

NJ Center for Tourette Syndrome

CELEBRATING
10 YEARS
2014 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 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.



Dear Friends and Families,

Ten years ago, NJCTS opened in a tiny basement office in Somerville, NJ. Our mission was to make the world a better place for children and families living with Tourette Syndrome. And together we're doing just that. Over the past ten years, our advocacy has benefited more than 500,000 people – more than 50,000 people each year.

As the nation's first Center of Excellence for Tourette Syndrome, NJCTS has set a new course for TS research, trained over 70,000 teachers to make their schools a safer place for kids with TS and its associated disorders, created a new generation of doctors with expertise in recognizing and treating the complexities of TS, and delivered direct support and referrals to thousands of families. NJ-inspired federal legislation could soon improve life for hundreds of thousands of Americans with TS. We are proud that because of our efforts, a child facing a TS diagnosis today has many more resources and opportunities than just a decade ago.

We look forward to the future and I ask that you continue to partner with NJCTS as we innovate and deliver world-class programs and services. Your support through financial gifts and volunteer hours allows NJCTS to meet the ever-growing demand for services. To discuss your place in our future, please call me at 908-575-7350. I very much look forward to your call.

Congratulations to our staff, board, professional partners, and to our families on this special milestone.

Best wishes,

Faith W. Rice
Executive Director

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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 children and adults 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 5 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

Leadership Academy

NJCTS Tim Howard Leadership Academy

SOCCER SUPERSTAR AND NJCTS TEAM UP AND TRAIN TEENS AS LEADERS
AT RUTGERS UNIVERSITY

“Show us your grit!” said Faith Rice as she watched the group of teens stand together for a photo.

Among the group – a pilot, a playwright, a professional actress, a classically trained singer; just to name a few. Each one unique, but all unified by TS.

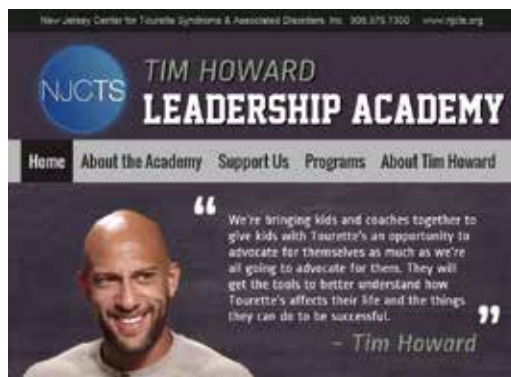
Having a neurological disorder in childhood forces an early maturity.

“Because kids with TS often refine their ability to focus at a very early age (often on suppressing tics), they have a broad range of extremely refined talents,” said Melissa Fowler MA, MEd, education outreach coordinator for the NJ Center for Tourette Syndrome (NJCTS). “They have tremendous dedication to their passions and hobbies.”

Fowler had the task of developing curriculum to give this group of extraordinary adolescents the tools necessary to understand their disorder, learn to advocate for themselves and others – the mission of the NJCTS Tim Howard Leadership Academy.

The Academy focuses on the three main areas of biology, psychology and the social components of having a TS diagnosis. Participants learn about the brain mechanisms behind Tourette, the psychological disorders that present challenges and the social aspects of having a stigmatized condition – with a big emphasis on resilience.

Content was developed through consultation with educators, advocates, psychologists, occupational therapists and social workers.



With their suggestions in place, Rice recruited leading experts while Fowler mapped out the program. Renowned genetics researcher Dr. Jay Tischfield spoke about neurobiology, Dr. Robert King of the Yale Child Study Center delivered a presentation on the biological implications of TS. Dr. Lisa Cox of Stockton University, herself living a vibrant life with TS, ran a workshop on overcoming the feelings of social isolation that come with such a visible disorder.

Each of the 22 participants contributed thoughtful questions and were eager to share life-skills tips with one another. The teens were divided into groups led by “coaches” – young adults with TS living successful lives.

Given the opportunity to ask questions in panel discussions with experts and coaches, the young adult mentors were grilled on the major concerns of teens everywhere: dating, driving and college. And to their delight, the unanimous conclusion achieved over the three-day program at Rutgers University, is that you can drive, date and do well in college despite Tourette Syndrome.

“Having a role model in the coaches meant so much to each of the teens,” said Rice, “Knowing that there’s light at the end of the tunnel, that you can live a happy life with TS is a reassurance that’s invaluable.”

“I wanted them to feel like they had learned enough to become



Academy kids around piano: It didn't take long for friendships to form and interests to collide.



Melissa Fowler, MA, MEd (upper right) leads a group discussion on empowerment.

Leadership Academy

experts both about TS (and co-morbidities) AND about themselves; able to speak confidently about their own strengths and their own obstacles, to recognize what they need to be successful and advocate for it; to feel comfortable enough about themselves that they feel resilient, able to face a public who is miseducated and misinformed about TS (and its associated disorders),” said Fowler.

Over the course of the weekend, participants spoke of resilience, courage and grit. With the lessons and skills imparted through the Academy, it's no doubt this inaugural class will continue to show their grit in the skies, on the stages, in the classroom and beyond.



Participants, coaches and speakers gather to celebrate a successful Academy launch.



Dr. Jay Tischfield discusses current genetic research that will one day lead to a cure.



Jules Bliss (front) and Max Smeader listen to a session on resilience led by Dr. Lisa Cox.



Dr. Robert King leads a workshop on Brain Biology, a comprehensive understanding of the neurological mechanics involved in the cause and treatment of TS.

NJCTS THANKS OUR COACHES

Jordan Chervin	Jay Geyer	Danielle Piacentile
Emily Fleischman	Marisa Lenger	Amanda Silvers
Drew Friedrich	Steven Lindenbaum	Ben Stark



Danielle Piacentile takes in a compelling story from a fellow Academy member. The group formed an instant bond, and were comfortable to share candid experiences coping with TS.



Coaches served an important role in bringing out the best in each participant and providing approachable examples of how it's possible to succeed in college and the workforce with TS. (Left row, from top) Steven Lindenbaum, Jay Geyer, Amanda Silvers, Emily Fleischman, (Right row, from top) NJCTS Education Outreach Coordinator Melissa Fowler, Drew Friedrich, Ben Stark, Jordan Chervin, Danielle Piacentile.



The success of the program relies heavily on participants' willingness to share. The class of 2014 delivered beyond our expectations.

THE 2014 NJCTS TIM HOWARD LEADERSHIP ACADEMY CLASS

ALLY ABAD	North Brunswick, NJ
JACOB BAIRD	Lake George, NY
ANNA BALDWIN	Mantua, NJ
SARAH BALDWIN	Mantua, NJ
JACQUELINE BECKHARDT	Melville, NY
DEVON BELLINO	Canasota, NY
JULES BLISS	Brigantine, NJ
TYLER BLOCH	Jerhico, NY
BECKY CERVİ	Depew, NY
SARAH ETHRIDGE	Chatham, NJ
NOAH FELDSTEIN	Randolph, NJ
JILLIAN FIRENZE	Clay, NY
ADAM FISHBEIN	Elkins Park, PA
GRACE HAWRUK	Butler, NJ
MIKE HAYDEN	Hillsdale, NJ
HALLIE HOFFMAN	Belle Mead, NJ
RYAN INZEO	Williamsville, NY
TOMMY LICATO	South Plainfield, NJ
MAX SMEADER	Clay, NY
ANDREW TONEY	Kenmore, NY
LEWIS VICTOR	East Aurora, NY
KAELA WELLER	Hamilton, NJ

Education Outreach

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

Through the Peer In-Service Program, NJCTS delivers a powerful anti-bullying message of acceptance to students in schools across the state. In-Service presentations are conducted by

professional educators, psychologists and specially trained NJCTS Youth Advocates.

In 2014, NJCTS reached many new teachers and students through both programs. This work is helping to construct a more inclusive, safe and successful classroom environment for students with TS and its associated disorders.



Melissa Fowler, MA, MEd



Janine Howley, MA



Tracy Lederman, EdD



Aliyssa Letts



Cheryl Ludwig, MA,
CCC-SLP



Robert Zambrano, PsyD



Graham Hartke, PsyD



Meir Flancbaum, PsyD



Michelle Lubonski,
MS Ed

FACULTY IN-SERVICE PARTICIPATING SCHOOLS 2014

H&M POTTER ELEMENTARY SCHOOL	Bayville	WILLOWGLEN ACADEMY	Sparta
VETERANS MEMORIAL ELEMENTARY SCHOOL	Brick	MORGAN ELEMENTARY SCHOOL	Hamilton
THE FORREST LAWN SCHOOL	Fair Lawn	ST. JOSEPH'S SCHOOL	Carteret
OAKVIEW ELEMENTARY SCHOOL	West Deptford	BAYSHORE MIDDLE SCHOOL	Middletown
STONE BROOK SCHOOL	Branchburg	WHITMAN ELEMENTARY SCHOOL	Turnersville
HOLY CROSS SCHOOL	Rumson	WESTWOOD JR. & SR. HIGH SCHOOL	Washington Township
LEROY GORDON COOPER ELEMENTARY	Cliffwood Beach	NEW ROADS SCHOOL	Somerset
MELVIN H. KREP SCHOOL	East Windsor	YARDVILLE HEIGHTS ELEMENTARY SCHOOL	Hamilton
GREEN HILLS SCHOOL	Newton	CARPENTER ELEMENTARY SCHOOL	Old Bridge
SHEPARD MIDDLE SCHOOL	Kinnelon	PARSIPPANY HILLS HIGH SCHOOL	Parsippany

Education Outreach

Youth Advocates Make a Lasting Impression

Sarah Ethridge has spoken to crowds of all ages and sizes during her two-plus years as a Youth Advocate for the NJ Center for Tourette Syndrome & Associated Disorders. Her presentation is captivating, informative and essential – regardless of whether it's being given to a handful of educators or to an auditorium of more than 500 junior high students.

Her presentation at Warren Middle School was one to remember. Not only did the students, teachers and parents in attendance learn that Tourette Syndrome is an inherited, misdiagnosed, misunderstood neurological disorder that affects one in 100 kids, they were so impressed that they decided to give back.

As a result of Ethridge's presentation – described as “inspiring” by many of those in attendance – the Warren Middle School staff, students and Parent Teacher Organization donated \$200 to NJCTS – a first resulting from a talk given by a Youth Advocate such as Ethridge.



“Sarah is a remarkable young woman,” said Anya Muhlhauser, a member of the Warren Middle School Cultural Arts Committee. “She engaged our students so well, and I so admire her courage, honesty and bravery in her mission to educate and enlighten others about Tourette Syndrome (through) her message of acceptance and support.”

Ethridge, a student at Chatham High School, addresses concepts such as tics – involuntary sounds and movements that accompany TS – anti-bullying and self-advocacy during her 30-minute presentation.

SCHOOLS PARTICIPATING IN THE YOUTH ADVOCATE PROGRAM

OAKVIEW ELEMENTARY SCHOOL	West Deptford
CAMPBELL ELEMENTARY SCHOOL	Metuchen
STONE BROOK SCHOOL	Branchburg
CLEARVIEW REGIONAL MIDDLE SCHOOL	Mullica Hill
PLEASANT VALLEY SCHOOL	Mullica Hill
ST. FRANCIS CATHEDRAL SCHOOL	Metuchen
LEROY GORDON COOPER ELEMENTARY	Cliffwood Beach
BAYSHORE MIDDLE SCHOOL	Leonardo
LENAPE VALLEY REGIONAL HIGH SCHOOL	Stanhope
GREEN HILLS SCHOOL	Newton
CAMBRIDGE ELEMENTARY SCHOOL	Kendall Park
SCHUYLER COLFAX MIDDLE SCHOOL	Wayne
THOMAS JEFFERSON ELEMENTARY SCHOOL	Turnersville

2014 YOUTH ADVOCATE PRESENTERS

Emily Fleischman
Grace Hawruk
Tommy Licato
Tess Kowalski
Sarah Ethridge
Sarah Baldwin
Anna Baldwin

Education Outreach

In 2014, NJCTS delivered a variety of workshops, presentations and lectures to groups and students across the state including thousands of teachers and administrators through professional development conferences, and thousands of medical and education students through college and hospital lectures.

Tourette Syndrome is a complex disorder, frequently accompanied by challenging co-morbid disorders. Each person with Tourette Syndrome presents a unique set of challenges to the medical and education communities. Professionals who work with children with TS – including doctors, nurses, psychologists and teachers – need accurate information and practical strategies. Our reputation for delivering timely and functional education speaks for itself. Education Outreach is one of the ways NJCTS is fulfilling its mission to improve the lives of people living with TS.



NJCTS reaches tens of thousands of educators each year through the NJEA convention in Atlantic City.



Providing resources and training to New Jersey schools is part of our mission.

2014 NJCTS PRESENTATIONS THROUGHOUT NEW JERSEY

MARTIN LUTHER KING MITZVAH DAY	Congregation B'nai Israel	Millburn
LEARNING DISABILITIES PRESENTATION	JCC MetroWest	West Orange
JUVENILE JUSTICE PRESENTATION	Statewide Parent Advocacy Network	Somerville
TS WORKSHOP	Virtua Hospital	Voorhees
ABILITIES AWARENESS DAY	Centenary College	Hackettstown
PSYCHOLOGY GUEST LECTURE	Rutgers University	Piscataway
FACETS OF DYSLEXIA CONFERENCE	Rowan Univ. Med School	Stratford
NJ COALITION FOR INCLUSIVE EDUCATION CONFERENCE	Montclair State University	Montclair
COMMUNITY SERVICE FAIR	Millburn High School	Millburn
SCHOOL HEALTH CONFERENCE	American Academy of Pediatrics	Edison
NJEA CONVENTION	NJ Education Association	Atlantic City

Education Outreach

Scholarship Winners

Since 2001, the NJCTS Children's Scholarship Award has been given to more than 200 outstanding high school seniors in New Jersey who have excelled in their schools, communities and lives – representing themselves as excellent advocates for Tourette Syndrome.



FIRST PLACE WINNER

MICHAEL TYRELL

Iselin

Michael's winning essay, titled "No Limits", highlighted his philosophy for living with TS. His impressive list of extracurricular activities included membership in the National Honor Society, Science National Honor Society, Business Honor Society and several varsity sports teams. Tyrell is also an Eagle Scout. He graduated from John F. Kennedy Memorial High School in Woodbridge and attends North Carolina University.

HONORABLE MENTION WINNERS (Not pictured: **Michael Zarro**, *West Orange*)



Mickey Avenoso
Bridgewater



Mary Kate Donahue
Marlton



Julia Funcheon
Fair Lawn



Grace Hawruk
Butler



Daniel Henderson
Rahway



David Letts
Hillsborough



Tabitha MacKenzie
Atco



Noah Mazzeo
Rumson



Matthew Nussbaum
River Vale



Matthew Rosen
Little Silver



Matthew Santucci
Oradell



Owen Taggart
Rockaway

Medical Outreach

NJCTS Hosts New Jersey's First Annual Childhood Mental Health Symposium

EVENT FOCUSED ON NEUROPSYCHIATRIC DISORDERS

Neuropsychiatric disorders, including Tourette Syndrome, tics, obsessive-compulsive disorder (OCD) and trichotillomania affect tens of thousands of children across New Jersey. NJCTS is proud to have partnered with the NJ Chapter of the American Academy of Pediatrics, the NJ Psychiatric Association, the NJ Council of Child & Adolescent Psychiatry and Rutgers University to share the latest and best information with the state's medical, mental health and education community.

Program highlights:

- A guided tour of the world's largest university-based biorepository and home to the National Institute of Mental Health (NIMH) Center for Collaborative Studies of Mental Disorders- which includes samples from families with schizophrenia, bipolar disorder, Alzheimer's disease, autism, OCD, depression and ADHD.
- A panel discussion offering insight into the personal challenges of managing mental health disorders and the best practice approach for achieving optimal wellness. Parents and children participating in this discussion focused on social, educational, sibling and parenting issues.
- Continuing Medical Education credits were given to qualified professionals for participating in this event

Featured Speakers:



Robert A. King, MD

Medical Director, Tourette/OCD Clinic at Yale Child Study Center

Dr. King leads a team committed to treating and preventing childhood mental illness through the integration of research, clinical practice, and professional training.



Lori Rockmore, PsyD

Former Director of the Tourette Syndrome Program, Graduate School of Applied and Professional Psychology at Rutgers University

Dr. Rockmore is a clinical psychologist with expertise in child development, impulse control disorders, and social and emotional learning.



Michael Bloch, MD

Assistant Director, Yale OCD Research Clinic & Assistant Unit Chief, Clinical Neuroscience Research Unit (CNRU)

Dr. Bloch focuses on developing better treatments for children and adults with mental disorders by examining predictors of long-term outcome with an emphasis on neuroimaging. Dr. Bloch is also an expert in psychopharmacology.



Jay A. Tischfield, PhD, FFACMG

Duncan and Nancy MacMillan Distinguished Professor of Genetics, Pediatrics and Psychiatry, Scientific Director & CEO, RUCDR Infinite Biologics®, Executive Director, Human Genetics Institute of New Jersey

Dr. Tischfield studies the genetic causes of common, complex diseases. His experience in organizing, leading and executing large scale projects involving hundreds of thousands of human subjects provides the background expertise for RUCDR Infinite Biologics.

Medical Outreach



Dr. Lori Rockmore explores a variety of treatment modalities and their effectiveness.



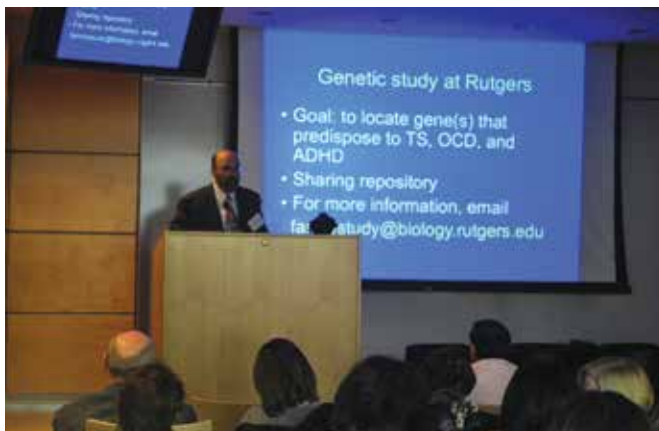
NJCTS welcomed professionals from across the region to the first ever Annual Childhood Mental Health Symposium.



Faith Rice (left) discusses the day's itinerary with an attendee.



Dr. Robert King of Yale University discussed the causes and factors that lead to neuropsychiatric disorders like OCD and TS.



Dr. Jay Tischfield introduces the audience to the DNA and Cell Repository at Rutgers University and how this data is currently available to scientists worldwide.



NJCTS member families participated in the family panel at the first Childhood Mental Health Symposium

Medical Outreach

Patient Centered Medical Education Program

The Patient-Centered Medical Education program is a critical tool in helping physicians and other healthcare professionals understand the challenges that come with TS. Since 2010, NJCTS has trained young people and their families to share TS from their unique and personal viewpoint.

Each presentation is led by a medical professional with expertise in diagnosing and treating TS and accomplishes the following learning objectives while presenting a patient-centered perspective of life with TS.

- Identifying and differentiating between the signs and symptoms of patients with varying tic disorders
- Describing and identifying the most common associated conditions in individuals with TS
- Giving the latest advances and comprehensive approaches in treatment for individuals with tic disorders



The Arnold P. Gold Foundation works with healthcare professionals in training and in practice to instill a culture of respect, dignity and compassion for patients and professionals. In 2014, the Foundation awarded \$5,000 to support the NJCTS Patient-Centered Medical Education Program.

Teens and Specialists Deliver Critical Medical Training

Physicians spend a lot of time in training – but when it comes to understanding the challenges of Tourette Syndrome (TS), there's a “gap”, according to Tolga Taneli, M.D.

“TS is diagnosed too late – from its first symptoms to diagnosis sometimes takes a decade or more,” said Dr. Taneli. “There is a training gap in physicians to make them able to recognize early symptoms.”

He emphasizes a “critical” need to train first-line physicians like family practitioners, pediatricians and internists – doctors who are more likely to encounter a patient before they seek the help of a specialist.

The NJCTS program consists of a specialist with TS expertise and teen advocates, living with TS, who are able to convey the emotional toll and communication challenges in a way that transcends clinical terms.

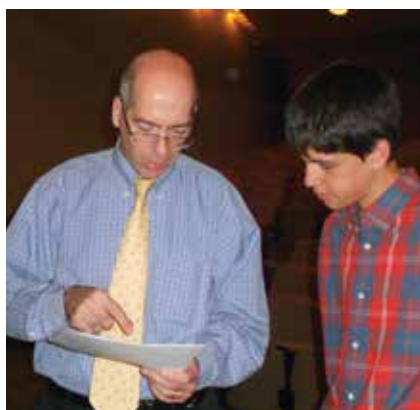
In October, Dr. Taneli was joined by Michael Hayden of Hillsdale at Hackensack University Medical Center. The teen knows sharing his story is important to help a new generation of kids facing a TS diagnosis.

“I hope [the doctors] have a better understanding of how to diagnose the

disorder soon after symptoms are reported,” said Hayden. “Kids deserve that so they can deal with the stress that accompanies TS.”

Stress, particularly for people living with a neurological disorder, takes many forms. Hayden explained how TS shapes his daily perspective:

“My tics go way up when school starts. Aside from the work aspect of school, the social part is stressful, too.



Dr. Tolga Taneli and Michael Hayden prepare to share the clinical and personal implications of TS to a group of resident physicians at Hackensack University Medical Center.

“Some peers do not exactly understand Tourette, which can result in a number of things – the worst of which is bullying. Bullying is amazingly stressful...but educating the bully on what Tourette is has worked for me in the past. Other stressors vary from person to person.”

Dr. Taneli recognizes the impact of having teens explain the human toll of TS.

“The teen advocates are well-received and give a good sense of what the disorder is beyond what is described in medical books – it gets the most praise,” he said.

Making an impact today, according to Dr. Taneli, is necessary for improving the quality of care and proficient diagnosis for children and families in the future.

“[The impact] will be seen years from now in how it impacts the doctors' ability to diagnose TS,” said Dr. Taneli.

Hayden is hopeful that his participation in the NJCTS Patient-Centered Medical Education Program will increase compassion and commitment to helping kids with TS.

“If you do not have a good doctor that you are comfortable around, you are really not going to get anywhere with your TS,” he said. “I cannot stress how important this is.”

Medical Outreach

NJCTS Medical Outreach Partner Honored by NJ Senate



Dr. Stuart Green, who has guided the NJCTS Patient Centered Medical Outreach program, was honored for his anti-bullying work by the New Jersey state Senate.

NJCTS congratulates Stuart Green, DMH, LCSW on being honored by the New Jersey State Senate. Dr. Green is an NJCTS Advisory Board member and has worked closely to develop the TS Patient Centered Medical Education program.

Dr. Green was honored along with his New Jersey Coalition

for Bullying Awareness and Prevention in observance of National Bullying Prevention Month. The Coalition works to provide students, educators and other community members with the support necessary to address bullying. This includes explanations of school district policies and expectations, the law and reporting process and the legal consequences of

bullying in all forms. Students are empowered to avoid being a bully, victim or bystander.

The resolution was presented by Senators Joseph Vitale (D-19), Loretta Weinberg (D-37) and Diane Allen (R-7) for Dr. Green and the Coalition's "unwavering commitment to the eradication of all potential instances of bullying, intimidation and harassment."

Dr. Green is an associate director of Overlook Family Medicine Residency Program, the behavioral sciences director at Overlook Medical Center and a clinical instructor of medicine at Icahn School of Medicine at Mount Sinai. He founded and directs the New Jersey Anti-Bullying Coalition which is a statewide network of groups addressing childhood bullying, chaired New Jersey's Commission on Bullying in Schools and helped develop and obtain passage of the NJ Anti-Bullying Bill of Rights.

Dr. Green is a frequent collaborator and the Tourette Syndrome community is fortunate to have him as a friend. "This honor is very fitting, he is tireless in helping those who feel the stigma of Tourette Syndrome find a strong voice," said NJCTS Executive Director Faith W. Rice.

NJCTS maintains a Physician Referral List (PRL) as a direct link for families and professionals to access more than 200 medical professionals who have expertise in treating TS and associated disorders (ADHD, OCD, anxiety, depression, etc.) The list is compiled from interviews with clinicians and recommendations from our families and other clinicians. The PRL is a critical aspect of our work at NJCTS, and we are constantly updating and developing it to provide the best, up-to-date information on clinicians who have interest and expertise in these areas. The medical professionals on the PRL include:

Neurologists
Psychiatrists

Psychologists
Social Workers

Developmental
Pediatricians

RECENT PCME GRAND ROUNDS PARTICIPANTS

NEWARK BETH ISRAEL MEDICAL CENTER	Newark
JERSEY SHORE MEDICAL CENTER	Neptune
ROBERT WOOD JOHNSON UNIVERSITY HOSPITAL	New Brunswick
UNIVERSITY OF MEDICINE AND DENTISTRY	Newark
CHILDREN'S SPECIALIZED HOSPITAL	Mountainside
YALE UNIVERSITY	New Haven, CT
HACKENSACK UNIVERSITY MEDICAL CENTER	Hackensack

Family Support

Family Retreat Weekend Celebrates 10th Anniversary

Often described as “the best weekend of the year,” the NJCTS Family Retreat Weekend is a place where kids with TS can gather and enjoy fun without the feeling of being different. Providing a safe place for children and their families to grow and share is important to NJCTS.

Over the past decade, families from across the state have made memories to last a lifetime during the annual weekend at YMCA Camp Bernie. Traditional favorites like the Friday night campfire and Saturday night Talent Show are mixed with workshops and candid panel discussions.

NJCTS is proud of the fun, support and practical life skills this retreat has brought to over 2,000 children and families over the past decade. Here is how this special program makes our families feel:

“NJCTS and the Family Retreat Weekend were invaluable resources of support, community and information. We were in crisis and the friendship, encouragement and strength we gained was immeasurable.”

“It was wonderful to see [my son] relaxing and laughing and interacting with his peers! [The Family Retreat Weekend] is a safe place for us where we can recharge for whatever the future may bring.”



Doctoral students from the TS Program at Rutgers Graduate School of Applied and Professional Psychology attend the retreat to impart skills training. (Left to right) Shawn Ueyama, Logan Durland, Alycia Davis, Carolyn Spiro



NJCTS Youth Advocates Tess Kowalski, Amanda Silvers, Jordan Chervin, Ross Yellin, Steve Lindenbaum and Drew Friedrich answer kids questions in a powerful panel discussion led by Dr. Lisa Cox.



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

Members of the Rutgers University Cell and DNA Repository who set up a convenient one-stop mini clinic where families interested in participating in the TS Genetics Repository could enroll:

Donna Tischfield,
BSN, RNC-NICU
Jay Tischfield,
PhD, FFACMG

Gary Heiman, PhD
Nawei Sun, PhD
Cara Nassello, PhD
Nan Wang

Lily Li Deng
Cynthia Liang

Thank you to our sponsors:

The Brad Cohen Tourette
Foundation

Wegmans of Bridgewater

Costco

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Celebrating 10 years has never been sweeter

Family Support



As part of the 10th anniversary celebration, parents took part in a first-of-its-kind, no holds barred question and answer session with a panel of TS experts. (From the left) Developmental pediatrician Lawrence Laveman, school psychologist Graham Hartke, neurologist Roger Kurlan, epidemiologist Gary Heiman, psychiatrist Robert King and psychiatrist Tola Tanelli.



Family Retreat Weekends were made for dancing.



There was no shortage of giftedness at the Saturday Night Talent Show.



After a day of activities, the crowd still has energy for the Electric Slide.



Ed Baumann, the Family Retreat Weekend's resident DJ, leads fellow NJCTS families in a night of fun and memories.



The team from Rutgers Cell and DNA Repository demonstrate how convenient it is for families participate in the TS study during their mini-clinic at the Retreat.



The Family Retreat Weekend wouldn't be possible without the help of our superb volunteers.

We would like to thank our 2014 Retreat Volunteers:

Marilyn LaMarca
Liz LaMarca
Kim Rice
Mike Rice
Drew Friedrich
Steven Lindenbaum
Juliet Robinson
Ross Yellin

Family Support

Wednesday Webinar Series Covers the Details of Living Well with TS and its Associated Conditions

NJCTS understands the need for practical and accurate information about TS and its associated disorders exists for parents, educators and healthcare professionals. As a leader in the TS community, the Center aims to share this knowledge worldwide and is doing so through the Wednesday Webinar series. Since 2009, thousands of parents and professionals have attended presentations delivered by NJCTS' cadre of 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.

Part of what makes Wednesday Webinars so powerful is that attendees have the opportunity to ask questions during the live presentation and are invited to access a web-based chat room where they can post additional questions to the topic-presenter. In many cases, this allows families who do not have regular access to professionals with experience in TS the chance to interface with an expert. Credits are offered to qualified professionals, making this an important learning tool as well. All presentations are archived at NJCTS.org for continued viewing.



*Susan
Connors,
MEd*

504 Accommodation Plan vs IEP (Individualized Education Plan)

Ms. Connors explores the differences between the 504 and IEP plans, in order to help parents and educators understand which is most appropriate for a student with TS, an associated neurological disorder or other special-needs condition. She discusses eligibility criteria and how the system works from the perspective of a 30 year veteran of the education system.

Accommodations, Strategies and Techniques for Working with Students with Tourette Syndrome

An explanation of creative accommodations and strategies for working with children with Tourette Syndrome in the classroom and at home. Ms. Connors also includes strategies for accompanying disorders such as OCD, ADHD, executive dysfunction, sensory issues, learning disabilities and dysgraphia (writing deficits).



*Martin E.
Franklin,
PhD*

Treating Specific Phobias: When & How?

Dr. Franklin talks about the differences between phobias and age-appropriate fears, such as monsters under the bed. He explains how exposure therapy is used in the treatment of specific phobias, such as the fear of spiders and dogs. Dr. Franklin discusses the process of exposure therapy, gauging response and how to maintain its progress.



*Brian Chu,
PhD*

Getting Unstuck: How to Overcome Anxiety and Mood Problems with Behavioral Activation and Exposure

Dr. Chu explains the principles behind Behavior Activation as a program that takes a comprehensive and focused approach to helping children and families address depression and anxiety. This presentation includes examples of how teens can use the techniques to develop a more active coping approach toward life.



*Rachel Strohl,
PsyD*

Body Focused Repetitive Behaviors: Helping Teens and Young Adults Manage Stress and Anxiety

Dr. Strohl explores ways teens and young adults who have trichotillomania or other related body focused repetitive behaviors (BFRBs) learn to improve their management of stress and worries. She offers stress management tools, such as relaxation and paced breathing, sensory grounding, cognitive therapy and exposure tasks to decrease symptoms of stress and worry.



*Kathleen
Nace,
MT-BC, NMT*

Using Creative Arts in Therapy: Benefits of Music, Dance/Movement and Art Therapy

Ms. Nace shares how Creative Arts Therapy is used to help reduce anxiety, as well as lifting mood and self-esteem building. She explains how this type of therapy can assist with expressive language, memory, relationship development and pain management.

Family Support



Cathy
Budman,
MD

Impulse Control Problems and Tourette Syndrome

Dr. Budman offers insight into the impulse control disorders people with Tourette Syndrome often struggle with. In addition to an exploration of the most common features of impulse control observed among children and adults, Dr. Budman discusses treatment options and their effectiveness.



Lawrence W.
Brown, MD

Tourette Syndrome and Developmental Disabilities

Dr. Brown defines developmental disabilities and their prevalence as related to Tourette. In this presentation, Dr. Brown identifies how different neurodevelopmental conditions disturb the same brain networks in the growing child that are disrupted in Tourette Syndrome.



Joelle
McGovern,
PhD

Treating Very Young Children with Obsessive Compulsive Disorder

Dr. McGovern discusses cognitive and exposure based activities for the very young. She says keeping it playful helps to engage the child, which in turn, leads them to mastering and controlling their OCD. Dr. McGovern also discusses how parents and schools can work together to create developmentally sensitive treatments to help the child at home and school.



Mark Mintz,
MD

Sports-Related Concussions and Brain Injury

Concussions are a form of traumatic brain injury that can impact behavior and cognitive functioning – the mental processes of thinking, reasoning, learning, remembering, problem-solving and creativity. Many children and young adults experience significant psychological stress from their injuries. Dr. Mintz shares interventions for concussions, the risks of recurrent concussions and how to help individuals suffering from residual problems to maximize their functioning at home, school, work and community environments.



Michael Osit,
EdD

Ten Ways to Make a Great School Year

Dr. Osit offers ways we can approach school differently for a successful year including suggestions on sleep, schedules and ways to handle the dreaded issue of homework. He addresses the busy lives of children and parents while offering ways to ease the load.



Tolga Taneli,
MD

Trade Secrets of a Tourette Syndrome Doctor

Dr. Taneli delivers an insider's perspective on the drug approval process and offers insights on how to get physicians to collaborate on a case. In this presentation, Dr. Taneli also shares tips on ways to involve your child's school in the collaboration process.



Andrew J.
Lee, PsyD

Mental Health Issues in Today's Asian American Community

Dr. Lee explores Asian cultural values and how they impact today's Asian Americans, including the model minority myth and how these perceptions feed into the stigma of seeking mental health services. Dr. Lee offers helpful suggestions on how to avoid the pitfalls in talking about mental health issues.



Christine
Adkins-
Hutchison,
PsyD

Mental Health Stigma and Help Finding Services in the African American Community

Dr. Adkins-Hutchison discusses the economic and social roadblocks for African Americans in seeking mental health services. She addresses the need for more therapists to be culturally competent and the need for ethnic populations to find providers who mirror themselves physically.



Graham
Hartke, PsyD

Getting Kids Motivated for School! Strategies to Foster your Child/Teen's Motivation to Achieve in School

Dr. Hartke offers strategies to increase students' self-motivation to succeed in the classroom. This includes tips on organizing and fighting procrastination on projects.



Nadia S.
Ansary, PhD

Bullying and Vulnerable Populations

Dr. Ansary sheds light on bullying – both traditional and cyberbullying, and gives recommendations for helping to effectively address the problem. Her presentation also identifies risk groups and individuals vulnerable to bullying.



Courtney
Weiner, PhD

Monsters, Robbers and Nightmares, Oh My! Simple Steps to Improve Your Child's Sleep

Dr. Weiner explores good bedtime routines and hygiene as a way to help conquer sleep issues in children. This presentation also identifies common sleep problems, ways to help and when it's time to consider professional intervention to alleviate sleep anxieties.

Family Support

Social Media & Blogs

Part of NJCTS' commitment to providing critical support and information to families means putting it in the most approachable terms on a variety of different platforms. People with TS and those who love them made important and poignant connections through NJCTS' social media channels – NJCTS.org, Facebook and Twitter. Our parent and teen blogs continued to reach further into the global TS community in 2014. With ever-increasing numbers of page hits, followers and likes; here's a look at what our community is creating:

Blogs:

TSParentsOnline www.njcts.org/tsparents
Teens4TS www.njcts.org/teens4ts



TSParentsOnline and Teens4TS are online communities for parents and teenagers affected by Tourette Syndrome from all over the world. These pages regularly feature touching stories, new ideas, personal experiences, and a glimpse into the hopes and dreams of people who are looking for others to identify with what they are going through. In 2014, the blogs received nearly 65,000 page hits and more than 600 messages from across America and several countries worldwide. Teens4TS is a comfortable atmosphere where adolescents can share their thoughts and creative expressions (like poetry and music) on topics ranging from relationships, bullying and managing tics. TSParentsOnline allows concerned mothers and fathers to share strategies, frustrations and encourage one another.

NJCTS.org www.njcts.org



NJCTS's website offers resources for families including assistance for kids in school, scholarships and professional awards; as well as a host of information for educational and

medical professionals. A complete list of support groups, links to TS resources and a history of our organization are just a few of the other features of the site, which receives as many as 130,000 hits per month. Visitors can view archived presentations and sign up for upcoming events like seminars, Wednesday Webinars, advocacy events and more.

Facebook www.facebook.com/TouretteSyndrome



NJCTS provides a beacon of support and information for people living with TS around the world through social media outreach and Facebook has caught the attention of thousands in 2014. As the number of views, likes and comments continues to grow, each visitor is reminded of the services and community offered by NJCTS.

Twitter <http://twitter.com/NJCTS>



NJCTS relies on Twitter to call attention to issues of interest to the TS community at home and around the globe – ranging from local event reminders to breaking news of interest to families and professionals with interest in TS and its associated conditions. By the end of 2014, NJCTS reached over 2,000 followers – 649 more than in 2013.

REFERRALS AND SERVICES FOR KIDS, FAMILIES
AND PROFESSIONALS DEALING WITH TS

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New Jersey Center for Tourette Syndrome
AND ASSOCIATED DISORDERS, INC.

Collaborative Partnerships for the Tourette Syndrome Community



www.NJCTS.org

Family Support

Parent Connection Grows and Goes Virtual

NJCTS and the Tourette Syndrome Association of New Jersey (TSANJ) have made it easier than ever for parents to get the support and encouragement that can only come from people who have shared the same challenges. Through partnerships at hospitals throughout the state, the Parent Connection meetings allow parents to meet face-to-face to share friendship and reduce the isolation that accompanies Tourette Syndrome. Our families met at the following regional “connecting points”:

Atlantic/Ocean: Richard Stockton College

Burlington/Camden: Virtua-Marlton

Middlesex/Union: JFK Medical Center

Somerset/Hunterdon: RWJ-Somerset

Morris/Sussex: St. Clare's-Denville

North Jersey: Chilton Medical Center

In 2014, NJCTS gave parents who wish to connect with others, but could not attend one of our regional Parent Connection groups, the chance to participate online. We know the program is providing comfort for the parents we serve.

“Thanks for organizing the support group discussion (online), it was both *in*formative and emotionally beneficial.”

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

Increase in Demand for Services in 2014

The phone kept ringing in 2014, and NJCTS was there to answer an increase in requests for support, literature, physician referrals and information about our TS Clinic at Rutgers University. These calls come from parents hoping to find a diagnosis for their child; teachers who want to help a student with TS reach their potential; or social workers trying to connect their client to the right doctor. The phone rang 2,651 times for these requests and others in 2014 and here's how we were able to help:

NJCTS VOLUNTEER NETWORK

Our world-class programs and services come to you with the help of our team of talented and dedicated volunteers. Our network helped us accomplish the following in 2014:

EVENT VOLUNTEERS

- Family Retreat Weekend
- NJCTS Tim Howard Leadership Academy
- NJ Walks for TS at Mendham and Princeton
- NJCTS Parent Connection facilitators
- Annual conventions and expos, like the New Jersey Education Association (NJEA) Convention in Atlantic City

OFFICE VOLUNTEERS

- Contacting medical professionals on our Physician Referral List (PRL) to update our records
- Mailings
- Flyer distribution
- Grant writing
- Fundraising
- Seeking corporate sponsorship opportunities
- Graphic design

PRESENTATION OPPORTUNITIES

- Teens for the Youth Advocate Program
- Families for the Patient-Centered Medical Outreach Program

Awareness & Advocacy

Hundreds Gather as NJ Walks for TS at Princeton

On a bright and crisp afternoon, 200 kids and adults walked for a better future for their friends and family with Tourette Syndrome – and for those they haven't even met. The debut of NJ Walks for TS at Princeton took place at Mercer County Park. It's an offshoot of the highly successful NJ Walks for TS at Mendham which started in 2010 in North Jersey to support the Education Outreach programs and services of NJCTS.

Sunday, April 6th, was Central and South Jersey's turn to step out in support of the 1 in 100 children affected by TS. What's remarkable is that this event was coordinated, in large part, by 14-year-old Tess Kowalski of Plainsboro who has been an NJCTS Youth Advocate since 2011. She along with her sister Paige, mom Leslie and father Tim organized and conducted the inception of the Princeton-area walk and activities for the day.

Assemblywoman Donna Simon (R-16) and Assemblyman Daniel Benson (D-14) were in attendance along with groups of walkers from across the state- including Cherry Hill and points south.

Assemblyman Benson presented a joint legislative resolution signed by Senate President Stephen M. Sweeney and General Assembly Speaker Vincent Prieto stating "the strength and success of the State of New Jersey, the vitality of our communities, and the effectiveness of our American society depend, in great measure, upon organizations exemplified by the NJ Center for Tourette Syndrome, that unite voluntarily, act together and provide their unique talents to further a cause, to perform a necessary service to support one another and their communities or to relieve others from unavoidable hardship."

NJ Walks for TS at Princeton exists to promote awareness, acceptance, action and advocacy of Tourette Syndrome and its associated disorders at a day of fun and empowerment for kids, by kids and about kids.



Assemblywoman Donna Simon and Assemblyman Dan Benson, part of the event's Honorary Committee, presented NJCTS with a resolution commending the work of NJ Walks for TS.

NJ Walks for TS at Princeton 2014 Sponsors

Advanced Dental Arts, P.A.

Remax Excel

Gold Medal Plumbing, HVAC & Electrical

Kadar Orthodontics, P.A.



Nothing brings families together like standing up for a loved one. At NJ Walks for TS families and friends are proud to rally behind the kids in their life living with TS.

Awareness & Advocacy



NJCTS Board member Tim Kowalski and daughter Tess, an NJCTS Youth Advocate, brought the walk to Central Jersey.



Carrying the banner for more than 20,000 school-age kids in New Jersey living with TS.



Tim, Leslie and daughters Tess and Paige made a family commitment to raising awareness and support for TS. NJCTS is grateful for their help and the participation of each individual, team and sponsor who made the event a real success.

2014 PRINCETON WALK HONORARY COMMITTEE

Tim Howard, starting goalkeeper for the United State Men's National Soccer Team and a member of the NJCTS Board of Directors

Craig Carton, radio host on WFAN Sports Talk Radio and an Honorary Member of the NJCTS Board of Directors

Dr. Jay A. Tischfield, Human Genetics Institute of New Jersey

Dr. Robert King, Yale University Child Study Center and Yale TS/OCD Clinic

Dr. Stuart Green, Overlook Medical Center in Summit

Debra L. Wentz, PhD, Executive Director of the New Jersey Association of Mental Health Agencies

Rebecca Spar, Esq., educational rights attorney for Cole Schotz of Hackensack

NJ Senate President Stephen M. Sweeney (D-3)

NJ Senator Jim Whelan (D-2)

NJ Senator Christopher "Kip" Bateman (R-16)

NJ Senator Joseph M. Kyrillos (R-13)

NJ Senator Linda R. Greenstein (D-14)

NJ Senator Joseph F. Vitale (D-19)

NJ Assemblyman Vincent Mazzeo (D-2)

NJ Assemblyman Troy Singleton (D-3)

NJ Assemblywoman Celeste M. Riley (D-3)

NJ Assemblyman Daniel R. Benson (D-14)

NJ Assemblyman Wayne P. DeAngelo (D-14)

NJ Assemblywoman Bonnie Watson Coleman (D-15)

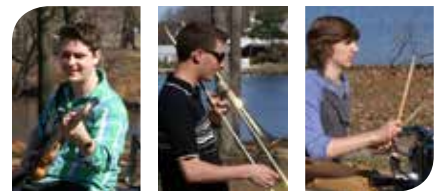
NJ Assemblyman Jack M. Ciattarelli (R-16)

NJ Assemblywoman Donna M. Simon (R-16)

NJ Assemblyman John S. Wisniewski (D-19)



Tim and Tess accept a proclamation from the New Jersey Assembly.



Live music kept the crowd peppy and ready to hit the trail.



Girl power was in full supply at the Princeton walk.

Awareness & Advocacy

NJ Walks for TS at Mendham Celebrates 5 Years as Flagship Advocacy Event

When it comes to showing support for family and friends with TS, cold weather is not enough to deter the walkers, runners, and volunteers who have made the New Jersey Walks for TS at Mendham an annual tradition. Their presence in Mendham Borough Park on November 15th is a testament to the growing advocacy movement by NJCTS.

Each year the event inspires families and partners through the spirit of advocacy and self-empowerment. Proceeds from the Walk 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 its associated conditions including obsessive-compulsive disorder, attention-deficit disorder and other mental health conditions. NJCTS accomplishes this through school in-service workshops and assemblies to make the classroom a safer environment for a struggling student with TS; and hospital grand rounds and professional conference trainings to educate doctors, nurses and mental health professionals to diagnose and treat TS more effectively than ever. In addition, the NJCTS Education Outreach Program identifies and develops a new generation of TS advocates.

Mendham Sponsors and Top Donors

- Asurion
- Highpoint Solutions
- Oppenheimer Funds
- James Concepcion
- Atlantic Health System
- Bernice Rydell van Steyn
- New Jersey Natural Gas
- Comcast of Southern New Jersey
- B&H Consulting Services
- The Frank Mastropaolo Fund of the Community Foundation
- In Memory of Emilio Gianfrancesco
- DCH Montclair Acura
- Jeffrey DuBois
- Giovanina Gianfrancesco
- Jose Mendoza
- Cedar Hill Prep School
- Banasiak & Neptune Orthodontic Associates



NJCTS Board President Tim Omaggio serves as emcee for the day.



NJ Walks for TS is a day for all ages – although, it's easier on wheels.



As 2014 Youth Co-Chairs Sarah Ethridge, Erin Miskell and Tommy Licato spread the word and recruited walkers. Each shared their experience and gratitude during the event.



Snow on the ground didn't deter the crowd from enjoying a crisp morning and a great cause.

With in-kind support from:

- Shop Rite of Bernardsville
- Whole Foods of Madison
- Kings of Mendham
- Elite Island Resorts Carribean
- Harvest Moon Brewery and Cafe
- New Jersey Devils
- Diggerland Adventure Park
- Rob Wilson Photography
- Spuntino Wine Bar
- GoodWorks Band
- WDHA 105.5 FM

Awareness & Advocacy

2014 MENDHAM WALK HONORARY COMMITTEE

Congressman Leonard Lance (R-7)

Congressman Albio Sires (D-8)

Congressman Rodney Frelinghuysen (R-11)

Congressman Rush Holt (D-12)

State Senator Shirley Turner (D-15)

State Senator Christopher Kip Bateman (R-16)

State Senator Joseph Vitale (D-19)

State Senator Thomas Kean, Jr. (R-21)

State Senator Michael Doherty (R-23)

State Senator Anthony Bucco (R-25)

State Senator Richard Codey (D-27)

State Senator Ronald Rice (D-28)

State Senator Paul Sarlo (D-36)

Assemblywoman Bonnie Watson Coleman (D-15)

Assemblyman Reed Gusciora (D-15)

Assemblywoman Donna Simon (R-16)

Assemblyman Jack Ciattarelli (R-16)

Assemblyman Joseph Cryan (D-20)

Assemblyman Erik Peterson (R-23)

Assemblyman Anthony Bucco (R-25)

Assemblyman Jay Webber (R-26)

Assemblywoman Mila Jasey (D-27)

Assemblyman John McKeon (D-27)

Assemblywoman L. Grace Spencer (D-29)

Assemblyman David Rible (R-30)

Assemblyman Raj Mukherji (D-33)

Assemblyman Carmelo Garcia (D-33)

Assemblyman Thomas Giblin (D-34)

Assemblyman Gordon Johnson (D-37)

Assemblyman Timothy Eustace (D-38)

Assemblywoman Holly Schepisi (R-39)

Assemblyman Robert Auth (R-39)



The crowd on the trail making a step in the right direction for TS.



Once off the trail, the next traffic jam is at the silent auction table.



"Christian's Crusaders" came out in force and lead the fundraising efforts.



Crossing the finish line on behalf of tens of thousands of NJ kids is a good feeling.



The work of NJCTS aims to make a brighter day for a new generation of children – and our work doesn't only benefit kids with TS. NJ Walks support the Education Outreach program, which delivers in-school anti-bullying and empowerment training to kids across the state.



The GoodWorks Band, a group of musicians dedicated to helping nonprofits, treated the crowd to some smooth classics.



Awareness & Advocacy

State Senate President Visits and Describes NJCTS as 'a Lifeline' to Families

Senate President Stephen Sweeney visited NJCTS in July on the heels of some very good news. Four years after severe budget cuts, the Center received a \$250,000 supplemental grant in the state budget to meet the growing demand for services.

Describing the work of the Center as a lifeline to families, Sweeney likened NJCTS to other important organizations. "These are programs that, for a small amount of money, have enormous

impacts," said Sen. Sweeney. Regarding the work of NJCTS specifically, Sweeney says, "it's one of these programs a lot of people on both sides of the aisle believed in and pushed for."

"By visiting with TS families firsthand, he delivered the legislature's support – I know that means a lot especially to our teens who are learning to advocate for themselves and others," said NJCTS Executive Director Faith W. Rice.



Talking with families, according to Rice, gave Sweeney a good sense of what life is like with TS and the need for services.



Faith Rice gives Senate President Stephen Sweeney an overview of programs.



NJCTS families were proud to share their stories with the Senate President.

Awareness & Advocacy



NJCTS Recognized in Congress During TS Awareness Month

Congressman Albio Sires (D-NJ-3) showed his support before Congress where he took the opportunity to recognize the work of the NJ Center for Tourette Syndrome & Associated Disorders (NJCTS). Rep. Sires stood before the U.S. Congress and commended NJCTS for its “tireless pursuit to improve the lives of those impacted by this disorder.”

Collaborative Academic Research Efforts for Tourette Syndrome Act of 2014

A bill to spur federal health officials to study TS and improve treatment for the neurological disorder was championed in Congress. The Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2014 (H.R. 4221) 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 version 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 will host world-class, targeted clinical research into TS and its 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 be used in an effort to provide better understanding of the disorder, and guide strategy into the future of TS research.

Voters passionately voiced their support in their own words:

New Jersey's 11th District:

“This bizarre illness affects every area of an individual's life. For sure, children are cruel and often not accepting of a child with TS. Adults are often discriminated against. There is a serious need for more research for better medications. Educating these children is not like educating an average child and there needs to be more research into how to best reach the children diagnosed with TS

so they can achieve their best in school; many of these children are extremely bright but TS interferes with their learning. And, without correct and appropriate teaching methods, these children miss out on so much of their learning. And it is very important to make the public more aware of TS because the lack of awareness causes a great deal of discrimination and emotional abuse. I am a psychotherapist and work with children and see regularly what they have to go through in their daily lives because of the lack of understanding... Please pass this bill allowing research to be done. It is so important. Just imagine if YOUR child had to live his life with these symptoms and there was nowhere to turn for help!”

California's 30th District:

“My 23 year old son has lived with Tourette Syndrome since his diagnosis at age six. There is little medical support and medications for TS, let alone anything close to a cure. Life is a struggle for people with Tourette. Imagine being a young student trying to get through the school day but you can't control what your body is doing so your teachers think you are a troublemaker and classmates think you are weird. Some uneducated teachers do as well. The simplest of tasks become overwhelming. It takes extreme intervention, and diligent oversight by parents to help their child struggle to get an education. It's not a matter of intelligence or desire that makes school a monumental achievement, it's the insidious betrayal of one's own body... There is much to be learned about Tourette Syndrome, and much, much more to be done on a multitude of levels.”

New Jersey's 5th District:

“I have a beautiful 5 yr old grandson who I want to have a bright future not filled with anxiety and embarrassment due to this condition where there are no working medications let alone a cure.”

Research

Excellence In Medicine Awards Recognizes Faith Rice



NJCTS celebrates its 10th year in 2014 and Faith W. Rice is honored for her vision and innovative partnerships to change the course of life for

children with TS in New Jersey and beyond.

Rice won the 2014 Verice M. Mason Community Service Leader award, part of the Edward J. III Excellence in Medicine Awards presented by MDAdvantage. The award is presented to an individual who has personified, led and provided the vision for an organization, and to the organization served, for extraordinary commitment to improving the health and welfare of citizens of New Jersey.

NJCTS is helping tens of thousands of families and

professionals support the needs of individuals with Tourette Syndrome and its associated disorders. The organization was formally initiated in 2004, but Rice's grassroots efforts in Tourette Syndrome advocacy trace back a decade earlier when her son was diagnosed with the disorder. Before establishing NJCTS, Rice was in marketing, human resources and strategic planning with a large corporation. That extensive for-profit experience has allowed her to structure NJCTS as a non-profit organization that promotes

collaboration and partnerships among individuals, universities, hospitals and other resources to provide services and support for the 1 in 100 children and their families affected by this neurological condition.

These collaborations and partnerships have resulted in the formation of the world's first Tourette Syndrome Cell & DNA Sharing Repository and a Tourette Syndrome Clinic (both at Rutgers University). Both programs are working actively to improve diagnosis and treatment which will ultimately lead to a cure for TS.

TS Clinic at Rutgers Graduate School of Applied and Professional Psychology

The TS Clinic at Rutgers University furthers the mission of NJCTS 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. Five doctoral students are trained each year in this popular practicum which currently has a waiting list. This is the only such program in the nation and, in 2007, won the Rutgers President's Award.

While NJCTS has partnered with GSAPP for a dozen years to provide a teaching practicum and psychological clinic, the Center helped GSAPP celebrate its 40th anniversary in 2014.



Dr. Lew Gantwerk, an instrumental force in developing the TS Clinic at Rutgers, discusses his tenure at GSAPP.



Dr. Lori Rockmore, Dr. Gary Heiman and Faith Rice huddle at the GSAPP Gala.



Faith Rice and Dr. Stanley Messer share a dance at GSAPP's 40th Anniversary. Dr. Messer is Dean of the Graduate School of Applied and Professional Psychology.

Research

Rutgers Partnership Program NJCTS Cell & DNA Sharing Repository

Every day, scientists and geneticists are working to find a cure for Tourette Syndrome. NJCTS is working with Rutgers University and families to make that happen.

Data collected through the National Institute of Mental Health NJCTS Genetics Sharing Program is helping researchers understand the causes of TS. Ultimately, this will lead to a cure – closer with each new participant.

NJCTS-affiliated experts are bringing the latest information to New Jersey families through Tourette Syndrome Workshops led by Dr. Gary Heiman, a team leader at the repository. In 2014, Dr. Robert King, a 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.



Dr. Gary Heiman, a team leader at the NJCTS Genetics Sharing Program, discusses the state of TS research with families at Virtua Medical Center.

NJCTS Sharing Repository collaborators collect samples at these sites around the world

USA

CT Yale University School of Medicine
IA University of Iowa
IN Indiana University School of Medicine
MO Washington University in St Louis
NJ Rutgers, The State University of New Jersey
NY New York University and Nathan S. Kline Institute
NY Columbia University
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 Hospital, Dresden
Germany University Hospital of Ulm
Germany Hamburg University-Eppendorf
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
UK Guy and St Thomas, London

KOREA

Anyang Hallym University Sacred Heart Hospital
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
Seoul Seoul Metropolitan Eunpyeong Hospital



Year in Pictures



Legendary actor and New Jersey resident John Amos joins Faith Rice in wishing Tim Howard and Team USA the best in the 2014 World Cup.



Support, friendship and a night of laughs at the South Jersey Get Together.



Tim Howard was quite the newsmaker in 2014, and he graciously shared some of the spotlight with NJCTS. Leanne Lowenthal, Sarah Ethridge and Santina Reichenbach are pictured with cameraman Frank Bivona and CNN reporter Lena Jakobsson (front).



Friendships take on a new meaning when you can understand shared challenges and victories.



To celebrate TS Month, Cresskill school district organized a Jeans Day – students and faculty made a donation to wear denim, with proceeds benefitting NJCTS. The kids and teachers raised \$900!



Letting loose at the South Jersey Get Together.

South Jersey families organized a get-together for parents and kids in Marlton.



Year in Pictures

More from our 10th annual Family Retreat Weekend



So much to enjoy at the Saturday night Talent Show.



Families were introduced to NJCTS research projects while at Family Retreat Weekend.



The lineup of Dads can only lead to a few laughs...and pictures.



"It's fun to stay at the Y.M.C.A!"



Ed Baumann, the Family Retreat Weekend's resident DJ, leads fellow NJCTS families in a night of fun and memories.



Emcee Jamee Silenzio introduces our talented performers.

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Executive Director
NJCTS



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Santina Reichenbach
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Kelley Teabo
Project Coordinator



Martha Butterfield
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Leanne Loewenthal, MSW
*Family Outreach &
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Melissa Fowler, MA, MEd
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Alyssa Letts
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Maria Carew
*Administrative
Assistant*



Daryl Ball
*Bookkeeper & Data-
base Administrator*



Gina Jones, MEd
*Education Out-
reach Coordinator*

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Jordan Chervin
Sarah Ethridge

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NJ Center for Tourette Syndrome

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