45 YEARS OF DEDICATED SERVICE

The Tourette Association of America was founded in 1972 with the aim of improving the lives of all people affected by Tourette Syndrome (TS) and Tic Disorders. The TAA invests in research which may lead to tomorrow’s breakthroughs in diagnosis and treatment. Our research programs are central to the mission of improving the lives of those impacted by Tourette and Tic Disorders.

SUCCESSES: TREATMENTS, CARE, RESEARCH

To date, the TAA has awarded over $21 million to nearly 450 projects across 16 countries. Every $1 of TAA grant funding has helped investigators obtain approximately $10 in grant funding from the National Institutes of Health (NIH), leveraging TAA’s initial seed investments toward larger research impact. Together we:

• Facilitated the first FDA approval of a drug for Tourette in over 30 years (Abilify) [aripiprazole].
• Discovered a new class of drug, ecopipam, effectively reduces tics, with little adverse effects in children and adults.
• Developed and clinically demonstrated that Comprehensive Behavioral Intervention for Tics (CBIT), a medication-free behavioral therapy, is as effective as drugs in some individuals.
• Showed Deep Brain Stimulation (DBS) can effectively treat severe Tourette Syndrome and developed guidelines for its clinical use in scientific and medical journals.
• Helped to identify genes and genetic variations (eg. CNTNAP2, SLITRK, HDC, NRXN1 and CNTN6) that cause rare forms of Tourette Syndrome, increase the risk of developing the disorder, and link Tourette Syndrome with other conditions like Obsessive Compulsive Disorder.
• Established a wide range of research resources that facilitate global collaboration and accelerate research including Brain Bank, Gene Sample Collections, International Consortium on Genetics, Neuroimaging Consortium, International Deep Brain Stimulation Registry and Behavioral Sciences Consortium.
• Funded and supported ongoing development of novel and promising treatment approaches, such as medical cannabis, dental orthotic devices and home-based behavior therapies, some of which already have obtained US patent protection and Federal business grants to support commercialization and development.

PROGRESS IN AWARENESS, SUPPORT AND RESEARCH

For over a decade, the TAA has partnered with the CDC (Centers for Disease Control and Prevention) to produce educational materials and facilitate programming to educators, schools, patients and medical professionals. Our program with the CDC has delivered over 1,000 free educational opportunities (in person and online) to nearly 350,000 care providers, school personnel, families, individuals and members of the general public.
RESEARCH HIGHLIGHTS

TAA researchers discover new genes for the disorder, providing clues to underlying brain mechanisms.

In breaking research published this spring, researchers from two major genetics consortia identified new gene abnormalities linked to Tourette Syndrome. In one study, led by Drs. Jeremiah Scharf at Massachusetts General Hospital for Children, Giovanni Coppola at the University of California Los Angeles, and Carol Mathews at the University of Florida, deletions of a gene called NRXN1 and duplications of a different gene named CNTN6 were shown to substantially increase the risk of developing Tourette in some individuals. The Tourette Association of America International Consortium for Genetics (TAAICG) and its collaborators studied genetic material from over 2,400 individuals with Tourette Syndrome and 4,100 without to determine that individuals with Tourette were up to 20 times more likely to have abnormalities in these 2 genes.

In a second study, led by Doctors Matthew State at the University of California San Francisco and Jay Tischfield of Rutgers University, 325 Tourette disorder parent-child groups from the Tourette International Collaborative Genetics cohort and a replication sample of 186 parent-child groups from the TAAICG identified four additional possible risk genes: WWC1, CELSR3, NIPBL, and FN1. The new genes identified from both of these studies are thought to play unique roles in brain development and brain communication processes, opening up countless new avenues for experimental research targeted toward new treatments. Both of these studies were published in the prestigious scientific journal Neuron.

Brain Structure Changes Identified in Children with Tourette Syndrome

In a collaborative multicenter study published in the journal Molecular Psychiatry this summer, Drs. Bradley Schlaggar and Kevin Black from Washington University School of Medicine used structural magnetic resonance imaging (MRI) to compare 103 children and adolescents with Tourette Syndrome to a well-matched group of 103 children without tics. Kids with Tourette Syndrome demonstrated lower white matter volume in the orbital and medial prefrontal cortex brain regions, and increased grey matter volume in other specific areas of the brain, namely the posterior thalamus, hypothalamus and midbrain. These brain regions are involved in various processes, including awareness of internal body sensations, which is important given the occurrence of premonitory sensations that precede tics in many patients.

“Our study is the tip of the iceberg in understanding the complex biological mechanisms underlying this disorder. With recent advancements in genetic research, we are at the cusp of identifying many genes involved in Tourette Syndrome”

Jeremiah Scharf, M.D., Ph.D., Assistant Professor of neurology and psychiatry at Harvard Medical School and Massachusetts General Hospital, Boston, and co-corresponding author of the study.
Michael Ullman, PhD, Georgetown University, Washington DC

Recent evidence suggests that children with TS may show enhanced procedural memory performance. Procedural memory, which underlies numerous motor and cognitive skills, such as driving and grammar, is rooted in certain brain circuits affected in TS. In this project, Dr. Ullman and team will comprehensively examine procedural memory, the brain, and clinical correlates in children with Tourette Syndrome. Understanding the mechanisms underlying this enhanced memory could result in the development of novel therapies targeting these pathways.

Hannah Reese, PhD, Bowdoin College, Brunswick, ME

Psychosocial treatments for Tic Disorders have substantially improved in recent years. However, a significant number of individuals either do not respond to the current treatments, find them unacceptable, or cannot access them. Initial pilot data suggest that a mindfulness-based intervention may be beneficial for adults with tic disorders. In the present study, Dr. Reese and team aim to further develop this mindfulness-based intervention, adapt it to be delivered online to enhance accessibility, and conduct a single-blind randomized controlled trial comparing it to online group psychoeducation, relaxation, and supportive therapy.

Joseph McGuire, PhD, University of California Los Angeles, Los Angeles, CA

* Funded in partnership with the American Brain Foundation and the American Academy of Neurology

While behavior therapy significantly reduces tic severity, neurocognitive functioning (e.g., difficulty paying attention, inhibiting responses, remembering instructions, etc.) may impact the magnitude of benefit obtained from behavior therapy. This project will identify the neurocognitive profile of youth who do and do not respond to behavior therapy and will explore changes in brain structure following behavior therapy. This information will be used to revise current treatments and identify augmentative strategies to help patients with Tourette Syndrome obtain further benefit from behavior therapy.

Flint Espil, PhD, Stanford University, Stanford, CA

* Funded in partnership with the American Brain Foundation and the American Academy of Neurology

Persistent Tic Disorders, including Tourette’s Disorder, may occur because of problems in an area of the brain called the prefrontal cortex. A recent study found that some areas of the prefrontal cortex were not as active in those with tics when compared to people without tics, and lower activity predicted poor response to treatment. The goal of this study is to examine whether the same areas of the prefrontal cortex are underactive in youth (ages 10-17) with Persistent Tic Disorders, and whether this also predicts whether or not they will respond to therapy for their tics.
Medical Cannabis as a treatment for TS and other neurological conditions.

There is increasing interest in medical cannabis (marijuana) as a potential treatment for tics and other symptoms in Tourette Syndrome. Over the past 6 years, the TAA has funded 5 grants to scientists from Israel, Canada and the US to investigate the potential of medical cannabis and novel drug candidates targeting medical cannabis pathways. As a result of our funding, research examining the therapeutic potential of targeting the endocannabinoid system has demonstrated positive laboratory results and achieved US patent protection. Currently, the TAA is working to facilitate careful and rigorous laboratory and clinical exploration in this area and tackling unique challenges such as variability in manufacturing and regulatory issues.


Deep Brain Stimulation or “DBS” is a procedure that utilizes an implantable electrode to alter the activity of brain circuitry. The procedure is FDA approved for Parkinson’s disease, essential tremor, dystonia and OCD, and currently utilized for patients who have not responded to standard medical or behavioral therapy. To investigate the potential for DBS to benefit Tourette Syndrome patients, the TAA sponsored the development of a registry, led by Dr. Michael Okun from the University of Florida and co-sponsored by Medtronic.

NEWLY FUNDED GRANTS TO STUDY TOURETTE SYNDROME

The TAA’s newest grant awardees are tackling ways to improve treatment for Tourette Syndrome by testing brain surgical methods, mindfulness strategies, and methods to improve the success of behavioral interventions and enhance our structural understanding of brain changes that occur in the condition.

Kevin McCairn, PhD, Kyoto University, Japan
(In collaboration with Mayo Clinic Department of Neurosurgery)

One of the least understood symptoms of Tourette Syndrome is the emergence of involuntary vocalizations such as throat clearing, coughing, grunting, or barking in more mild cases or obscene language or other contextually inappropriate phrases in more complex cases. Previous work supported by the TAA has identified a network in the brain, a region associated with emotional processing called the limbic system, which when made over excited, induces vocal tics. In this upcoming study, Dr. McCairn and team will investigate how brain chemicals are changed during the change from a normal state to one where vocal tics express themselves, and how intervention with brain surgical methods, namely Deep Brain Stimulation (DBS), may help alleviate these symptoms. Planning for this study is currently underway.
Centers of Excellence Locations
The Tourette Association of America’s Center of Excellence (CofE) program aims to improve the quality of life of people with Tourette Syndrome and other Tic Disorders by promoting the highest level of care, research, education & training, and advocacy & awareness for these conditions.

Baylor College of Medicine
Houston, TX
(713) 798-2273
Children’s Mercy Hospital
Kansas City, MO
(816) 346-1384
Johns Hopkins Hospital
Baltimore, MD
(410) 955-4259
Massachusetts General Hospital
Boston, MA
(617) 726-5532
University of California, Los Angeles
Los Angeles, CA
(310) 825-0122

University of Utah
Salt Lake City, UT
(801) 585-7575
Yale Child Study Center
New Haven, CT
(203) 785-5880
New York State Consortium:
Weill Cornell Medical College
New York, NY
(212) 821-0789
University of Rochester Medical Center
Rochester, NY
(585) 275-2808
Icahn School of Medicine at Mount Sinai
New York, NY
(212) 659-1660

South East Regional Consortium:
Emory University School of Medicine
Atlanta, GA
(404) 776-3444
University of Alabama at Birmingham
Birmingham, AL
(205) 638-6820
University of Florida Gainesville, FL
(352) 294-5400
Palmetto Health – USC Medical Group
Columbia, SC
(803) 434-7961
University of South Florida St. Petersburg, FL
(727) 767-8230

TAA National Board of Directors
Rovena Schirling, Chair
Monte Redman, First Vice Chair
Marcie Kirkpatrick, Second Vice Chair
Alice Kane, Third Vice Chair
Cindy Kurtz, Fourth Vice Chair
Reid Ashinoff, Director
Dr. Azad Anand, Director
Stephen Barron, Director
Joseph Campolo, Director
Susan Courey, Ph.D., Director
Fred Cook, Finance Committee Chair
Paul S. Devore, Director
Julie Haddon, Director
Peter Hollenbeck, Ph.D., Director
David Koch, Director

Jeffrey Kramer, Director
Nancy Kramer, Director
Stephen McCall, M.Ed., Director
Julie Moelis, Director
Bruce Ochsman, Director
Chris Ovitz, Director
Robin Small, Director
Randi Zemsky, Director

TAA Leadership
John Miller, President/CEO, Tourette Association of America
Diana Felner, Vice President, Public Policy
Sonja Mason-Vidal, Vice President, Finance & Administration
Diana Shineman, Ph.D., Vice President of Research & Medical Programs
Amanda Talty, Vice President, Resource Development & Marketing

42-40 Bell Blvd., Suite 205, Bayside, NY 11361 tourette.org 888-4TOURET
Facebook @TouretteAssociation | Twitter @TouretteAssn
Instagram @TouretteAssociation | YouTube @Tourette TV