



NJCTS A YEAR OF **GROWTH** 2011

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Dear Friends and Supporters of NJCTS,

These are exciting times. At a time when many organizations are scaling back, the New Jersey Center for Tourette Syndrome is expanding!

The vision of federalizing the NJCTS Sharing Repository at Rutgers University was realized in September 2011. The repository was established with state funding through a partnership in 2007, and in less than five years, NJCTS and our collaborators at Rutgers and Yale universities have taken the initial investment and established a model that is now fully funded with federal resources.

In addition, the project is growing to include an additional 26 screening and collection sites in the United States, Europe and Asia, where data and blood samples will be collected by TS researchers and clinicians and sent to our repository at Rutgers. This will exponentially expand the world's only cell and DNA sharing repository dedicated to the study of Tourette Syndrome – our flagship at Rutgers.

We expect to see a twenty-fold increase in the number of samples processed with our uniform-coding method over the short term – giving researchers unprecedented access to a wide sample of cell lines linked to Tourette Syndrome and its associated conditions. In just a few short years, the Center has redefined the landscape for researchers with interest in TS. Together, we can lead the next major discovery in the treatment of TS.

The Center celebrated another achievement on the federal level in 2011. Our longtime supporter, Congressman Albio Sires, introduced legislation for every American with Tourette Syndrome. The Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2011 would make changes to the existing Public Health Service Act to include more research and provision for TS. This is a game-changer for the way TS is regarded among researchers and health policy makers. If passed, this legislation will create Centers of Excellence for TS across the country.

The future for individuals with Tourette Syndrome is looking brighter. And your ability to make a difference has never been easier. Please, contact your Congressional representatives and ask them to support H.R. 3760. A simple phone call doesn't take a lot of time and could ensure the chance of a better life for all people with TS.

Now, more than ever, we rely and appreciate your support. We thank you for your commitment and enthusiasm and ask that you continue to grow with us. We know 2012 has a lot of exciting new initiatives in store and we look forward to working together to reach each new milestone.

Sincerely,

Faith W. Rice

Research

Tourette Syndrome DNA material is now collected at 26 sites around the world and sent to the NJCTS Sharing Repository at Rutgers University

Through a partnership with the Rutgers University Department of Genetics, NJCTS established a sharing resource of clinical and genetic data which can be accessed by qualified researchers worldwide. That resource, the NJCTS Sharing Repository, is the world's first source for access to DNA and cell lines for the sole purpose of studying Tourette Syndrome. Research has shown that TS has a genetic (inherited) component. So to help scientists understand what causes this disorder in 2007 NJCTS partnered with Rutgers University to establish a place where qualified researchers from around the world can have access to genetic material and data from families. In less than five years, our project demonstrated that we have the ability to collect, store and distribute samples to further important research into the causes of TS. In September 2011, the federal government recognized the success and impact of the NJCTS Sharing Repository on the research community and began to provide federal funds for operating expenses as well as adding it to their list of national resources as the National Institute of Mental Health Sharing Repository for TS.

The Repository and NIMH efforts are led by Dr. Jay A. Tischfield, Director of the Human Genetics Institute at Rutgers, who says the purpose of this research is to understand the relationship between genes, Tourette Syndrome and its associated disorders. "The major stumbling block to doing research on Tourette has



Dr. Jay Tischfield

been a lack of DNA samples," Dr. Tischfield said. "You can't just do research on samples from five or 10 people. You need hundreds, if not thousands, of samples because the disorder itself is very heterogeneous - meaning it doesn't have the same cause in everybody." The increase in sample collection will enable research to move into a much more ambitious phase. "Once we have a large enough sample, we intend to apply for funds to do a full-fledged molecular genetics analysis of the entire set of DNA samples, and that is a very expensive proposition," Dr. Tischfield added.

The proposition will require about 5,000 samples, which would include between 1,500 and 2,500 from individuals affected by Tourette Syndrome and the remainder from their families. "This is a long haul," said Dr. Tischfield, who has been doing research for four decades. "With TS, it will take years to define the neurological pathways associated with the disorder, and it will take more years to define drugs that could affect those pathways." And we are off to a good start.



Dr. Jay A. Tischfield, the Director of the Human Genetics Institute at Rutgers University, guides United States Congressman Albio Sires (D-NJ13) around the National Institute of Mental Health Sharing Repository.

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 | Ilisan Hospital (National Health Insurance Co.) |
| Seoul | Korea Institute for Children's Social Development (KICSD) |
| Seoul | Yonsei University Severance Hospital |
| Seoul | Seoul Metropolitan Eunpyeong Hospital |



Research

NJCTS Sharing Repository helping researchers such as Yale's Dr. Robert King further study of Tourette Syndrome



In 2011, the National Institutes of Health recognized the Center's process for collecting and screening genetic data through the NJCTS Sharing Repository at Rutgers University with a grant to expand the program around the world. This grant will enable the Center to collect DNA at 26 new research and clinical sites in the United States, Europe and

Asia and establishes the Center's procedures as the uniform standard. Federal funding will exponentially expand the world's only sharing repository dedicated to the study of TS and associated disorders started through collaborative efforts in New Jersey and now worldwide.

Having a large pool of data, processed using the same standards, marks a major milestone for TS research. Now researchers can confidently draw from a recognized repository and know that the methods and procedures used during the collection process meet the highest standards. One such researcher is Dr. Robert King of Yale University. Dr. King, professor of child psychiatry and medical director of the TS/OCD Clinic at the Yale University Child Study Center, is a longtime collaborator with NJCTS who was instrumental in developing these uniform collection tools. NJCTS families know Dr. King from our from TS presentations held across the state, but Dr. King also interviews families interested in participating in the genetics program. His message is simple: Anyone connected to Tourette Syndrome should become part of this ground-breaking research and help in finding the cause and cure for TS. If you have a loved one with TS, please consider doing your part to advance research breakthroughs by e-mailing familystudy@biology.rutgers.edu.



Rutgers University employees show off the many uses of the National Institute of Mental Health Sharing Repository on the university's Busch Campus in Piscataway.

Research & Family Support

TS Clinic at Rutgers University expands

The Tourette Syndrome Clinic at Rutgers University is a collaboration between NJCTS and the Graduate School of Applied and Professional Psychology. Facilitated by clinical director Lori Rockmore, Psy.D, and augmented by assistant supervisor Shawn Ewbank, Lewis Gantwerk, Psy.D, and Dr. Stanley Messer, the clinic expanded its number of clinicians to six in 2011 – allowing it to service more families annually. In 2011, the clinic helped its highest number of patients since the program began in 2007. It also received a grant from the Van Ameringen Foundation to continue developing its programs, including a study

on the effectiveness of habit reversal training. The clinic is the nation's only standalone university-based student clinician program for individuals and families with TS. Treatment methods include Cognitive Behavioral Therapy (CBT) and Habit Reversal Therapy (HRT)

to cope with TS, OCD, ADHD, anxiety and mood disorders. These noninvasive treatments are used as an alternative in many cases to medication. Clinicians work with families to develop behavioral intervention planning at home and school. This holistic approach includes

family therapy sessions and social skills groups. Research obtained through the observation and treatment of children and families provides important insight into the needs of the TS community and evidence-based treatment approaches.



Lori Rockmore
TS Clinic Supervisor



Lewis Gantwerk
*Executive Director
Center for Applied
Psychology*



Stanley Messer
Dean of Rutgers GSAPP



Shawn Ewbank
*TS Clinic Assistant
Supervisor*



From left, Rachel Merson, Rob Happich, Chelsea Hetrick and Nathan Lambright received training in the Graduate School of Applied and Professional Psychology TS Practicum at Rutgers University.

Education

Educator in-service program

NJCTS offers on-site in-service programs for educators, guidance counselors, child study teams, administrators and support staff. These sessions are designed to inform and enlighten professionals about TS and co-occurring disorders such as OCD, ADHD, learning disabilities, depression, anxiety and the impact they can have on a child's school performance. The workshops also provide educators with specific classroom strategies and accommodations that can have a positive impact on a student's academic success. Our presenters are teachers, school nurses or other professionals with education or medical backgrounds. Most presenters have first-hand knowledge of TS.

Schools from all over the state were clamoring for educator in-services in 2011, and the Center responded. Educator in-service presentations, are coordinated by our Outreach Consultant, Melissa Fowler, MA, M.Ed. Melissa is helping us expand our program content and develop new initiatives within the education community to reach students with TS and associated disorders. The 2011 in-service presentations took place across the state and were facilitated by Janine Howley, MA, a professional educator for more than two decades and a middle school Teacher of the Year in Ocean County; Graham Hartke, a New Jersey Certified School Psychologist in Morristown; Dr. Robert Zambrano, Psy.D, who has worked as a clinician at the NJCTS TS Clinic at Rutgers University; and Cheryl Ludwig, a nationally certified and licensed speech language pathologist who for 35 years has worked with children in public schools, private practice and as an adjunct professor at The College of New Jersey.

Also part of the NJCTS in-service team are Ann L. Deutsch, MSN, who has given workshops on TS for professionals at several NJ schools and community colleges; Tracy Lederman, and Mariann Fimbel.

PROGRAM LOCATIONS

HIGHLAND ACADEMY – Galloway,
JAMES CALDWELL HIGH SCHOOL – West Caldwell
ROCKAWAY VALLEY SCHOOL – Rockaway
EMERSON MIDDLE SCHOOL – Union City
STAFFORD INTERMEDIATE SCHOOL – Manahawkin
PITMAN HIGH SCHOOL – Pitman
RIVERDALE PUBLIC SCHOOL – Riverdale
GLEN ROCK HIGH SCHOOL – Glen Rock
WOODGLEN SCHOOL – Califon
ROCKAWAY VALLEY SCHOOL – Boonton
THOMAS JEFFERSON ELEMENTARY SCHOOL – Turnersville
ORCHARD ELEMENTARY SCHOOL – Skillman
FAIRVIEW ELEMENTARY SCHOOL – Red Bank
SCHUYLER COLFAX MIDDLE SCHOOL – Wayne
VILLAGE ELEMENTARY SCHOOL – Holmdel
MILFORD BROOKS ELEMENTARY SCHOOL – Manalapan
CHARTER TECH SCHOOL OF PERFORMING ARTS – Somers Point
MONTGOMERY TOWNSHIP UPPER SCHOOL
MONTGOMERY TOWNSHIP MIDDLE SCHOOL
WALTER M SCHIRRA ELEMENTARY SCHOOL – Old Bridge
BERGEN COUNTY PACADA – Paramus
LOWER MIDDLE SCHOOL – Skillman
HAMMONTON MIDDLE SCHOOL – Hammonton
SOMERSET COUNTY SCHOOL NURSES ASSOCIATION
ARC OF SOMERSET COUNTY
NJ SOCIETY OF MEDICAL ASSISTANTS
GSAPP CHILD PSYCHOPATHOLOGY – Piscataway
NJEA CONVENTION – Atlantic City
DHSS SPECIAL CHILD WORKSHOP – Trenton



Melissa Fowler



Dr. Graham Hartke



Janine Howley



Tracy Lederman



Cheryl Ludwig



*Dr. Robert
Zambrano*



Ann L. Deutsch

Peer in-service program

Since inception, NJCTS peer in-service presentations have been sensitive to the social needs of all students with challenges or disabilities. We have built our program on the foundations of empathy and fair treatment to break the stigma and bullying often attached to TS and its associated disorders. In 2011, the State of New Jersey introduced a comprehensive new law aimed at reducing bullying in schools. As a longtime member of the New Jersey Anti-Bullying Coalition, NJCTS is proud that this issue is now receiving the support it deserves. We continue to incorporate our tried and true message of acceptance and advocacy for one's self and others into everything we do, including making and distributing anti-bullying bracelets at several events throughout 2011. We are not alone in promoting empathy among New Jersey's students.

To that end, NJCTS offers on-site, age-appropriate peer in-service to present information about TS to classmates of an individual TS student, or to the general student population. These workshops are presented by a trained professional who leads student attendees in several activities

designed to broaden their knowledge and understanding of TS. Prior to the presentation, parents of the student with TS are consulted about how the information will be presented to their child's classmates. At the request of the student's parents, our presenter will discuss the workshop directly with the TS student and answer any questions he/she may have about the workshop content. In support of New Jersey's recent anti-bullying legislation, this presentation carries a strong message against bullying, encouraging empathy and compassion, offering students both knowledge and tools to help them stand up for themselves and each other against harassment, intimidation and bullying. Our presenters are teachers, school nurses or have a medical background, and most have first-hand knowledge of TS.

The educator in-service presentations were not the only ones to be in high demand during 2011. Many schools, parents and houses of worship across New Jersey requested that a trained professional come to their town to talk to students about TS.

PROGRAM LOCATIONS

CHARTER TECH HIGH SCHOOL FOR THE PERFORMING ARTS in Somers Point, *presented by Janine Howley, MA*

TEMPLE AVODAT SHALOM in River Edge, *presented by teenager Emily Fleischman*

ORADELL PUBLIC SCHOOL in Oradell, *presented by Emily Fleischman*

GRANT SCHOOL in South Plainfield, *presented by Dr. Robert Zambrano, Psy.D*

LOWER MIDDLE SCHOOL in Skillman, *presented by Cheryl Ludwig, MA, CCC-SLP*

ROCKAWAY VALLEY SCHOOL in Boonton, *presented by Dr. Robert Zambrano*

EMERSON MIDDLE SCHOOL in Union City, *presented by Dr. Robert Zambrano*

THOMAS JEFFERSON ELEMENTARY SCHOOL in Turnersville, *presented by Melissa Fowler, MA, M.Ed.*

VILLAGE ELEMENTARY SCHOOL in Holmdel, *presented by Dr. Robert Zambrano*

WARREN COUNTY VOCATIONAL & TECHNICAL HIGH SCHOOL in Washington, *presented by Melissa Fowler*

NORTHERN VALLEY REGIONAL SCHOOL in Demarest, *presented by Dr. Robert Zambrano*

NEARLY 2,200 STUDENTS AND
FACULTY TOOK PART IN IN-SERVICE
PRESENTATIONS IN 2011

2,200

Student-led peer in-service program

NJCTS offers student-led in-service presentations, which provide information about Tourette Syndrome and the co-morbid disorders to classmates of an individual TS student or to the general student population. These presentations foster understanding, sensitivity and tolerance of TS and its symptoms by describing the symptoms, causes and effects of the disorder. In addition, these presentations work to displace the myths and stereotypes that are often attributed to TS and contain a strong anti-bullying message. Student presenters may or may not have TS or one of the co-morbid disorders themselves, though all have first-hand experience. Student-led in-service presentations are appropriate for all age groups and might be used in the school setting, for sports leagues, scout troops, camps or after-school programs.

EMILY FLEISCHMAN



One of the Center's top student peer in-service presenters is River Dell High School junior Emily Fleischman, New Jersey's 2010 National Youth Ambassador for the Tourette Syndrome Association. Fleischman has made it her mission to advocate for TS to elementary school students. With help from NJCTS, Fleischman presented her message to hundreds of fifth- and sixth-graders in Bergen County. Her message: She has Tourette Syndrome, but

she does not let the neurological disorder that affects as many as 1 in 100 people – or its side effects – define her life. Fleischman is an accomplished person, leading a fulfilling life. She just so happens to have TS. But perhaps an even more important message – one that Fleischman repeated over and over during her 30-minute power-point presentation – is that people with Tourette Syndrome never should be bullied. "It's OK to be yourself, and other people

should never take that away," said Fleischman, 16. "I held in my tics so I wouldn't be bullied. It took me a long time to learn that it's OK to be different, that people shouldn't bully you, and that if someone bullies you, they're not your friend." Fleischman believes the more children and adults alike learn about what bullying can actually do to someone, the more it will decrease in schools, homes and other places of social and learning activity.

Education is key, and Fleischman is not alone in helping to bring these important messages to the public. The Center has recruited several young presenters, including 21-year-old Steven Lindenbaum of Marlboro, 16-year-old Amanda Silvers of East Brunswick and 12-year-old Tess Kowalski of Plainsboro to give similar talks to people of all ages across the state.

"I held in my tics so I wouldn't be bullied. It took me a long time to learn that it's OK to be different, that people shouldn't bully you, and that if someone bullies you, they're not your friend."

~EMILY FLEISCHMAN

Patient-centered training program

NJCTS works with hospitals throughout New Jersey and the greater New York and Philadelphia areas to present grand rounds and workshop trainings for doctors, nurses and other health care providers. For the first time in 2011, NJCTS presented several patient-centered presentations, including ones where a teenager with TS and her family – in conjunction with a

clinical director from NJCTS' Tourette Syndrome Clinic at Rutgers University – discussed TS and their experience with groups of 75 or more physicians. This program was developed in partnership with Dr. Stuart Green of Overlook Medical Center in Summit. In 2011 alone, NJCTS facilitated resident trainings at Saint Peter's University Hospital in New Brunswick, Overlook Medical Center in Summit,

Jersey Shore Medical Center in Neptune and Robert Wood Johnson University Hospital in New Brunswick. These educational sessions consist of a one-hour conference in which two or three adolescents with TS, and their parents, describe their experience with the condition at school, at home and in the community. The presentations focus on the experience of initial diagnosis, on quality of life and on encounters with

physicians and the health-care system. The goal of this project 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 skill in patient encounters. Many of these sessions are open to community professionals as well.

AMANDA SILVERS



One of NJCTS' brightest young minds, 16-year-old Amanda Silvers of East Brunswick, redefined what "patient-centered trainings" mean to the Tourette Syndrome community. Silvers gave presentations to resident doctors at Jersey Shore Medical Center and Saint Peter's University Hospital in 2011, speaking

to a combined total of more than 150 doctors about how there is a big need for everyone, including doctors, to know more about how to diagnose, treat and react to someone with TS. "I want the doctors to know what the patients want," said Silvers, who was diagnosed with Tourette Syndrome, OCD and ADD at age 5. "I want them to be understanding of patients and their needs. My neurologist focuses on my life, rather than my tics." Dr. William Bernstein, the pediatric residency program director at Saint Peter's, loved the seminar and believes more doctors should take note of such presentations. "Most doctors are trained in all the different neurologic disorders, including Tourette Syndrome, but there is never enough training," Bernstein said. "There is always more knowledge, more treatments, more awareness that is necessary."

Assisting Silvers with the presentation was 21-year-old Steven Lindenbaum, a graduate of Rider University, a mentor at the annual NJCTS Family Retreat Weekend at YMCA Camp Bernie, and the coordinator for the Middlesex County Tourette Syndrome Family Support Group.



Amanda Silvers and Steven Lindenbaum bring their message to an audience of more than 150 doctors at Saint Peter's University Hospital in New Brunswick

Professional conferences

The year 2011 was a year of many firsts for the Center, including the inaugural NJCTS and Atlantic Health Statewide Medical Symposium on Tourette Syndrome. This conference, which took place at Overlook Medical Center in Summit, featured internationally recognized experts who discussed the latest in TS diagnosis, treatments and research. Individuals with TS, often present with a complex neuropsychiatric syndrome that can include obsessive-compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD) and other behavioral problems which present diagnostic and treatment challenges for physicians

and others who deal with these patients, such as behavioral health professionals and school personnel. The conference helped clarify some of the complexity around TS by providing the latest and most complete information available, thanks to an incredible panel of experts that included:

Dr. Roger M. Kurlan, a neurologist and the Medical Director of the Movement Disorders Program at Overlook's Atlantic Neuroscience Institute

Dr. Barbara J. Coffey, Director of the Tics and Tourette Clinical and Research Program at the New York University Langone School of Medicine and an Associate

Professor in the Department of Child and Adolescent Psychiatry Research

Dr. Cathy L. Budman, an Associate Professor of Psychiatry at Hofstra University's School of Medicine and the Director of the Movement Disorders Program in Psychiatry at North Shore University Hospital

Lori Rockmore, Psy.D., Clinical Director of the Tourette Syndrome Program at Rutgers University's Graduate School of Applied and Professional Psychology

Dr. Jay A. Tischfield, the Director of the Human Genetics Institute of New Jersey. Dr. Tischfield has been conducting

Tourette Syndrome research for four decades and is working to define the neurological pathways associated with the disorder.

TS families from South Jersey in October flocked to Cooper University Hospital in Voorhees for an NJCTS symposium on Tourette treatments and research with Dr. Larry Brown of the Children's Hospital of Philadelphia and Dr. Gary Heiman of Rutgers University. Dr. Brown presented recent clinical advances in medication and other state-of-the-art treatments for Tourette Syndrome and associated conditions, while Dr. Heiman discussed information on the genetics of TS as part of his ongoing research with the Tourette International Collaborative (TIC) Genetics Group at Rutgers.

NJCTS works in many ways to meet the needs of professionals that interact with students with TS and associated disorders. Each year, NJCTS leads an informative training for educators at the New Jersey Education Association (NJEA) Convention – between 35,000 and 40,000 educators had the opportunity to view the NJCTS booth in 2011 alone – and providing keynote speakers and exhibits for the New Jersey Division of Early Education annual conference; gatherings for school nurses and social workers such as the Association of School and



The panel of experts at the inaugural NJCTS and Atlantic Health Statewide Medical Symposium on Tourette Syndrome, which took place at Overlook Medical Center in Summit, spoke at length about the diagnostic and treatment problem for physicians of patients with TS.



Dr. Larry Brown of the Children's Hospital of Philadelphia lectures at a symposium on Tourette Syndrome treatments and research at Cooper University Hospital in Voorhees.



The conference hall at Overlook Medical Center in Summit was packed for the first annual NJCTS and Atlantic Health Statewide Medical Symposium on Tourette Syndrome.

Agencies for the Handicapped (ASAH), Latino Psychological Association of New Jersey, National Association of Social Workers, NJEA, New Jersey Coalition for Inclusive Education, Somerset County Disability Services, Statewide

Parent Advocacy Network and the MetroWest Resource Fair; and the annual ASAH convention for professionals who concentrate on working with special needs students.

College workshops

Through partnerships with colleges and universities across the state, NJCTS offers a comprehensive workshop for community professionals on educating children with TS and associated disorders. This three-hour program provides numerous practice-based strategies and accommodations appropriate for students of varying ages and grade levels. These presentations, which are done at more than 16 colleges around the state, enable educators to create a learning environment that supports the social, emotional and intellectual development of all students in the classroom.

The presentation discusses the implications of a TS diagnosis outside of the classroom environment as well as efforts to facilitate a partnership between parents and educators. Interventions and modifications for behavior management are featured. Disorders such as ADHD and OCD as well as anxiety, depression, auditory processing and other learning disabilities are also addressed. Professional development credits are given to qualifying professionals at the completion of this course. New components of these presentations include topics such as recognizing the early warning signs of TS and the co-morbid disorders, and workshop offerings for medical professionals and school nurses.

These workshops took place multiple times in 2011 at colleges around the state, including Bergen Community College, Ocean County College, Raritan Valley Community College, Warren County Community College, Camden County College and Mercer County College.

Family Support

Wednesday Webinars

Through the Wednesday Webinar Series, which debuted in 2008 and in 2011 alone reached more than 3,100 people in 43 states, the District of Columbia and 7 countries, NJCTS brings the strength and information of professional seminars electronically to families and professionals in the disabilities and mental health communities. Topics of interest in 2011 included a popular four-part series on anxiety, how to manage hoarding, preventing bullying, reducing stigma, recognizing problems with executive function, and how to deal with neurological disorders such as Tourette Syndrome, ADHD and OCD. During these webinars, questions often are broached and subsequently answered concerning understanding behavior modification therapy, family coping strategies and techniques for success in school, peer relationships, in the workplace and in the community.

Presentations are delivered by practicing professionals including neurologists, psychiatrists, psychologists, nurses, teachers, attorneys and others. Viewers, who have logged on from locations as far away as Australia and Tasmania, have the opportunity to ask questions during the presentation and have access to a web-based chat room where they can post additional questions to topic-speaker. Credits are offered to qualified professionals and all webinars are archived for continued viewing.



(L-R): Dr. Diana Antinoro, Dr. Brian Chu, Dr. Daniela Colognori, Dr. Shawn Ewbank

2011 WEBINARS

FEBRUARY

- Understanding and Responding to Behavioral Difficulties and Rage Behaviors in Children and Adolescents

- Selective Mutism: Coordinated Behavioral Approaches for Therapists, Parents, and Schools

MARCH

- The Impact on Marriage and Family in Raising a Child with Neurological Issues

APRIL

- Anxiety and Its Impact on Sports, Academics
- Performance: Understanding the Mental and Emotional Side of Performance

MAY

- Mindful Awareness and How it Relates to the Classroom, Workplace and Family Life
- Do You or Your Child Seem Disorganized?: How to Recognize Executive Function Disorder

JUNE

- More than Shyness: What is Social Anxiety Disorder and how is it Treated?

JULY

- Child Anxiety: What Does Treatment Entail for the Child and Family
- "Developmentally-Appropriate Anxiety: How to Help, and When to Seek Help"

AUGUST

- Building Positive Social Environments for Children

OCTOBER

- Nothing to Talk About but Fear Itself: How to Interact with Children About Anxiety

NOVEMBER

- Beyond the Incident: Preventing Bullying

DECEMBER

- The Nature and Treatment of Hoarding



(L-R): Gayle Forman, Dr. Martin Franklin, Dr. Stuart Green, Dr. Graham Hartke, Dr. Joelle McGovern, Dr. Yevgeniya Ratnovsky, Dr. Kenneth Schneider, Dr. Ken A. Verni

TSParentsOnline & Teens4TS blog

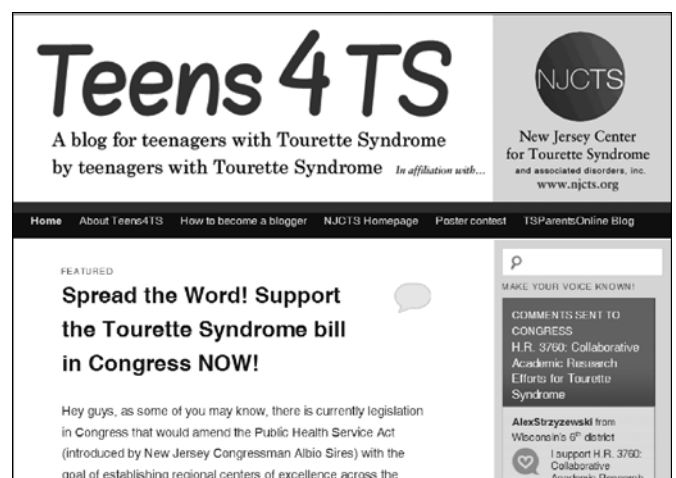
Parents of children with Tourette Syndrome are constantly looking for resources that might help that child and their family. As our society becomes more and more technologically advanced, the ability to get resources into the hands of families in need is becoming easier. That mode of thinking led to NJCTS' fourth-quarter 2011 launch of two weblogs – websites of running information dedicated toward helping parents of children with Tourette and teenagers with TS.

The parents blog – TSParentsOnline, available by visiting www.njcts.org/tsparents – has become an online community of dozens of parents from all over the world who regularly share stories, ideas, experiences, hopes and dreams. In the blog's first few months of existence, more than 10,000 page hits were received on more than 90 entries from parents in countries such as the United States, Canada, England, Germany, Belgium, the Netherlands, Australia and Indonesia. Some of the hard-hitting topics that have been broached include homeschooling, stress, doctors, medication, dealing with tics and infant behavior. Parents also have engaged in conversation about relevant national events such as the students with Tourette-like symptoms in Upstate New York and the federal Tourette Syndrome legislation that was introduced in December 2011.

The teens blog – Teens4TS, available by visiting www.njcts.org/teens4TS – initially was the brainchild of New Jersey teenager Harrison Kaminsky, who approached NJCTS early in 2011 about the idea of starting an online community for teens with TS. Once the blog was started, with Harrison kicking it off with a post about how teens with TS just want to be accepted. Other entries on topics such as the New Jersey Walks for TS – which was founded by a teen on behalf of her cousin, who has TS – how to do a peer in-service training about TS, controlling tics and how to succeed in school followed. The blog has been an enormous success – a boon to teenagers looking for a place to vent and fit in, and continues to grow, thanks to the presence of seasoned teenage bloggers who have brought the flavor of their websites to Teens4TS.



www.njcts.org/tsparents



www.njcts.org/teens4TS

Family Support

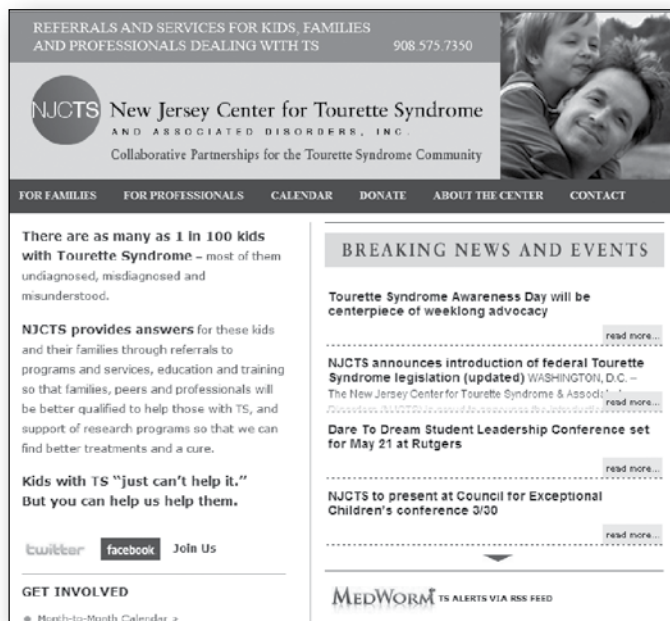
Gaining efficiency through technology and social media

Throughout 2011, the Center placed an increasing importance on using social media to disseminate its message, mission and catalog of events and programs. The mediums of Facebook, Twitter, LinkedIn and even our home page, www.njcts.org, continue to grow and play a big role in how people come to discover what the Center is all about. We encourage you to visit and become a member, “friend” or “follower” of each of these social media platforms!



www.NJCTS.org

The Center’s website features resources for families and professionals – help for kids in school, awards and scholarships, information about family retreats, a calendar of activities and much more. A complete list of support groups, links to additional TS resources, the latest news pertaining to the organization’s efforts and outreach, and a complete history of the Center are just a few of the other features of the website, which receives as many as 124,000 page hits each month from people all over the world. Visitors also can find multiple ways to contact the Center, obtain downloads of information, explore opportunities to donate and sign up for Wednesday Webinars, seminars, blogs, advocacy events and more.



Facebook

www.facebook.com/TouretteSyndrome

NJCTS’ presence on the social media giant has increased over the past year, and its following has seen a subsequent bump – 25 percent growth over the fourth quarter of 2011 alone. NJCTS’ Facebook page, which can be found by visiting www.facebook.com/TouretteSyndrome, features information about the organization, photographs from important events such as the New Jersey Walks For TS and is the homepage for “Wednesday Is TS Day!”, a movement created to make each and every Wednesday a day to raise awareness and do something to help kids with TS. The page also hosts one of NJCTS’ blogs, TSParentsOnline, access to events such as support groups and webinars, and the ability to connect with other members of the TS community.



Twitter

twitter.com/TSParentsOnline
twitter.com/Teens4TS

NJCTS uses this social media platform to inform not only the TS community, but people from all walks of life all over the world, about its programs, services and events. Over the fourth quarter of 2011, NJCTS’ Twitter following increased by a whopping 236 percent, as more and more people logged on to read streams of information from the New Jersey Walks For TS, access links to TS resources, peruse blog entries, repost TS tweets to their followers and more. The NJCTS Twitter account is available by visiting <http://twitter.com/NJCTS>. The Center also uses Twitter to disseminate the information from its blogs. The TSParentsOnline blog’s Twitter account is available by visiting twitter.com/TSParentsOnline, while the Teens4TS blog’s Twitter account can be found by visiting twitter.com/Teens4TS.

Roadmaps & Support

Physician Referral List

The Physician Referral List (PRL) list is comprised of more than 200 doctors, physicians, pediatricians, neurologists, psychiatrists, psychologists, counselors and social workers who have expertise in treating Tourette Syndrome. The list, available for Helpline, support group coordinators, school in-service presenters and office staff, is compiled from bi-annual interviews with clinicians and recommendations from our members as well as other clinicians. Our referral can sometimes make a difference in how quickly a patient can be seen by a particular clinician. It is a direct link for families to medical professionals across the state in variety of fields relevant to the TS community such as ADHD, OCD, anxiety and depression. Our Physician Referral List is a critical aspect of our work at NJCTS, and we are constantly updating and developing it to provide the best, most up-to-date information on clinicians with understanding of TS and its co-occurring disorders.

The Physician Referral List also is used to inform doctors and other medical workers of scholarly articles related to TS in which NJCTS has been mentioned, such as "Histidine Decarboxylase and Tourette Syndrome" in the New England Journal of Medicine and "NJCTS Sharing Repository: Methods and Sample Description" in BMC Medical Genomics.

For information on access to the Physician Referral List:
E-mail us at: info@njcts.org.

SUPPORT GROUPS

The Center knows it's important for TS parents to get the chance to listen, learn and speak to each other about their experiences raising kids with Tourette and associated disorders, and that's why support groups are a longstanding part of what we offer. Support groups met at hospitals all around the state throughout 2011. If you didn't get the chance to check one out, consider joining one of the following hospital-based groups in your area:

Somerset/Hunterdon Counties

Somerset Medical Center, Somerville

Atlantic/Cape May Counties

Atlantic City Medical Center, Pomona

Morris/Sussex Counties

St. Clare's Hospital, Denville

Burlington/Camden Counties

Virtua Hospital, Marlton

Middlesex County

JFK Medical Center, Edison

For more information:

Call: 908-575-7350

E-mail: info@njcts.org

Visit our calendar: www.njcts.org/calendar.php

Visit our Facebook page: www.facebook.com/TouretteSyndrome

Helpline: 732-972-4459

When a family is diagnosed with Tourette Syndrome, NJCTS provides a roadmap for services, support and clarity. One of the ways that is accomplished is through our helpline, which is manned by a dedicated support group of volunteers and loyal staff.

For doctors, teachers, newly diagnosed families and others needing information and support.

Family Support

NJCTS family retreat: The best weekend of the year

A perfect mixture of fun, education and advocacy has been the name of the game for the past seven years during the annual NJCTS family retreat weekend at picturesque Hunterdon County's YMCA Camp Bernie in Port Murray.



Children and teenagers with Tourette Syndrome and their families have plenty of reasons to flock to the June retreat – activities such as archery, canoeing, campfires, talent shows, arts & crafts, etc. The seventh installment of the family retreat weekend featured dozens of families, each of which had the chance to meet other families who “get it” when it comes to Tourette, the opportunity to make new friends who understand what their peers are going through and time for listening to experts, therapists, support group leaders and volunteers talk about various subjects pertaining to TS.

Some of the biggest hits from the weekend were the study skills class, the rock painting session and the performance of the Band of Jugglers group. “This weekend was an invaluable experience that we wouldn’t miss for the world,” said Melissa Kuperman, who brought her family to the retreat weekend in 2011. “There’s nothing that compares to being with all those families that truly understand what it’s like to have and live with Tourette Syndrome. It means so much to my children to have one weekend when they’re not different and for us to have those moments of camaraderie

with other parents.” The family retreat weekend would not have been possible, however, without support from the HAPI Foundation and our wonderful volunteers, including:

Marilyn LaMarca
Liz LaMarca
Kim Rice
Jay Geyer
Steven Lindenbaum
Emily Fleischman
Niranjan Ramanand
Ed Baumann
Jamee Silenzio
Laurie Foster



Campers enjoy many activities at the annual NJCTS Family Retreat Weekend at YMCA Camp Bernie in Port Murray, N.J., including a ropes course and time to get to know other families.

“Being together in a place with the family where you feel totally comfortable...
I get emotional talking about it...it's the best weekend of the year.”

~MARK BRUNNER, NJCTS PARENT



The Kowalski family, which regularly attends the family retreat weekend, always has a blast!



Camaraderie is one of the many things emphasized by our team of volunteers at Camp Bernie.



Florence and Emily Fleischman are all smiles as they canoe around Camp Bernie's lake.



The Band of Jugglers performing act was one of the many highlights from the 2011 camp.



Several campers were brave enough to tackle the camp's rock wall.

Awareness

Bill H.R. 3760: Landmark federal legislation introduced for Tourette Syndrome

One of the most important events in the past 40 years to happen to the TS community took place in 2011: Federal legislation for Tourette Syndrome was introduced by U.S. Congressman Albio Sires (D-NJ13). Titled the Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2011 with bill number H.R. 3760, this legislation would amend the Public Health Service Act to provide for the expansion, intensification and coordination of the programs and activities of the National Institutes of Health (NIH) with respect to Tourette Syndrome. "Tourette Syndrome is a misunderstood

disorder that affects 1 in 100 people and is too often stigmatized," Congressman Sires says. "While symptoms can be suppressed for short periods of time, too many individuals – particularly children – face the everyday challenge of trying to manage tics, whether at school or in various social settings. Through expanded and collaborative research, we can learn more about the cause and treatment of the disorder to help improve the lives of those individuals impacted by Tourette Syndrome." Congressman Sires worked closely with NJCTS Executive Director Faith W. Rice; Dr. Jay A. Tischfield, Director of the Human Genetics Institute at

Rutgers University; and other NJCTS leadership to craft this legislation. Says Rice, "New Jersey has changed the face of TS research, education and support through partnerships and collaborations. We hope to model that process nationwide." A primary purpose of this legislation is to establish regional centers of excellence across the country to conduct research into the cause, diagnosis, early detection, prevention, control and treatment of Tourette Syndrome and associated disorders. If passed, this legislation could change the way TS is treated, viewed and advocated for nationwide.



Congressman Albio Sires introduced bill H.R. 3760, the Collaborative Academic Research Efforts for Tourette Syndrome Act of 2011.

"...Through expanded and collaborative research, we can learn more about the cause and treatment of the disorder to help improve the lives of those individuals impacted by Tourette Syndrome." ~CONGRESSMAN ALBIO SIRES



Congressman Sires tours the NJCTS Sharing Repository at Rutgers University.



Rutgers President Richard McCormick (left), Rutgers Dean of Life Sciences Kenneth Breslau and Dr. Jay Tischfield talk with NJCTS Executive Director Faith Rice and Congressman Albio Sires at the NJCTS Sharing Repository.

Governor Christie proclaims TS Awareness Month

May and June were important months for the Center. New Jersey Gov. Chris Christie honored the work of NJCTS through a proclamation declaring May 15 to June 15 “Tourette Syndrome Awareness Month.” According to the Centers for Disease Control, as many as 1 in 100 children exhibit symptoms of TS- a neurological disorder characterized by uncontrollable motor movements and vocalizations known as tics. The majority of people with Tourette Syndrome also have co-occurring conditions, most commonly attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), anxiety disorders, depression, learning disabilities and sleep

disorders. “As many as 28,000 kids here in New Jersey may have TS,” NJCTS Executive Director Faith Rice said. “The New Jersey Center for Tourette Syndrome exists as a way to bring together the resources and services to educate and train families, their doctors and their teachers. With support from our local leaders, including State Senator Kip Bateman and partners like Somerset Medical Center, NJCTS delivers comprehensive services for the community dealing with TS and associated disorders across our state.” Since 2000, NJCTS has received recognition from federal, state and municipal leaders on multiple occasions, including other Tourette Syndrome Awareness Month proclamations by Governors

Christine Todd Whitman, Donald DiFrancesco, James McGreevey, Richard Codey and Jon Corzine.

The “Wednesday is TS Day” awareness and anti-stigma campaign has drawn wide support throughout the region. A

growing number of lawmakers have stood up and publicly declared Wednesday as “TS Day” in the following communities:

| | |
|----------------|-------------------|
| Newark | Somerville |
| Trenton | Wildwood |
| Camden | Denville |



Senator Kip Bateman (left) presents Eliot Goldstein and Faith Rice with the 2011 Tourette Syndrome Awareness Month proclamation from Gov. Chris Christie as Somerset Medical Center President/CEO Kenneth Bateman looks on



FAMILIES RAISE MONEY FOR NJCTS THROUGH FUNDRAISERS

Kevin Staine brought some high-speed awareness to TS in 2011. When he's not at work or spending time with his family, Staine is a tri-athlete. In July, he competed in the Randolph Lake Triathlon and used the opportunity to honor his son Conner and raise funds for NJCTS from friends and family. The Staines are one of many families who have committed to help the Center continue to deliver the services and programs TS families have come to rely upon. We are grateful for every contribution and appreciate the energy and follow-through from these special parents and children. Also in 2011, Jeff and Gerri Decicco raised \$8,000 for NJCTS with a Fun Day at an indoor athletic facility. Thank you to our families and partners!

Outreach

New Jersey Walks for TS in Mendham, Nov. 19

It is only fitting that the second annual New Jersey Walks For TS at Borough Park in Mendham took place in the week leading up to Thanksgiving. Several hundred walkers and runners showed up on a brisk but sunny November morning to show their support for NJCTS and help raise more than \$27,000 to benefit the Center. This event started in 2010 as a youth-initiated grassroots movement, fueled by teens with the desire to show their peers that they care. Now, it's a statewide event attracting people from both the TS community and the general public. "A ton of people came out and showed a lot of support. I saw a lot of new faces, as well as some people that are having their anniversary of finding out and being diagnosed," said Rosemary Carrara, whose daughter, Emily, is the founder of the event. "I think it's great that they



are automatically and very quickly showing support for NJCTS and what they are doing for families." The walk featured entertainment from Sparkee, the Somerset Patriots' official mascot; the Band of Jugglers; balloon artist Leigh McLachlan; Al Stark (Al Pal the Town Clown); DJ Ed Baumann; and Danielle Piacentile, who sang the National Anthem. And you couldn't help but notice the throng of local teenagers who showed up to volunteer as walk guides, set up tables and chairs, and lend a helping hand whenever needed. Park Ridge resident Mike Puzzo was part of Team Flanagan, one of many family-based teams at the event, and thoroughly enjoyed the walk. "It was a great event," Puzzo said, "and it's always great to raise awareness for Tourette Syndrome."



Teenager Danielle Piacentile sings the National Anthem prior to the start of the New Jersey Walks for TS in Mendham.



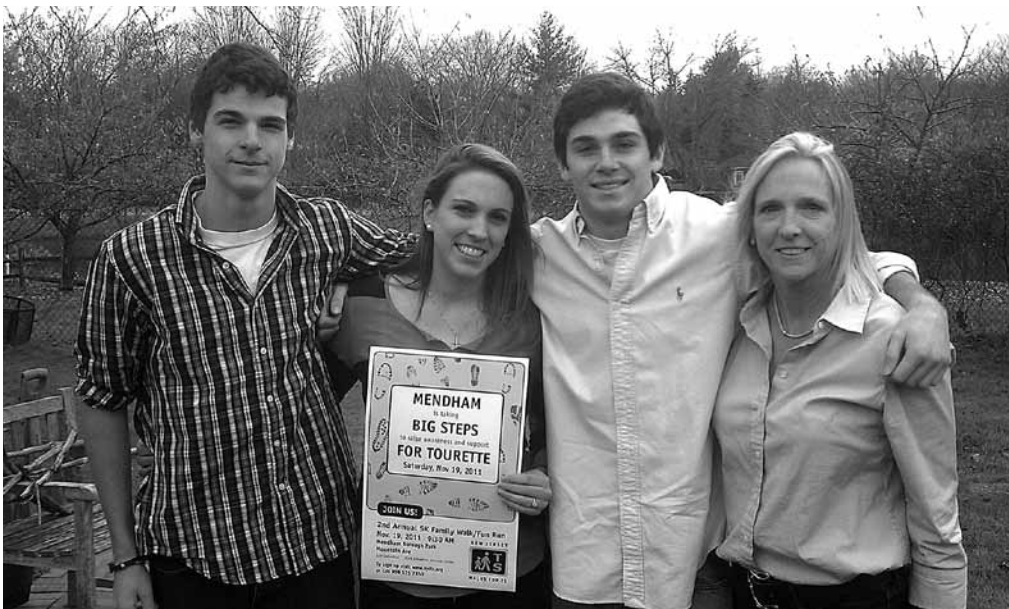
Team Lederman was one of the largest groups, with more than 25 people, at the 2011 walk. Great job, Lederman family! Thank you so much!



Amanda Silvers and Dean Roncati walked and talked during the 2011 New Jersey Walks for TS.



This event started in 2010 as a youth-initiated grassroots movement, fueled by teens with the desire to show their peers that they care.



From left, T.J. Stanley, Emily Carrara, Brendan McCarthy and Rosemarie Carrara once again helped NJCTS organize the 2011 walk.



The Somerset Patriots Baseball Club brought one of their mascots, Sparkee, to the 2011 walk to entertain kids and adults alike!

TS advocate and soccer superstar teams up with NJTS



Tess and Paige Kowalski got to spend time with star soccer goalkeeper Tim Howard during the trip to England their family won as part of NJCTS' Team Up With Tim Howard raffle.

Aside from his stardom as one of the world's most famous soccer players, Tim Howard is an advocate for the Tourette Syndrome community. Howard has partnered with NJCTS on numerous occasions, and in 2011, he came through once again by taking part in the "Team Up with Tim Howard" raffle, the proceeds from which have gone to support the Center's programs. Howard knows what it's like to be a kid with a neurological disorder which causes erratic muscle movements or uncontrollable sounds. He also knows what it's like to overcome obstacles like TS and achieve great success. There are many reasons why Tim Howard is an inspiration, and his commitment to children and families with TS is certainly at the top of the list. All of those attributes

were on display when the winning family, the Kowalskis of Plainsboro, won the raffle and the opportunity to fly to England to see Howard – who also stars for the U.S. National Soccer Team – play for his club team, Everton of the Premier League. The Kowalskis also got some one-on-one time with Howard and were thrilled with the experience. During a 90-minute lunch, Howard fielded questions from the Kowalski's daughters – Tess, 12, and Paige, 8 – about life, soccer and TS. The Kowalski girls, who never before had shown any interest in sports and only after winning the raffle said for the first time, "I want to play soccer," left the lunch even more excited about Howard's sport. But it was Howard's stories about growing up with Tourette that captivated the Kowalskis the most. "He said that when he was a kid, the tics would overwhelm him and they would come out. Now, I get the sense that they just pass through him. It was a different take on 'You grow out of it,' " said Leslie Kowalski, whose girls also were treated to time in the Everton team store and exclusive players' lounge before the game. "I just loved that my girls were seeing someone who is so free with his tics. He wants to be who he is. He was just so comfortable with himself. I could see by the way they looked at him and talked about him that they were inspired."



The Kowalskis learned a lot about Tourette Syndrome from Howard and his mother, Esther, during their trip to England.

Children's Scholarship Award

Each year, NJCTS awards scholarships to graduating New Jersey high school seniors with Tourette Syndrome with the Children's Scholarship Award. All applicants must complete an application and meet the following criteria: be a New Jersey citizen, be planning to attend a college or trade school on a part- or full-time basis, provide a record of high school grades to date and submit an essay of 1-2 pages describing how TS has played a part in your life. Since 2003, NJCTS has awarded nearly 200 scholarships to graduating high school seniors.

Meet the 2011 winners, who were selected for academic achievement, community involvement and accomplishments as an individual with Tourette Syndrome:

Rachel Herman and **Graham Reeve** were both selected from Cherry Hill High School East.

Dalton Kinnard, who graduated from West Morris Mendham High School in Mendham.

Andrew Friedrich, who graduated from Pequannock Township High School.

Zachary Modelski, who graduated from DePaul Catholic High School in Wayne.

Melanie Claudio, who graduated from Rosa Parks High School in Paterson.

James Siluk, who graduated from Clifton High School.

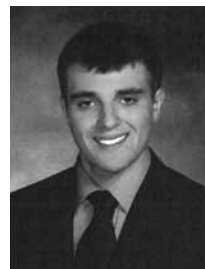
Joseph Putignano of Hackettstown and **Ryan McDonald** of Great Meadows were both selected from Hackettstown High School.

Samuel Stuhler, who graduated from Hopewell Valley Central High School in Pennington.

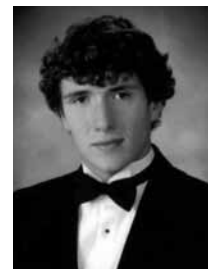
Dean Terrell, who graduated from Bridgewater-Raritan High School in Bridgewater.



Graham Reeve



Dalton Kinnard



Zachary Modelski



Melanie Claudio



Joseph Putignano



Ryan McDonald



Dean Terrell

NJCTS recognizes 2011 Educator of the Year

Without caring teachers, students with Tourette Syndrome would very much be on an island when it comes to their education. Many teachers help students with TS, but only a select few go out of their way to ensure those students get the attention they need. Since 2003, NJCTS has presented 11 special teachers with the Educator of the Year Award to recognize a New Jersey educator who has made a significant difference in the life of a child with Tourette. In 2011, the winner was psychologist Dr. Chris Leuper of Allentown High School. He was nominated by Dawn Bryan on behalf of her son, Tommy. When Leuper was first introduced to Tommy, it was by Dawn, who let Leuper know

that Tommy was diagnosed with Tourette Syndrome and, as a result, had special educational needs. Leuper not only paid attention to those needs, he went above and beyond to ensure Tommy received a personal aide and assistive technology – as well as paved the way for other teachers to be educated about TS. Leuper has provided Tommy with a laptop that features special software that helps Tommy deal with his dyslexia, books on tape from Learning Ally and personal aides who regularly work with Tommy. Leuper also has maintained an open-door policy, allowing Tommy someone to whom he can speak when needed.



Dawn Bryan (left) nominated Dr. Chris Leuper (center) for the 2011 NJCTS Educator of the Year Award. Helping him receive the award is Allentown High School Principal Constance DeNicola Embley.

NJCTS Advocate Award established in 2011

Teenager Emily Carrara of Mendham was the first recipient of the NJCTS Advocate award. She was commended for her accomplishments in raising public awareness and launching the annual New Jersey Walks for TS event in Mendham to benefit the TS community. The award was presented at West Morris Mendham High School's Board Awards night on June 7 as part of TS Awareness Month. The NJCTS Advocate Award is given to an individual whose contribution makes a difference to the Tourette Syndrome community. An NJCTS Advocate is a person whose dedication and actions improve awareness and help break the stigma of Tourette by educating the public, medical professionals and educators about TS and by supporting kids and families living with this often devastating neurological disorder.



Emily Carrara



www.njcts.org

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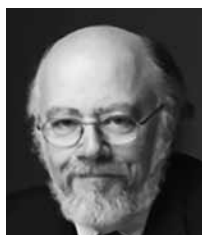


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New Jersey Center for Tourette Syndrome

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Collaborative Partnerships for the Tourette Syndrome Community

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