccer, his experience playing in the world cup, and living with Tourette Syndrome.

The friends and fans attending Team Up with Tim Howard gave the soccer star a welcome he won't soon forget.



Tim Howard scored \$105,000 for his favorite charity: NJCTS. Howard's sponsor, El Jimador, presented NJCTS with a check at the “Your Shot at \$1 Million” event finale in October, wrapping up a nationwide sweepstakes and #kickTS social media campaign.



EDUCATION OUTREACH

Faculty In-service Program

The NJCTS School In-service Program provides educators with tools and strategies for assisting students with TS and associated disorders throughout New Jersey.

In-service presentations are conducted by educators and medical

professionals, and help create a positive, inclusive, and successful learning environment for all students.

In 2015, NJCTS reached 82% more educators and students through school in-service presentations than in 2014.



NJCTS Education Outreach Coordinator Gina Maria Jones, M.Ed, led a presentation to more than 150 Newton school district faculty and staff at Newton High School.

Faculty In-service Participating Schools in 2015 included:

NJEA Convention, Atlantic City
Belleville High School, Belleville
Blackwood Elementary School, Blackwood
Somerset Co. School Counselor Assn., Bound Brook
Milltown School, Bridgewater
Hammarksjold Middle School, East Brunswick
Youth Consultation Services, East Orange
George G. White Middle School, Hillsdale
Wallace School, Hoboken
NJ Assn. of School Social Workers Conference, Iselin
Liberty Corner School, Liberty Corner
Marlton Elementary School, Marlton
Marlton Middle School, Marlton
Atlantic County Special Services School District,
Mays Landing
Millville School District Child Study Team, Millville
Montclair State University, Montclair

Ironbound Community Corp., Family Success
Center-Early Learning Center, Newark
DCF Regional School-Essex, Newark
Newton High School, Newton
North Caldwell School District, North Caldwell
Bergen County Community College, Paramus
Hilldale School, Pine Brook
Rutgers University GSAPP, Piscataway
Nellie Bennett Elementary School, Pt. Pleasant
Bunker Hill Middle School, Sewell
The Center School, Somerset
Teaneck Community Charter School, Teaneck
School Nurses Association, Toms River
Cumberland County School Nurses Assn., Vineland
Green Fields Elementary School, West Deptford
Westfield High School, Westfield
Haddon Township High School, Westmont

Presenters:

Diana Antinoro-Burke, Psy.D.
Carolyn Baldwin
Lisa Cox, Ph.D., LCSW, MSW
Meir Flancbaum, Psy.D.
Melissa Fowler, MA, M.Ed
Graham Hartke, Psy.D.
Gina Maria Jones, M.Ed
Tracy Lederman, Ed.D.
Michelle Lubonski, M.S., Ed
Cheryl Ludwig, MA, CCC-SLP
Michelle Miller, Psy.D.
Julie Ryan, Ph.D.
Rob Zambrano, Psy.D.

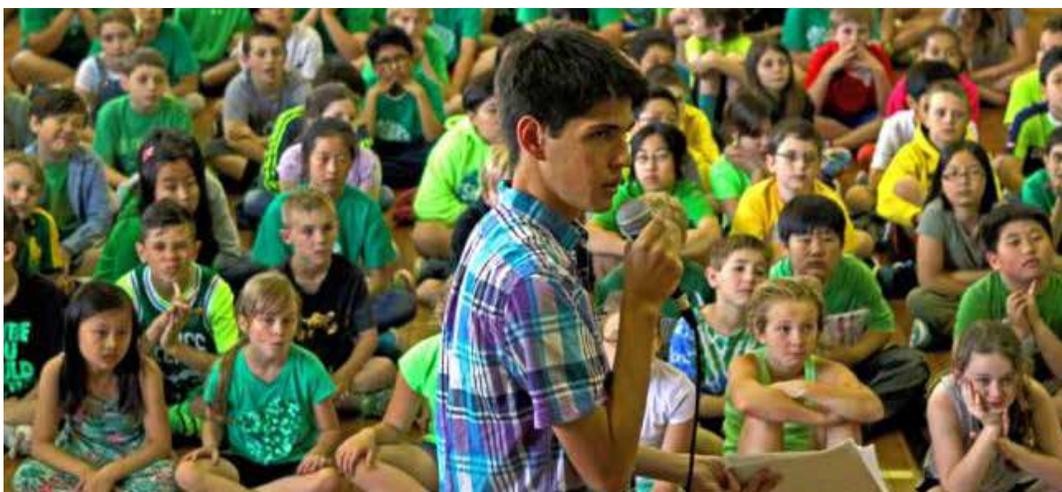
EDUCATION OUTREACH

Youth Advocates Spread TS Education and Awareness and Anti-Bullying Message to all Corners of New Jersey

Classrooms and organizations across New Jersey gained 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 250 presentations, raising awareness, standing up to bullying, and increasing understanding of this misunderstood disorder. In 2015, Youth Advocates led 27 workshops, reaching thousands across the state—including 900 in one presentation alone.

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.



NJCTS Youth Advocate Mike Hayden presented to 250 students in Cresskill, NJ.

Youth Advocate Presentations were conducted at the following institutions:

Stony Brook School, Branchburg
Presbyterian Church of Chatham Township, Chatham
Cresskill High School, Cresskill
Cresskill Middle School, Cresskill
Edward H. Bryan School, Cresskill
Merritt Memorial Elementary School, Cresskill
Kennedy Health, Cherry Hill
Gateway Regional High School, Deptford Township
Memorial Middle School, Fairlawn
West Freehold School, Freehold
Galloway Township Middle School, Galloway
George G. White Middle School, Hillsdale
Lions Wrestling Camp located at Rider University, Lawrence
Weston Elementary School, Manville

Marlton Elementary School, Marlton
Marlton Middle School, Marlton
Alan B. Shepard Elementary School, Old Bridge
Pine Hill Middle School, Pine Hill
Hilldale Elementary School, Pine Brook
Wrestling Camp located at Princeton University, Princeton
William J. McGinn Elementary School, Scotch Plains
Sewell School, Sewell
Indian Mills School, Shamong
Green Fields Elementary School, West Deptford
Haddon Township High School, Westmont
Mt. Pleasant Elementary, West Orange

Youth Advocates who led presentations in 2015:

Ally Abad
Anna Baldwin
Eric Baldwin
Sarah Baldwin
Sarah Ethridge
Emily Fleischman
Drew Friedrich
Grace Hawruk
Mike Hayden
Anna Hecklen
Ava Hecklen
Hallie Hoffman
Wyatt Gray
Charles Griebell
Paige Kowalski
Tess Kowalski
Tommy Licato
Cameron Mehlman
Jacob Nowacki
Joseph Nowacki
Liane Sturrock

Youth Advocates who were trained in 2015:

Blair Abney
Jacob Gerbman
Wyatt Gray
Charles Griebell
Anna Hecklen
Cami Jimenez
Ethan Lederman
Cameron Mehlman
Anthony Palmeri
Sam Regen
Casey Silenzio
Madison Silenzio
Liane Sturrock

EDUCATION OUTREACH

Youth Scholarship Winners

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 2015, 16 graduating seniors joined the ranks of the NJCTS Scholarship Club, representing themselves as outstanding advocates for Tourette Syndrome. This year, NJCTS broke with tradition and selected two first-place winners.

FIRST PLACE WINNERS



MARGARET ESPOSITO

Whippany

Esposito's award essay was titled "(MAGGIE) tics quietly in the background." She is the news editor at the school newspaper and prose editor for the literary magazine. She loves acting in musicals and performs with the Madrigal Singers.



JACOB FRANKENTHALER

Haddonfield

Frankenthaler's award essay was titled "Holding My Breath." He started a new after school club for students interested in engineering and physics and hopes to be an Aerospace Engineer some day.

HONORABLE MENTION WINNERS



Julia Bisirri
Marlton



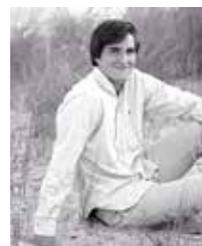
Emily Brenner
Basking Ridge



Hayley Faber
Egg Harbor Twp.



Maro Gamboa
Ringwood



Jordan Kean
Fair Haven



Nolan Kelly
Lyndhurst



Michael Lapolla
Westfield



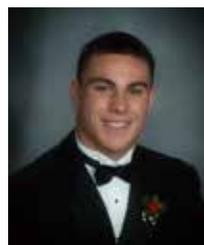
Sanjit Singh
Plainsboro



Nyameke Smith
Paterson



Jordan Stimmell
Edison



Bryan Walkley
Perrineville



Meghan Ward
Ocean



Alec Wolf
Short Hills

Not pictured: **Eric Fuertes**, *Linwood*

EDUCATION OUTREACH

Educator of the Year



Nokomis School Principal Carole Ramage (left) accepted the 2015 NJCTS Educator of the Year Award from Faith W. Rice at NJ Walks for TS at Medford Lakes on Sept. 20.

Since 2004, NJCTS has recognized outstanding educators who have made a difference in the lives of students with TS. In 2015, Principal Carole Ramage of Nokomis School in Medford Lakes, NJ was selected as the NJCTS Educator of the Year.

Ramage is an ongoing source of support and compassion in Anna and Ava Hecklen's lives. She took the girls under her wing, going above and beyond her responsibilities as a school administrator. When Anna's and Ava's tics became more noticeable to their peers, Ramage encouraged them to make presentations to their classes about Tourette Syndrome.

"The presentations changed their lives and Anna and Ava now feel comfortable knowing that everyone knows about TS and supports them," said their mother, Jen Hecklen.

The Hecklen family recognized Ramage on the last day of school and the award was presented to her at NJ Walks for TS at Medford Lakes on September 20.

NJBiz Healthcare Heroes

NJCTS was proud to be among six finalists selected for the 2015 *NJBiz* Healthcare Heroes Award in the Education Hero—Organization category.

The 2015 Healthcare Heroes awards program honored the best individuals and organizations that make a significant impact on the quality of health care in New Jersey. Winners were announced during a breakfast ceremony held at The Palace at Somerset Park in Somerset, NJ, on June 23. More than 400 guests attended the event and the corresponding issue of *NJBiz* was distributed to some 15,000 business leaders throughout New Jersey.

Other finalists in the Education Hero—Organization category were AtlantiCare, CentraState Healthcare System, Fairleigh Dickinson University School of Pharmacy, Meridian Health, NJCTS, and winner: The Liberty Science Center. NJCTS was honored to be in the company of such esteemed nominees.

Accepting the certificate on behalf of NJCTS was Executive Director, Faith W. Rice.



NJCTS was recognized by the *NJBiz* Healthcare Heroes Awards as a finalist in the Education Hero—Organization category.



MEDICAL OUTREACH

Educating the Medical Community about Tourette Syndrome and Associated Disorders

NJCTS works with hospitals throughout New Jersey to present Grand Rounds and Patient-Centered Medical Education (PCME) workshop trainings for doctors, nurses, and other healthcare providers.

Grand Rounds are presented by Tourette Syndrome experts and a teenager or young adult with TS to groups of between 50 and 100 physicians and many of these sessions are also open to community professionals.

PCME sessions are presented to residents in pediatrics, neurology, and family practice by a teenager or young adult with Tourette Syndrome, along with their parents. The presenters describe their experience with

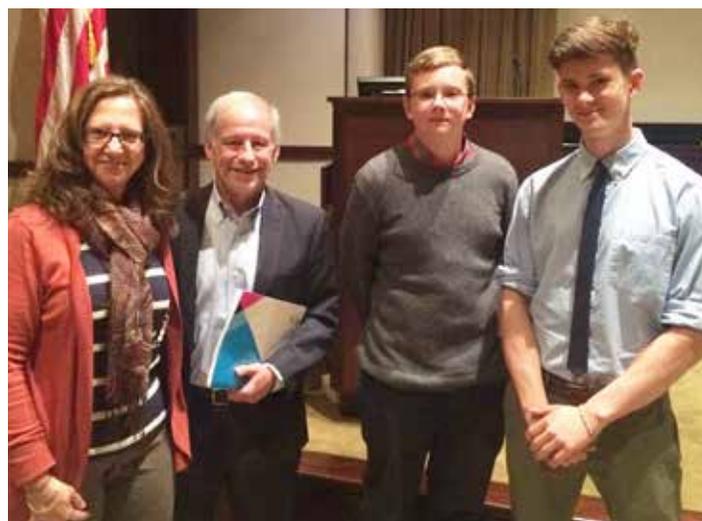
TS at school, at home, and in the community, and focus on initial diagnosis, quality of life, and encounters with physicians and the healthcare system.

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 2015, NJCTS reached nearly 400 medical professionals through Grand Rounds and PCME trainings at hospitals throughout the state.



Tolga Taneli, MD, Rutgers Medical School, led a Grand Rounds presentation accompanied by NJCTS Youth Advocate Tess Kowalski at Newark Beth Israel Medical Center.



Harvey Bennet, MD, Atlantic Health System, led a Grand Rounds presentation accompanied by NJCTS Youth Advocates Jacob and Joseph Nowacki and Anna Nowacki at Atlantic Health's Morristown Medical Center.

Grand Rounds and PCME participating institutions in 2015 included:

O'Leary Counseling, Barrington
Cooper University Hospital, Camden
Monmouth Medical Center, Long Branch
Goryeb Children's Hospital, Morristown
Morristown Medical Center, Morristown
Rutgers Medical School, Neurology Grand Rounds, Newark
Rutgers Medical School, Pediatrics Grand Rounds, Newark
Newark Beth Israel, Newark
Capital Health Medical Center, Pennington
Capital Health, Philadelphia
Overlook Medical Center, Summit

Presenters:

Harvey Bennett, MD	Anna Baldwin
Lawrence Brown, MD	Eric Baldwin
James Lechman, MD	Sarah Baldwin
Tracy Lederman, Ed.D	Grace Hawruk
Cheryl Ludwig, MA, CCC-SLP	Tess Kowalski
Tolga Taneli, MD	Jacob Nowacki
Meir Flancbaum, Psy.D.	Joseph Nowacki
Rob Zambrano, Psy.D.	

COMMUNITY OUTREACH

Informing the Community about Tourette Syndrome and Associated Disorders

NJCTS offers community trainings designed to support professionals in community-based organizations across New Jersey by providing information about Tourette Syndrome and associated disorders.

In 2015, NJCTS emphasized 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, and 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.



Volunteer Tina Swords represented NJCTS with Education Outreach Coordinator Gina Maria Jones at the Division of Children and Family Services Open House, Newark.

Community Presentation Participating Organizations in 2015 included:

National Association of Social Workers, Atlantic City
GenPsych, P.C., Brick
Bridgewater Public Library, Bridgewater
Jewish Community Center Resource Fair, Cherry Hill
Youth Consultation Service, East Orange
Family Based Services Association, Eatontown
Centenary College Awareness Fair, Hackettstown
Mental Health Association in Southwestern NJ,
Haddon Heights
Family Support Organization of Burlington County,
Lumberton
New Jersey Coalition for Inclusive Education,
Montclair
SPAN Conference, Montclair
Division of Children and Family Services Open House,
Newark

Project Self-Sufficiency, Newton
Straight & Narrow, Inc, Paterson
Learning Disabilities Association of New Jersey,
Piscataway
Randolph High School Resource Fair, Randolph
Bergen's Promise Resource Fair, Rochelle Park
Bay Counties Administrators of Special Education,
Salem
School Nurses Association Conference, Somerset
Somerville Street Fair, Somerville
Partnership for Children, West Orange
Children's Inter-Agency Coordinating Council (CIACC)
of Atlantic, Bergen, Burlington, Camden,
Cumberland, Essex, Gloucester, Mercer, Monmouth,
Morris, Ocean, Passaic, Salem, Somerset, Sussex,
and Union counties

Presenters:

Penny Dragonetti
Gina Maria Jones, M.Ed
Tracy Lederman, M.S., Ed.D
Cheryl Ludwig, MA, CCC-SLP
Julie Ryan, Ph.D.

Volunteers:

Carolyn Baldwin
Kathleen Donahue
Susan Everett
Marie Flynn
Jen Hecklen
Bobbie Israelsky
Nicole Janiec
Christina Nowicki
Alicia O'Hara
Maddie Pucciarello
Tina Swords

NJCTS IMPACT BY THE NUMBERS

IN JUST 2015, NJCTS HAS REACHED:

3,235

Educators and students through school in-service presentations

390

Medical professionals through Grand Rounds and PCME presentations

7,742

Participants from around the world through the Wednesday Webinars series

600+

More than 600 families—new and returning—through phone support

81

Teens and young adults living with TS through the NJCTS Tim Howard Leadership Academy Alumni Association

200

Individuals in a fun, safe, and supportive environment at the 11th annual Family Retreat Weekend

SINCE 2010, NJCTS HAS REACHED:

284,000+

Individuals through NJCTS core programs

13,931

Students and education professionals through in-service presentations

4,294

Medical professionals through NJCTS presentations and programs

31,336

Wednesday Webinar participants from around the world

10,755

Individuals served by family intake and phone support

222,721

Professionals at conferences and conventions



FAMILY SUPPORT

Family Retreat Weekend—“Where The GreatS Gather” since 2004

Families from across the region affected by Tourette Syndrome and associated disorders joined in a fun-filled weekend at YMCA Camp Bernie in Port Murray, NJ, June 12-14. For the 11th year, NJCTS Family Retreat Weekend provided children and their families with the opportunity to meet others with TS, learn more about their diagnosis, and engage with peer mentors in a fun, safe, and supportive environment. Nearly 200 people traveled from far and wide, with more than half of the families attending for the first time.

“The Family Retreat Weekend has been an annual trip for us for 11 years now and is the highlight of our summer,” said Andy and Donna Friedrich. “Our son has gone from an 11-year-old camper to a 22-year-old mentor and enjoys coming back every year to work with and encourage other kids with TS. We also enjoy meeting with other parents to encourage them as they tread the waters of having children with TS.”

Families had many opportunities to bond and share their stories while participating in Camp Bernie’s activities, including swimming,

basketball, wall climbing, archery, arts & crafts, and so much more. Two of the biggest hits at the Family Retreat Weekend were the Friday night campfire and Saturday night’s Talent Show led by DJ Harry Hubert. Kids and parents also participated in the educational portion of the weekend, attending powerful workshops and round-table discussions.

“The weekend was an amazing milestone for our family. It was so special to be around other families dealing with TS,” said Lonny Kramer. “My kids flourished and felt free to roam around in the safety of camp. The panels were especially great. My son enjoyed asking questions of the older kids and hearing what they had to say.”

NJCTS Family Retreat Weekend is an important event for families affected by Tourette Syndrome to learn more about the diagnosis and, most importantly, to know that they are not alone and that support and services are available at every level.



Family Retreat Weekend builds friendships to last a lifetime.



New and returning families from far and wide enjoyed a beautiful weekend away.



Sam and Sydney Regen presented a hand-made sign to Faith Rice at the 2015 Family Retreat Weekend.



There’s always so much to enjoy at the Saturday night Talent Show—the highlight of the weekend.



Families were introduced to Dr. Robert King of Yale University and NJCTS research projects while at Family Retreat Weekend.



With so many ways to play, it’s no wonder the kids want to stay.

FAMILY SUPPORT

Physicians 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 state with expertise in 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 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.

Call-in Support Groups

Families are busier than ever, balancing school work, sports, and other after-school activities. NJCTS repeatedly hears that families want to connect with others but finding the time to squeeze in a support group meeting is a challenge for families.

In 2015, NJCTS added Call-in Support Groups for the convenience of families. Parents and care-givers are invited to dial in to a conference call line to ask questions and hear from others affected by Tourette Syndrome and associated disorders. The groups meet once each month at 7:30 pm for one hour. Parents and care-givers from across the country are encouraged to participate and new members are always welcome. Call-in Support Groups foster an informal and judgment-free environment where all are welcome.

“ I pushed myself to make the first call into the group discussion and my life will be forever changed by it. Thank you! ”

—TS Mom

“ It felt so good to speak with others who have similar experiences. ”

—TS Dad

FAMILY SUPPORT

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.

Sue and Pat encourage others to support the NJCTS Youth Development programs and ask you to consider making a donation in honor of or in memory of someone you love to help sustain the fund.

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 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 individuals and families to help.

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.

Volunteer opportunities:

- Become a school in-service 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 committee

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

NJ Center for Tourette Syndrome and 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
- Support the Jeff Vitek Memorial Fund for Youth Development

Program & Technology needs:

- Gift cards to Costco, BJ’s, Sam’s Club, grocery stores, Staples
- Office supplies
- Conference call phone
- Webcam
- Camera/Camcorder
- Netbook/Notebook

AWARENESS & ADVOCACY

NJ Walks for TS Expands Statewide

In 2015, NJ Walks for TS grew to cover all of New Jersey, thanks to the addition of the South Jersey walk in Medford Lakes. Each event, a 5K walk/fun run, serves as a day of fun, advocacy, awareness, and empowerment on behalf of the 28,000 NJ kids and families living with TS.

What makes NJ Walks for TS special is that it was started for kids, by kids, to help kids. Proceeds from NJ Walks benefit the NJCTS Education Outreach Program which aims to reach every teacher, student, and healthcare provider in New Jersey and educate them about TS and associated disorders to make the classroom a safer environment for a struggling student with TS and to educate doctors, nurses, and mental health professionals to diagnose and treat TS more effectively than ever.

On March 29, walkers and runners kicked off the season with NJ Walks for TS at Princeton with enthusiasm and a show of support for kids with TS by friends, family, and legislators. This event is led by Tess and Paige Kowalski and their father, NJCTS Board Member Tim Kowalski.

On September 20, NJ Walks for TS at Medford Lakes came on board in South Jersey. Over three hundred walkers, runners, and well-wishers gathered at Vaughan Hall to kick off a new tradition thanks to Jen Heicklen and her family who rallied their entire community behind the walk.

Cold temperatures couldn't keep dedicated families and friends from supporting NJ Walks for TS at Mendham on November 14. Youth Committee member Kyle Swords welcomed the crowd with a speech that summed up the spirit of this movement.

"Thank you all for coming, this is a really special moment for me. I am happy to participate in this activity. NJCTS is a really helpful and supportive group. They help me in my everyday life. When they first came to my school and told my fellow peers about my TS they stopped laughing at me. They also understood what I was going through. They gave me more respect and liked me more. I'd like to give a shout out to Sarah and Mike for coming to my school, and for teaching my peers about my medical condition. It has changed my life. Without this group my life would be so difficult. Thank you everybody for coming and donating to NJCTS, this means a lot to me."

—Kyle Swords, age 10, NJ Walks for TS Youth Committee



AWARENESS & ADVOCACY



The Kowalskis led hundreds of supporters through the trails at Princeton.



The Youth Co-Chairs of Mendham joined NJCTS board president Tim Omaggio in kicking off the day.



South Jersey families came out in droves in support of the tens of thousands of children with TS in the state.



NJCTS Educator of the Year Carole Ramage, Faith Rice, and Honorary Committee Chair Assemblyman Troy Singleton cut the ribbon at the first NJ Walks for TS in South Jersey at Medford Lakes.



Hundreds walked the walk in support of making a difference in the lives of those with the neurological disorder. Faith Rice is joined by Jarod Gilman (left) and Dr. Lawrence W. Brown of CHOP (right) at NJ Walks for TS at Medford Lakes.

2015 NJ Walks for TS Honorary Committee

Congressman Donald Norcross (D-1)
 Congressman Leonard Lance (R-7)
 Congressman Albio Sires (D-8)
 Congressman Rodney Frelinghuysen (R-11)

State Senator Jim Whelan (D-2)
 State Senator Stephen Sweeney (D-3)
 State Senator James Beach (D-6)
 State Senator Diane B. Allen (R-7)
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 State Senator Paul Sarlo (D-36)
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 Assemblyman Christopher Brown (R-8)
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 Assemblywoman Donna Simon (R-16)
 Assemblyman Jack Ciattarelli (R-16)
 Assemblyman Joe Danielson (D-17)
 Assemblyman Patrick Diegnan (D-18)
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 Assemblywoman Annette Quijano (D-20)
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 Assemblyman Sean T. Kean (R-30)
 Assemblyman Timothy Eustace (D-38)

Princeton Mayor Liz Lempert
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 Plainsboro Mayor Peter Cantu

NJ Walks for TS Committee

Princeton

Youth Co-Chairs:

Tess Kowalski
 Paige Kowalski
 Ethan Lederman
 Hallie Hoffman

Committee:

Tim Kowalski
 Stephanie Hoffman

Medford Lakes

Youth Co-Chairs:

Anna Hecklen
 Ava Heicken
 Hayley Faber

Committee:

Jen Hecklen
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Mendham

Youth Co-Chairs:

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Committee:

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AWARENESS & ADVOCACY

Remembering our friend Oliver Sacks, the neurologist who humanized the disorders he studied



Dr. Oliver Sacks speaking at the NJCTS gala in 2001.

Adapted from Faith W. Rice's opinion article in The Star-Ledger, Sept. 12, 2015

"I had the honor of getting to know neurologist and author Dr. Oliver Sacks when we were in the early stages of creating NJCTS and establishing the direction of the organization. He created enormous awareness and sensitivity around a TS diagnosis and shared with the general public his curiosity at unraveling the mysteries of Tourette Syndrome.

Dr. Sacks, based on his clinical work and research, focused on people living with TS and was, perhaps, the only author to write about those with TS in such a compassionate and understanding way, humanizing this often misunderstood and misdiagnosed disorder.

In 2001, we were honored to have Dr. Sacks as our guest speaker at our NJCTS gala held at the AT&T headquarters in Basking Ridge, NJ. On the day of the gala, Dr. Sacks arrived early and insisted that I sit and share with him everything about our work and plans for moving our organization forward. He was warm, brilliant, and compassionate.

Oliver Sacks shared our vision for the TS community. He was a truly gifted and brilliant individual who taught us so much about each other. He will be missed."

Collaborative Academic Research Efforts for Tourette Syndrome Act of 2015

A bill to spur federal health officials to study TS and improve treatment for the neurological disorder was once again championed in Congress. The Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2015 (H.R. 619) was reintroduced by Congressman Albio Sires (D-NJ 8).

Inspired by the work of NJCTS, Rep. Sires first introduced the legislation in December 2011, with a Senate companion bill introduced by Senator Robert Menendez (D-NJ). The CARE act amends the Public Health Service Act for the inclusion of coordinated programs and activities by the National Institutes of Health to provide intensive research into Tourette Syndrome (TS).

The CARE act does not authorize any new funding for TS, but rather reallocates existing funds towards new programs to more effectively

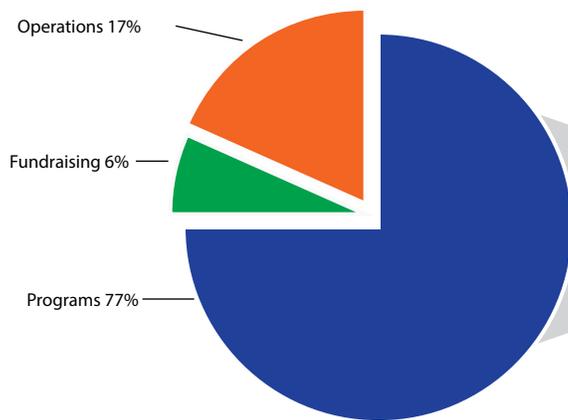
research and collect data on TS. The Act would require the NIH to award grants and contracts to academic, healthcare, and other institutions to support the establishment of four to six Collaborative Tourette Syndrome Research Centers in different regions of the country. These centers would host world-class, targeted clinical research into TS and associated disorders, which include mental health and learning disabilities.

That research would be used along with a wide-reaching collection of important data on various aspects of TS to provide better understanding of the disorder and guide strategy into the future of TS research.

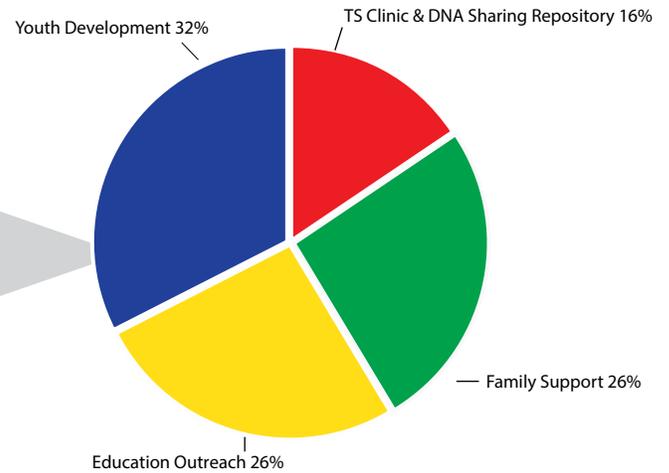
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Where the money goes:

Total Expenses



Program Expenses



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