Tourette Syndrome (TS) is a neurodevelopmental disorder, impacting an estimated 1 million Americans, that becomes evident in early childhood or adolescence. It is part of the spectrum of Tic Disorders and is characterized by uncontrollable motor and vocal tics.

While the onset and diagnosis of TS may take place in a child’s early years, the condition is lifelong. Some tics may be transient, but for 66% of individuals, TS persists into adulthood. In addition to tics, 86% of people with TS are affected by at least one co-occurring condition including Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), learning disabilities and more.

There is no cure for TS, but thanks to years of dedicated research, there are various treatment options available.
Welcome

Dear Friends,

We often hear that with a diagnosis of Tourette Syndrome comes a sense of relief and the clarity that solved mysteries evoke. The path to get there may be fraught with confusion and conflicting information, marked by a multitude of doctor visits and countless sleepless nights. While a diagnosis can be life changing, it might also mean having to endure stares, judgements, and endless explaining; which leads to increased isolation, poor self-esteem, anxiety and depression. Whatever the case may be, we know it is undeniably hard and you are not alone. We are a resilient group, leaning on one another to form a strong community and learning from personal experiences. Throughout our 31 Chapters, 83 Support Groups and via our national organization, connections made foster support and friendships that can last a lifetime. There is strength in numbers and these connections make us bigger and better.

A longtime donor who has had severe tics for most of his life summed up his TS experience succinctly: “The things you take for granted, going to the movies, having dinner at a restaurant, spending a quiet evening at home...those are the simple things I can’t enjoy.” As we continue to serve our community, we draw from this and remember not only how much those with TS and Tic Disorders need the Tourette Association of America on their side, but also how much the TAA needs you to join forces with us. The larger and more cohesive our network is, the more equipped we will be in fighting for our rights to make the simple things possible. As we look to the future, let’s work together in a variety of ways:

**To affect change.** Continue advocating for our rights and teaching others to accept differences, be less judgmental and more open to learning about Tourette Syndrome and Tic Disorders, and more willing to address health disparities including mental health issues.

**To live up to our potential.** Expand our reach through virtual and in-person programming, training, and awareness based activities. The more we do and the more people we reach, the more impact we will have. During the COVID-19 pandemic, our community needs us more than ever and we need your support more than ever.

**And most importantly to diagnose the other half.** As the only national organization dedicated to serving over 1 million individuals impacted by TS and Tic Disorders, we need to continuously grow, improve, and evolve to meet the challenges that lie ahead: to be the strongest possible support system for the 50% not yet diagnosed and for those not yet born.

We invite you to peruse through the Fiscal Year 2020 Annual Report that showcases how we were able to expand our reach and grow throughout the year. This includes highlights pertaining to local support across the nation, research progress, health and education outreach, our continuous presence in Washington, D.C. and fundraising events. This essential work comes at a cost but also a commitment from donors and partners to help spread the word and elevate the work of the Tourette Association of America to effect global awareness, improve time to diagnosis, increase access to treatment, bolster public education to reduce stigma, and fund cutting-edge research.

Tourette Syndrome understanding and social acceptance continues to evolve but you remain a critical part of our future. We are ever invested in underwriting research, working with our medical and scientific partners, establishing new Centers of Excellence for diagnosis and treatment, advocating for federal support, educating the medical, educational and general communities to better understand, accept and improve the lives of those living with TS, and providing new and improved tools to our community. To do all of this and more, we need your unwavering support. During these most difficult times, we hope we can count on you.

With appreciation and gratitude,
Mission & History

Founded in 1972, the Tourette Association of America is the only national organization serving the community, and works to raise awareness, advance research, and provide ongoing support to patients and families impacted by Tourette Syndrome and Tic Disorders. To this end, the TAA directs a network of 31 Chapters, 83 Support Groups and recognizes 18 Centers of Excellence across the country.

What We Do:

We raise awareness and **FOSTER SOCIAL ACCEPTANCE** through education and robust social media campaigns.

We **INVEST IN RESEARCH** that will advance scientific understanding, treatment options and care. Over $22 million has been awarded to over 450 research projects across 16 countries.

We **EDUCATE PROFESSIONALS** to better serve the needs of children, adults and families challenged by Tourette and Tic Disorders. Over 450,000 health care providers, school personnel, families, individuals and members of the general public have been reached through in-person and online trainings.

We **PROVIDE SUPPORT, HOPE AND HELP** through our network across the nation. We host virtual and in-person discovery and learning sessions, support groups for a variety of ages, and maintain a library of resources in various different languages to distribute and raise understanding.

We **EMPOWER THE COMMUNITY** to advocate for the most pressing issues facing the TS community. Over 1,000 Youth Ambassadors and their adult team members have been trained to educate their peers, adults, and government officials about TS. In addition, hundreds of congressional meetings are held annually with local representatives to lobby for continued funding and support for TS.
Finally, at 40, I was ready to talk. She invited me over to meet her son and talk with them. The love and support my friend and her husband are giving their little boy is just incredible! As I read the stories being posted on social media, I was so amazed at the bravery of these kids and young adults! They all seem so proud and confident, and I know that is due to having the unconditional love and support of their families and friends.

I think as we age, particularly in this uncertain time, it’s natural to reflect on how we’ve changed and grown and the things we’ve done and still have left to do. I often hear people say, ‘I wouldn’t change a thing because it made me who I am today.’ I am in awe of those people because there are so many things I would do differently! I often wonder what my life would be if I’d had even one person tell me as a little girl that I was OK just as I am and that I didn’t have to try harder to be quiet or sit still and that I wasn’t an embarrassment.

Don’t get me wrong! I absolutely know I’m stronger physically and mentally because of the challenges that come with TS, and I absolutely believe I’m more compassionate and accepting of others, too. I’ve had successes! I was valedictorian of my high school, finished college early on a full academic scholarship, landed some really great jobs, own a home, and I’ve even managed to travel to 26 countries and counting! I’ve run 26 half marathons in 15 states and I’m trying to get all 50 states by the age of 50. I’ve swam in the Great Barrier Reef, bungee-jumped in New Zealand, gone sky-diving, hang-gliding, zip-lining, and a ton of other crazy, adventurous things! But I’ve done those things the hard way by sheer grit and force-of-will. I can’t help but wonder what else I could have done if I’d just been brave enough to look for an organization like TAA sooner.

I want to tell all the parents out there who are working so valiantly to advocate for their kids with TS that you are phenomenal! I’ve seen many that want to do more to spare your children pain and to let them know they’re loved. I hope you know that just by finding resources and acknowledging their struggles, you’re doing exactly what they need!

I still struggle to say out loud that I have TS or to acknowledge that the “funny noises” or “twitches” are coming from me, but maybe someday I’ll be able to! In fact, maybe there’s a child out there who needs a mentor and just maybe that could be me!

For me, discovering the existence of the TAA and a whole community of people with TS has been both amazing and bittersweet. My tics began at age 8. My parents took me to a pediatrician who told them they were ‘bad habits,’ and they could either spank me when I had them or ‘pitch me a quarter’ if I went longer without them.

For my entire childhood, I thought I was weak and defective and that if I were just stronger, I’d be able to make them stop. It wasn’t until a college psych class that I saw a paragraph about Tourette. I was so blown away! It was the first time I had ever considered that I wasn’t alone. However, I was still too scared to look for help or support. About a year ago, a friend I’d gone to high school with posted a photo of her little boy with a TS ribbon. My heart was racing and I was so nervous, but I sent her a message.

Leigh Anne’s Story

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Our Work

Health and Education

The Tourette Association of America provides health education and awareness initiatives across the nation to various professional audiences, as well as impacted families and the general public. These efforts are joined under the Tourette Health and Education Program (THEP), which works to expand the ways in which information and education on Tourette is disseminated, especially targeting underserved areas with limited access to resources.

Overview

The Tourette Association of America advocates for the continued funding of $2 million supporting the nationwide Centers for Disease Control and Prevention’s Tourette Syndrome initiative. Through this funding, the Tourette Association of America Tourette Health and Education Program (THEP) is supported.

Since its inception 16 years ago, THEP has delivered hundreds of thousands of free educational opportunities (in-person and online) to health care providers, school personnel, families, and individuals of the general public. Through this powerful partnership, we’ve created and disseminated over 20 comprehensive resources in five different languages, improved the trajectory of treatment and care for those impacted through national trainings, and allowed for a more accurate time to diagnosis across the nation.1

National Trainings and Exhibits

In Fiscal Year 20, 479 individuals received an introduction to CBIT training, or were trained in CBIT, the recommended first-line treatment for TS. 6,010 took advantage of family and community-based education programming and 1,718 education professionals attended our education presentations. In addition, THEP participated in 12 partner exhibits to deliver free resources and information to audiences that overlap our community including child neurology (CNS), child psychiatry (AACAP), pediatrics (AAP), school nurses (NASN), school psychologists (NASP), school resource officers (NASRO), occupational therapists (AOTA), OCD community members and professionals (IOCDF), special education professionals (CEC), mental health professionals (NAMI), allergy, asthma and immunology professionals (AACAI), and speech-language pathologists (ASHA).

Online Support Groups

We understand the importance of providing greater access to our community through a variety of methods. Though we continue to grow and expand across the nation, not everyone has access to resources, information, health care

21,461
Individuals
Educated

Through in-person and online trainings to health care providers, school personnel, families, individuals and members of the general public.

175,000
Stakeholders
Worldwide

Comprised of physicians, allied professionals, researchers and educators, as well as a social media network of over nearly 50,000 constituents.

2,650,000
Reached

In a 4-week national awareness campaign aimed at providing resources and support to young adults.

1 In a 2018 impact study, led by the TAA, 71% of caregivers of children with TS reported receiving a diagnosis in less than 2 years, where most adults were diagnosed after 10+ years indicating our national awareness, education, and training efforts are working.
and TAA Chapters and Support Groups equally. In response to this, the TAA launched online support groups to reach underserved populations and communities across the nation. Since its launch in Fiscal Year 2018, the demand for online support has grown exponentially and over 100 parents and young adults have been served, with many on the waiting list. 100% of participants reported gaining tools to manage symptoms, stress, and social situations, as well as a deeper understanding of the condition. These online support groups have expanded to include Spanish-speaking participants.

**Small Grants Program**

In partnership with the CDC, we launched an internal small grants program to provide TAA’s Chapters, Support Groups, and Centers of Excellence the opportunity to facilitate community interactions through organized community events, conferences, or meetings focusing on Tourette Syndrome awareness, education, and support.

Projects funded in FY20 included:
- A series of virtual educational activities by TAA Center of Excellence Rush University which focused on TS and treatment options for patients and families living on the south side of Chicago.
- An annual one-day, dual-track education conference on TS for providers and families hosted by TAA Massachusetts Chapter and Mass General Hospital.
- A second annual Tourette Connections Conference, held virtually through a series of weekly webinars on topics related to education, disability accommodations and rights, and treatment of TS by the TAA Wisconsin Chapter.
- A second annual dual track virtual meeting for medical providers, patients, and family members called Tic Talk hosted by Washington University in St. Louis and the TAA Missouri Chapter.
- A series of three virtual education workshops for parents of youth with TS, educators and the next generation of mental health providers by NYU Langone.

**Young Adult Outreach**

While the onset and diagnosis of TS or a Tic Disorder may take place in early childhood, the condition is lifelong. 66% of individuals impacted will experience tics throughout the lifespan. In Fiscal Year 20, the TAA launched a nationwide lead generation campaign to improve TAA brand awareness and available resources among young adults, ages 18-26, who live in states with less than 20* THEP programs available. In two months, the campaign generated 2.65 million impressions across Twitter, YouTube, Facebook, and Instagram.

In addition to the campaign, in support of education and awareness amongst young adults, THEP hosted an additional Youth Ambassador (YA) training (read more about the impact of the YA program on page 12) and launched the inaugural Rising Leader (RL) Program. In total, 116 Youth Ambassadors, along with their adult team members, were trained as TS advocates and 24 Rising Leaders were trained as an extension to the popular YA program, which focused on professional development, community engagement, and TS advocacy.

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**THE CDC RELEASED A PUBLICATION FOCUSING ON CHILDREN WITH TOURETTE SYNDROME IN THE UNITED STATES.**

In July of 2019, a publication from the Centers for Disease Control and Prevention was released, analyzing parent-reported data of 115 children from the 2014 National Survey of the Diagnosis and Treatment of ADHD and TS. The findings showcase that the time to diagnosis of TS averaged less than 2 years from when tics were initially noticed. In addition, almost 70% of parents reported that fatigue and major transitions made their child’s tics worse.

This study provides insight into the current experiences of children with TS and their families in the United States. The TAA has reviewed these new results and compared them to the TAA Impact Survey in a commentary publication also published in the same month.

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**2,386 Connections Made**

At 12 national exhibits of partners and like-minded organizations overlapping with the TS and Tic Disorder community.

**5,503 Resources**

Have been downloaded from the website and used to educate the general public, educators and medical professionals.

**2,700,587 Website Visits**

To the Tourette Association website, tourette.org, to receive tools, resources and the latest information on TS and Tic Disorders.
Research

The TAA has awarded over 460 research projects across 16 countries, totaling over $23 million. Every $1 of TAA grant funding has helped investigators obtain approximately $10 in grant funding from the National Institutes of Health (NIH) demonstrating the long-term impact of our research seed funding. The scope of our work resonates beyond the United States to those affected globally. We continue to establish both national and international alliances, along with recognized experts, who can work together on shared goals to better treat and understand TS.

Annual Scientific and Medical Advisory Board Meeting
The TAA hosted its Annual Research and Medical Meeting of our Scientific Advisory Board, Medical Advisory Board and Centers of Excellence from April 9 – 10, 2019 in New York City. The meeting brought together leading experts in research, clinical care, and treatment for TS, as well as TAA partners and collaborators from the government and the pharmaceutical industry. The discussions focused on improving treatment and care for those living with TS, public health priorities, improving access to care in rural areas, and new treatments on the horizon. Presentations throughout the day featured updates from previously funded TAA scientists, alternative treatment approaches, and behavioral therapy delivered via telemedicine.

AAN Guidelines
In May of 2019, the American Academy of Neurology (AAN) released the first-ever treatment guidelines for the care of TS and Tic Disorders. The TAA was an ongoing participant in the development; ten co-authors are closely involved with TAA Chapters or Centers of Excellence.

The guide recommends Comprehensive Behavioral Intervention for Tics (CBIT) as a first-line therapy, which was developed by a team convened by the TAA and has been disseminated internationally. The guidelines also provide clear recommendations summarizing the risks and benefits of specific medications, assessing for co-occurring conditions, and the need for an individualized treatment plan for patients.

Treating Tourette Together (TTT)
TTT is a collaboration between the TAA, the Patient-Centered Outcomes Research Institute (PCORI) and leading behavioral sciences researchers, with a goal of incorporating patient, provider, and researcher feedback into the next generation of behavioral therapy for TS. In August of 2019 the TAA convened nearly 50 individuals with TS, healthcare providers, and researchers for a two-day summit in Minneapolis, Minnesota to look more closely at Comprehensive Behavioral Intervention for Tics (CBIT) and to develop an agenda for conducting the next generation of research on CBIT. As a result, we’ve identified four major areas to expand research, including: How can more people get CBIT? How can CBIT be improved? What else is there besides CBIT? And how does CBIT affect the whole person?

To read the full summary visit treatingtourettetogether.org.

PANS/PANDAS Statement
There have been discussions around tic and neuropsychiatric disorders being triggered by an underlying autoimmune or autoinflammatory response, collectively referred to either as PANDAS (“Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections”) or PANS (“Pediatric Acute-Onset Neuropsychiatric Syndrome”).

SUPPORTING RESEARCH SAVES LIVES

YOUR GIFT IN SUPPORT OF RESEARCH
RESEARCH GRANTS PROGRAM
ADVANCE TREATMENT & CARE OPTIONS
FUND NEXT GENERATION OF RESEARCHERS
INCREASE TRAINING FOR MEDICAL PROFESSIONALS
While these proposed conditions are of scientific interest, they have generated significant confusion amongst medical providers, families, and patients alike, as the diagnostic criteria have evolved over time, and are often conflated or misapplied.

Until further scientific evidence becomes available, it is our position that the vast majority of children who present with tics have primary Tic Disorders that are not caused by immunologic factors. Read the full statement at tourette.org/pans-pandas.

**Position Statement on the Use of Medical Marijuana for Tourette Syndrome**

Inquiries about the use of medical marijuana (cannabis) to alleviate the symptoms of TS have been on the rise. In response to this, the TAA has released a position statement on this topic. To better understand the role of medical marijuana in treating Tourette Syndrome and Tic Disorders, the TAA formed a Cannabis Consortium comprised of leading clinicians and researchers in the field. Read the statement at tourette.org/medical-marijuana.

**NEWLY FUNDED RESEARCH**

**2019-2020 YOUNG INVESTIGATOR GRANTS TO STUDY TOURETTE SYNDROME**

The Tourette Association of America hosts an annual Young Investigator Award Program to encourage early career researchers to invest their efforts and expertise in increasing our biological understanding of TS, clinical research aimed at improving patient care, and develop and test new therapies.

**MARC FUCCILLO, MD, PH.D.**
University of Pennsylvania
"Studying Brain Mechanisms Underlying Tourette Syndrome"

**KRISTEN DELEVICH, PH.D.**
UC Berkeley
"Studying The Influence Of Hormones On The Brain"

**IAIN PERKES, MD**
Prince of Wales Hospital
"Studying Brain Imaging To Understand Motor Activity"

**JOEY KA-YEE ESSOE, PH.D.**
Johns Hopkins School of Medicine
"Studying Learning Processes To Optimize Treatment Outcomes"

**JENNIFER VERMILION, MD***
University of Rochester Medical Center
"Studying anxiety in youth with tics to determine impact on their function"

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

**Improving Access to Deep Brain Stimulation Therapy**

Recently, the International Tourette Syndrome Deep Brain Stimulation (DBS) Registry and Database reached an important plateau for the field. The findings were published in JAMA Neurology and were widely disseminated in a publicly available website. The project received favorable enthusiasm from clinicians, investigators, patients, foundations, funders and the FDA. However, despite promising findings, access to DBS remains limited for many patients. In January of 2019, investigators, clinicians, patients and regulators convened in NYC to examine access to DBS. Improving partnerships between clinicians, patient groups, industry and the FDA will be a critical next step to ensure that smaller populations of patients receive equal access to device-based innovations. We aim to build on our successes in Tourette Syndrome (TS) to advance DBS therapy, further develop a model for international databases, and to develop recommendations to improve patient access.

When you invest in research, there is a clear and direct impact on the lives of individuals with TS. Please consider making a gift today that will bring hope, help, and acceptance to the hundreds of thousands of individuals who live with TS and Tic Disorders across the nation.
Central to our mission is the relentless effort to increase global understanding and acceptance of the disorder. This meaningful and life-changing work is accomplished by the collective efforts of many. Our efforts are making a difference, but we will not stop until we create a more inclusive environment free of stigma, judgement, and barriers to reaching one’s full potential.

Overview
The TAA raises awareness through a variety of efforts including partnerships with high-profile individuals and organizations, public relation efforts, national awareness campaigns, webinars, and working closely with the community to learn from and articulate the journey through storytelling. We believe in the powerful role that each of you play in shifting public perception and elevating global awareness for TS and Tic Disorders. Some of our most impactful initiatives are made through personal outreach and fostering compassion via our social media campaigns. These platforms help shine a light on those who struggle with TS and co-occurring conditions, allow others to feel supported by a greater network, and provide a platform to share their stories with the world.

Social Media
Involvement from our community, storytelling, the sharing of resources and helpful information has garnered nearly 110 million impressions on TAA social media channels over the last year and rallied for heightened awareness and participation through hashtags such as #Rally4Tourette, #TouretteAwareness, #TouretteSyndrome and #Tourette.

Tourette Syndrome Pledge
In 2019, we launched the Tourette Syndrome Pledge as part of TS Awareness Month to combat inaccurate, hurtful references about TS. 2,500 people across the nation took the pledge to help change the public perception of TS. It was an effort designed to educate and inspire others to be more open-minded and break free of the stigmas that surround this disorder. TS is not an excuse, slur or punchline and it is imperative that everyone sees that underneath the uncontrollable symptoms are children and adults – human beings with hopes, dreams and feelings.

Webinars and Facebook Lives
On a monthly basis, the TAA hosts a variety of webinars and Facebook Lives that can help further educate adults, youth, parents, educators, working professionals, and the general public about TS and provide ongoing support to the Tourette community. In 2019, we featured topics including Ask the Education Experts: frequently asked questions from parents and educators, Navigating Disclosure around Tourette Syndrome, Bullying Prevention Tips, Treatment Options, Driving and TS, Building and Maintaining Positive Partnerships with your Child’s School, OCD: A Primer for Patients and Families, Sleep Problems and Management in Youth with Tourette Syndrome, and so much more.

Diversity and Inclusion
The TAA re-invigorated its Diversity Committee to ensure mission delivery reflects the diverse needs of the TS and Tic Disorder community. The goal is to sustainably address health disparities by particularly increasing diagnosis rates in rural, minority, and/or economically disadvantaged communities; increase education and awareness to more diverse audiences; and to discuss national diversity issues. Together this effort has led to increased data collection about our population to help drive future awareness campaigns and programming.
Adult Task Force

66% of people impacted by TS and Tic Disorders continue to experience symptoms throughout adulthood. As an adult with TS, life often comes with a unique set of challenges, often without the family and parental support that youth with TS benefit from. Adults continue to experience unfiltered, unkind and in many cases, unlawful biases and stigma. To support this, the TAA launched the Adult Task Force, which has worked closely with adults from around the nation to develop and deliver new and helpful resources. In its first year, the goal was to provide more accessible resources to adults, the committee launched a six-part webinar series focused on adult support. In addition, a comprehensive tool kit resource was drafted for publication and dissemination.

Partnerships and Collaborations

TS is a layered disorder that remains misunderstood among the general public. There is no one-size-fits-all approach, and because of this, the TAA partners with like-minded organizations that support our efforts. In 2019, the Tourette Association of America worked closely with organizations that support suicide prevention, OCD, ADHD, anti-bullying efforts and others to overlap program delivery. In addition, we took part in national media opportunities to heighten awareness nationally.

Tourette’s Podcast

After 4 successful seasons, Ben Brown and Tourette’s Podcast offered a unique and exciting way to engage the community. In 2019, the TAA became the primary sponsor of the podcast and supported the effort by connecting our community to the series, supporting interview connections and more. Each episode features an individual from the TS community and highlights experiences, advice, tics, social interactions and daily management. Listen now at tourettespodcast.com.

Motherless Brooklyn

In November of 2019 was the release of Motherless Brooklyn, a film in which Edward Norton portrays a detective with TS. Leading up to the release of the film, the TAA had a unique opportunity to connect with Warner Brothers Entertainment and the cast on the production of the film. The TAA was granted a private screening of the film and distributed resources that were introduced by Writer, Director and Star, Edward Norton.

Oprah Magazine

The January 2020 feature of O, Oprah’s Magazine, featured a variety of women with disabilities. In collaboration with their team, the TAA helped to identify Nikki Burdine, WKRN co-anchor, as the highlight for TS.
Advocacy

The Tourette Association of America (TAA) advocates for the most pressing issues facing the TS and Tic Disorder community. Through this initiative, we represent the interests of the 1 million Americans impacted by TS, Tic Disorders, and co-occurring conditions and the 50% who have yet to be diagnosed. The TAA maintains a continuous presence in Washington, D.C. where we engage with members of Congress, the White House, and numerous federal agencies who have the power to provide financial, political, and social support.

Overview

The Tourette Association of America Public Policy team closely monitors and voices views on a variety of topics that directly impact our community including education and disabilities, general healthcare, telehealth, funding of research, access to treatment and care, and prevention of genetic and other forms of medical discrimination. To support this effort, the TAA’s 31 Chapters and 83 Support Groups, Youth Ambassadors and advocates work directly with their elected officials supporting national efforts to elevate understanding about TS and Tic Disorders.

CDC and Public Policy Efforts

The continuation of $2 million in funding for the TS Public Health Education and Research Program at the CDC National Center for Birth Defects and Development Disabilities is an ongoing priority for the TAA. In April, the CDC approved a portion of the funding, which maintains the THEP program as well as our efforts to raise awareness, understanding and acceptance. Read more about THEP impact on page 6.

Youth Ambassadors and National Advocacy Day

Each year a new class of talented teens impacted by TS are trained to advocate in their local communities, representing their needs and the needs of others with TS. This largely sought-after national training program helps with readiness for the future, public speaking and how to communicate effectively about the challenges and successes surrounding TS and Tic Disorders. The success of the YA program has warranted the launch of additional trainings each year (read more on page 7). The hallmark training takes place each March and is coupled with advocating for the most pressing issues facing the community on National Advocacy Day.

On March 5, approximately 150 new and formerly trained TAA Youth Ambassadors, parent/guardians, state Chapter leaders and Advocacy Day attendees went to Capitol Hill to meet with their Representatives and Senators, as well as their legislative aides, to discuss the needs of the TS community. More than 120 meetings took place, representing 24 states. While advocates were in Washington, D.C., nearly 500 people around the nation joined the efforts by sending virtual take action letters to their Senators and Representatives in support of the above priorities. Each and every participant made a tremendous difference and garnered new supporters for the CDC TS Program.

Congressional Briefings

The Tourette Association of America, in collaboration with the Congressional TS Caucus, hosts TS and Tic Disorder briefings on Capitol Hill. The importance of these assemblies has proven to be tremendous in showcasing the continued need for funding research and support from the government.

1,140+
Advocates Trained

Youth Ambassadors along with their adult team members have been trained to educate their peers, adults, other educators, and government officials since the program’s inception.

31
Chapters

Across 26 states providing a safe, inviting space for teens, adults and families to thrive. Within this network, individuals are provided emotional encouragement and information, as well as the opportunity to work collectively to develop and provide local programming.

83
Support Groups

$2M
Funding

Was approved in support for the nationwide CDC TS and Tic Disorder initiatives.
The first was held in conjunction with National Advocacy Day, where two newly trained Youth Ambassadors, Maren Carr and CJ Miller, shared struggles and successes of living with TS to an audience of Congressional staff and Washington, D.C. stakeholders. In addition to personal stories, the afternoon provided an overview about the importance of the CDC TS Program and its priorities. The speakers included, Dr. Georgina Peacock, CDC NCBDDD and Anthony Ervin, Olympic gold medalist swimmer living with TS.

During Advocacy Day, the TAA presented the 2019 Public Policy award to Rep. David Price (D-4-NC) for his leadership on neurological conditions, including TS, and securing funding for the National Neurological Conditions Surveillance System at the CDC.

The second recent briefing was Shining Light on TS: Medical and Scientific Advances in TS on October 16, 2019. Policy makers and staff gathered to learn about medical advances in TS and Tic Disorder research and treatment. Joining from the TAA was Randi Zemsky, Chairman of the Board of Directors, Diana Shineman, Former Vice President of Research and Medical, and Diana Felner, Vice President of Public Policy. Leading the discussions were prestigious medical professionals from the community including Joohi Jimenez-Shahed, MD, Matthew Capriotti, PhD, and Nicole Calakos, MD, PhD.

The TAA would also like to give thanks to our Congressional TS Caucus Co-Chairs Rep. Steve Cohen (D-TN) and Peter King (R-NY) for their instrumental role in both briefings, and for their continued leadership and support for TS and Tic Disorders.

Bills in Support of Tourette Syndrome

In Fiscal Year 20, the TAA signed on in support of the following bills in the 116th Congress that can directly support the TS and Tic Disorder community:

**Safe Step Act**
• Step Therapy bill to improve appeal process.

**Mental Health Parity Compliance Act**
• Increases transparency and compliance for mental and behavioral health coverage as required by law.

**Parity Enforcement Act**
• Provides authority for Department of Labor to enforce civil penalties if employer insurance programs are not complying with mental health parity as required by law.

**Improving Seniors’ Timely Access to Care Act**
• Electronic prior authorization and increased transparency for Medicare Advantage prescriptions.

**Respond, Innovate, Succeed, and Empower (RISE) Act of 2019**
• Creates a National Center for Information and Technical Support for Postsecondary Students with Disabilities and improves documentation colleges and universities shall accept for accommodations.

**Improving Mental Health Access for Students Act**
• Requires phone number for suicide hotline and campus mental health services to be included on student IDs.

Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act
• This bill requires the National Institutes of Health (NIH) to expand, intensify, and coordinate NIH research on TS.

The National Suicide Hotline Designation Act
• Creates designation of 988 as an easy-to-remember, universal number for those seeking help for mental health crises and suicide prevention and ensure this line is universally available and fully funded.

Connect for Health Act
• Removes some barriers for telehealth coverage for Medicare via the Social Security Act, expands coverage of telehealth for mental health, expands coverage for telehealth use in the home.

Medical Expense Savings Act
• Makes the temporary reduction permanent from 10% to 7.5% in the AGI threshold before a taxpayer can claim an itemized tax deduction for medical expenses.

24 States
Rallied for the continuation in $2 million FY20 funding for the CDC TS Program. Membership in the Congressional TS Caucus, continued funding increase at NIH’s NIMH and NINDS, continued funding for the National Neurological Conditions Surveillance System at CDC, co-sponsorship of the CARE for TS Act, and the expansion of telehealth.

120+ Congressional Meetings
Were held with local representatives on National Advocacy Day to lobby for continued funding and support for Tourette Syndrome.

650 Participants, from 24 different states
Represented TS on National Advocacy Day in Washington, D.C. These advocates raised awareness for the most pressing issues facing the community, consisting of Youth Ambassadors, parents and TAA staff.
Fundraising & Development

The important work being done by the Tourette Association of America on behalf of the community is only made possible through the generosity of our donors. Thanks to our countless volunteers, constituents, partners and corporations, we remain steadfast in our mission to enhance the lives of those impacted by TS. In Fiscal Year 20, we raised $4.1 million to carry out our important work.

Team Tourette

667
Individuals participated in a Team Tourette event across the nation.

$143,992.96
Raised by participants and sponsorships through our Team Tourette fundraising initiatives.

5.3 million
Steps taken by individuals across the nation who participated in a Team Tourette event in support of the mission, making a difference with every mile.

Team Tourette Races

2019 Star Wars 2019 NYC Marathon 2020 Walt Disney World Marathon Weekend
2019 National Walk 2019 San Diego Walk

Golf

The 2019 Illinois Golf Classic and Dinner & Ladies’ Game Day was held on Monday, June 24 at Bryn Mawr Country Club. The event brought out more than 270 individuals, raising over $170,000.

Funders Breakfast

In January of 2020, the Tourette Association of America held its first Funders Breakfast. The goal of the event was to provide participants with an overview of the organization, introduce new initiatives and present opportunities for partnerships. Foundation and corporate representatives as well as community members were invited to attend this special event.

Giving Tuesday

Tuesday, December 3 was Giving Tuesday, a global day of giving. Our community joined the movement to support the TAA by donating almost $60,000 through donations, hosting Facebook fundraisers, or by sharing TAA messages throughout the day.

Facebook Fundraisers

Members of the TS and Tic Disorder community had a memorable impact, tapping into their personal networks through Facebook Fundraisers, raising $93,777.21.
Gala raised roughly $1 million in support of TAA
November 18, 2019 honoring David Begnaud, Lead National Correspondent for CBS This Morning

On Monday, November 18, 2019 the Tourette Association of America hosted the annual Teal and White Gala. Honored at the gala was David Begnaud, Lead National Correspondent for CBS This Morning. The exquisite evening also featured keynote speaker Jumaane D. Williams, the Public Advocate for the City of New York and Youth Ambassadors Jordan Falkenstern and Mia Mantei. This event serves as the largest fundraiser for the year, and proceeds support the important and much-needed awareness efforts. Thanks to generous donors, the event raised nearly $1 million in support of the Tourette Association of America and our mission to make life better for all people affected by Tourette and Tic Disorders. It was a beautiful evening where hundreds of individuals came out to support the TS community.
National Presence

The Tourette Association of America provides local support across the nation through our 31 Chapters and 83 Support Groups. In addition, the TAA recognizes 18 Centers of Excellence (CofEs), which are medical institutions that offer the highest level of care, are undertaking groundbreaking research, are leaders in training and education and/or provide exceptional community outreach and advocacy for TS and other Tic Disorders. These efforts are majority volunteer led opportunities, and we are ever grateful for their efforts.

Alabama Support Group
University of Alabama at Birmingham, Birmingham, AL*
Arizona Chapter
Phoenix Children’s Hospital and Banner Health, Phoenix, AZ*
Johns Hopkins Hospital, Baltimore, MD*
Massachusetts Chapter
Massachusetts General Hospital, Boston, MA*
Northern California & Hawaii Chapter
Southern California Chapter
University of California, Los Angeles, Los Angeles, CA*
Rocky Mountain/Denver Support Group
Connecticut Chapter
Yale Child Study, New Haven, CT*
Delaware Chapter
Florida Chapter
University of Florida, Gainesville, FL*
University of South Florida, St. Petersburg, FL*
Emory University School of Medicine, Atlanta, GA*
Georgia – Northwest Support Group
Atlanta Support Group
Idaho Falls Area Support Group
Illinois Chapter
Chicago Support Group
Rush University Medical Center, Chicago, IL*
Indiana Chapter
Iowa Support Group
NE Iowa Support Group
Wellsville, Kansas Support Group
Kentucky Support Group
Louisiana Support Group
Louisville, Kentucky Support Group
Bardstown, Louisville Support Group
Maryland Chapter**
University of Miami, Miller School of Medicine, Miami, FL*
Minnesota Chapter
Montana Support Group
Northern Mississippi Support Group
Mississippi Support Group
Missouri Chapter

*Tourette Association of America Center of Excellence  **Mid-Atlantic Chapter
TAA Chapters and Support Groups are volunteer-led initiatives that aim to serve their local communities. In an effort to expand our footprint, programming and general knowledge of the condition, the TAA launched a pilot Chapter structure, in partnership with the TAA Southern California Chapter, to provide local Chapter boards with the support needed to deliver consistent and efficient services to their community. This initiative has led to strengthening the Chapter board, dedicated volunteers, a thriving in-person and virtual community, engaging programs for all ages, and a strong vision for the future.

An executive director position was established in 2020 to oversee all Chapter functions and key objectives including:

- Increase fundraising by building consistent streams of revenue
- Establish an annual event that generates significant recognition and income
- Build relationships with local corporations, colleges/universities, and nonprofit organizations
- Increase programming, education, and advocacy in the SoCal community
- Improve diversity and inclusion throughout the Chapter
Brian Lane’s Story

“I wear, and have worn, many hats in my adult life but I am most honored and humbled to serve on the TAA Educational Advisory Board and the Diversity Committee.”

Being born gay was hard enough – add in being born with Tourette Syndrome and several co-morbidities and life became very difficult to navigate at times. I started showing signs of tics around age 3 and was diagnosed at age 7, which was very rare way back in the old days. I was fortunate enough to be seen by a doctor that was just starting out in the medical profession who noticed my tics. He referred me to a neurologist and psychologist that identified why I made all these odd movements and funny noises. Many medical professionals were uneducated about TS and we were told that I would grow out of my Tourette as I grew into adulthood. That gave me hope for a better future as I started to move into puberty and my developmental teen years when the tics and associated conditions increased in severity. This was also when I KNEW something else was very different about me. Something that we were not supposed to talk about nor act upon at this time in our history. You see, this was the height of the ‘new gay disease,’ which we know as AIDS today. And thus, I hid my feelings from most everyone.

When I went to college to study vocal music performance and choral music education, I noticed a decrease in my tics. My confidence soared and around that time I found a small support group, called OUT, where we could gather and support each other. My life changed forever.

Contrary to the medical assessment I received when I was younger, my tics came back and came back strong in my 20s. I cried many days and nights. I worked so hard at suppressing and was very determined to not let anyone see me. But, like most of us, in the end, the tics won and I lost. It was at that moment I decided to share with my principal, my students, and their parents/guardians about my diagnosis. I was so shocked at the amount of support and love I found myself surrounded with!

Now, I was crying for a whole different reason. I knew then, I would not hide who I was and be proud as a gay man and as a member of the ticcing ‘family.’

Shortly after that I found out about the Tourette Association of America (TAA) and attended my first national conference. What an eye-opening experience.

For the first time in my life, I met and began to meet people JUST LIKE ME! It was a liberating and life-changing experience.

Many years later I am so PROUD to be a ticcer as a member of the greatest ‘family’ I have ever known - a member of the TAA. I wear and have worn many hats in my adult life - Volunteer Firefighter and EMT, former part-time Police Officer, serving as an IHSAA Official (Referee) for middle school and high school sports, and several other hobbies and professions, but I am most honored and humbled to serve on the TAA Educational Advisory Board and the Diversity Committee.

I am also a VERY PROUD out gay man getting ready to begin my 27th year in education having worked as a teacher, school administrator, and behavior specialist in public schools throughout Indiana and Florida throughout those many years.

My advice to all of you is NEVER give up and to always be PROUD of who you are no matter what you read, hear, or experience in our chaotic, often scary world.

We are, indeed, warriors that must stay strong, stay connected, and help each other in this unique and special ‘family’ we are all a part of. Much love to each of you. You are all a shining light in the often dark world!
Marc Schmidt’s Story

“I am a neuroscientist who has worked on the basal ganglia neural circuits that are impacted by Tourette Syndrome. Secretly, however, I think I’ve always also wanted to be a baker.”

The waffles are the perfect street food, we wrap each fresh warm treat in a small paper pouch that has a description about Tourettes and our website address for more information (waffles4tourette.com). By luring customers with the smell of fresh baked waffles and caramelized sugar, we have been able to educate and help countless families while also raising funds for the local and national Tourette Association. After all these years, my favorite days are spending my morning reviewing a grant for TAA investigating the role of cholinergic interneurons in striatal function and then driving to our kitchen and getting covered in flour making new batches of dough for the next market and hoping that I might be able to inspire others to be more understanding of mental health challenges.

When my daughter Maddy, now 23, was about 7 years old, she started showing signs of compulsive thoughts and then a little later, recurring motor tics. I had used the term Tourette Syndrome in one of my grant submissions years before Maddy was born, but I did not really appreciate the complexity of the condition and therefore did not recognize it at first. In a tale that likely is familiar to many parents, I ended going from one physician to the next, only to figure out Maddy’s diagnosis myself. The experience was incredibly frustrating even though I had all of the connections at my university. I cannot imagine how difficult it must be for a parent who does not have direct email access to colleagues in the neurology department.

In 2013, many years after Maddy’s diagnosis, our family was sitting around dinner and decided that for that year’s resolution, we would try to come up with a unique idea to help those in need. I decided that I could use my scientific background and experience navigating the system with Maddy to help and educate other parents while also raising money for Tourette. I thought that maybe I could combine this with my obsession with the Liege waffles. So, a few weeks later, with my younger daughter Emilie sitting next to me at a local coffee shop in our town, I just asked the owner if he knew what Liege waffles were and if we would be able to make them there? To my surprise, he was completely supportive of the idea and so the following week, Emilie and I sold our first liege waffles at Hobbs coffee shop in Swarthmore, Pennsylvania. This was the birth of Waffl es for Tourettes.

Almost seven years later, I have been making waffles every week and selling them at various local Farmer’s Markets and last year I turned the idea into a (very small) company. Because
It was just one piece of paper covered on both sides with a list of observations, yet it changed our lives in an instant. This list, presented to us after a visit to our son’s 2nd grade classroom, was put together by a psychologist we had been working with. For about a year or so before we had noticed behaviors and explosiveness that appeared to come out of nowhere. Our son had always been an anxious child, yet the noises, gasping for breath, gulping, worries, fears, and new rituals were concerning. The psychologist went down the list describing things we had also observed, and many that we had never even noticed. The list now included obsessions and tics and it was the first time we had explored the possibility of Tourette Syndrome (TS).

Even though my husband and I are both medical professionals, we knew very little about TS. I spent the next year subjecting my son to several professional evaluations searching for answers and hoping that it was not TS. Based on the stereotypes from movies and the media, this did not make sense at all. After a while my understanding of Tourette Syndrome and its complexities sank in, and we shifted our efforts to helping our son to live up to his potential.

The most impactful experience at the beginning of our journey with TS was attending my first TAA National Conference. I wanted to know everything about it and learn from those who were living with it. One of the first people I met was a young adult with significant coprolalia. I noticed him in the lobby and decided to walk right up and introduce myself. In between the obscenities and noises, we had a lovely conversation. This experience, coupled with a few other connections, made me feel that no matter what our future was to be, mild or severe, we would be alright. With the uncertainty of how this disorder would progress, we were going to search for ways to create the best life possible for our son and family.

After only attending a few meetings of the local TAA Chapter here in Georgia, I took on the role as the Executive Director in 2007, which has been the most rewarding role of my professional career. I attended school meetings for families all over the state, workplace discussions, support groups, fundraising events and presented lectures and talks. That experience led me to the opportunity to start a summer camp for children with TS at Camp Twin Lakes. With the help of an incredible group of volunteers, the focus of the next 10 years shifted to supporting children by implementing and growing the Camp Twitch & Shout (CTAS) program.

While there were many difficult struggles for our family…I am so thankful for what Tourette Syndrome has given us. I’ve watched my son become one of the first Youth Ambassadors and educate students and faculty at local schools and at the University of Georgia. He is now a college graduate and following his passions in Art and the Gaming industry. I have witnessed young leaders with TS give our children, families, and communities hope and excitement. The most important thing I’ve learned through all of my experiences is that all of us want to know that we are not alone.

I have met the most incredible people through the National TAA and camp. I have watched hundreds of families embrace Tourette’s, create friendships for a lifetime, look to the future with hope, and develop the resilience needed to face any challenge.

When I started out as a nurse in Emergency Medicine in 1983, I had no idea that Tourette Syndrome would be such a huge part of my personal and professional life.

I want to encourage parents, families, and individuals to go beyond the symptoms of TS and embrace the strengths of the incredible individuals living with it. They are talented, sensitive, empathetic, and loving. There may always be times of struggle, but with the right support and understanding, their lives will be full.

Tourette’s is just an explanation, and not a barrier to holding back from their dreams. When I meet others impacted by Tourette’s my first thought always is “welcome to my family.”
YOUR TAA DOLLARS AT WORK
BASED ON AUDITED FINANCIALS FOR FISCAL YEAR ENDED
FEBRUARY 29, 2020

OVERVIEW
Total revenue
Total expenses
Overall loss

EXPENSE
Program
Public Education
Professional Education
Centers for Disease Control (THEP) Program
Research
Total Program

Administrative
Management & General
Fundraising
Total Administrative

TOTAL EXPENSES

EXPENSE BREAKDOWN

2020

$4,131,823
$5,422,238
(1,290,415)

$1,681,992
$56,750
$940,653
$1,717,567
$4,396,962

$538,552
$486,724

$1,025,276

$5,422,238

PROGRAM RATIO 81/19

Public and Professional Education 32%
Research 32%
Centers for Disease Control (THEP) 17%
Fundraising 10%
Management & General 9%
# TOURETTE ASSOCIATION OF AMERICA INC.
## STATEMENTS OF FINANCIAL POSITION
### AS OF FEBRUARY 28, 2020 AND 2019

<table>
<thead>
<tr>
<th></th>
<th>2020</th>
<th>2019</th>
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<tbody>
<tr>
<td><strong>ASSETS</strong></td>
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<td>Prepaid expenses and other assets</td>
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<td><strong>TOTAL ASSETS</strong></td>
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<td><strong>LIABILITIES</strong></td>
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<td>Accounts payable and accrued expenses</td>
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<td>Research grants payable</td>
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<td>Permanently restricted</td>
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<td><strong>TOTAL NET ASSETS</strong></td>
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<td>11,009,621</td>
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### TOTAL LIABILITIES AND NET ASSETS

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<th>2020</th>
<th>2019</th>
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<tbody>
<tr>
<td><strong>TOTAL LIABILITIES AND NET ASSETS</strong></td>
<td>$11,065,052</td>
<td>$11,792,422</td>
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**TOURETTE ASSOCIATION OF AMERICA INC.**
**STATEMENTS OF ACTIVITIES**
**FOR THE YEARS ENDED FEBRUARY 29, 2020 AND 2019**

<table>
<thead>
<tr>
<th>For the Year Ended February 29, 2020</th>
<th>Total</th>
<th>For the Year Ended February 28, 2019</th>
<th>Total</th>
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<tbody>
<tr>
<td><strong>SUPPORT AND REVENUE:</strong></td>
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<tr>
<td>Public Support:</td>
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<tr>
<td>Fundraising events revenue</td>
<td>$ 1,236,771</td>
<td>$ 1,296,944</td>
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<tr>
<td>Less: direct benefits to donors</td>
<td>(189,465)</td>
<td>(171,355)</td>
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<tr>
<td>Net fundraising events revenue</td>
<td>1,047,306</td>
<td>1,125,589</td>
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<td>Grants, contributions and bequests</td>
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<td>2,083,758</td>
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<td>Membership dues</td>
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<td>C.D.C. grant</td>
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<td>1,082,899</td>
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<tr>
<td><strong>Total Government Support</strong></td>
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<td>1,082,899</td>
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<td><strong>Revenue:</strong></td>
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<td>Investment activity</td>
<td>264,891</td>
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<tr>
<td>Sales - emblems, audio visuals and publications</td>
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<td>-</td>
<td></td>
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<tr>
<td>Conference income</td>
<td>116,683</td>
<td>174,766</td>
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<td><strong>Total Revenue</strong></td>
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<td>381,161</td>
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<td><strong>TOTAL SUPPORT AND REVENUE</strong></td>
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<td><strong>EXPENSES:</strong></td>
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<td>Program services</td>
<td>4,396,962</td>
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<td>Management and general</td>
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<td>639,807</td>
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<tr>
<td>Fundraising</td>
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<td>531,006</td>
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<tr>
<td><strong>TOTAL EXPENSES</strong></td>
<td>5,422,238</td>
<td>5,208,657</td>
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<tr>
<td><strong>CHANGE IN NET ASSETS</strong></td>
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<tr>
<td>Net assets - beginning of year</td>
<td>11,009,621</td>
<td>11,502,881</td>
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<tr>
<td><strong>NET ASSETS - END OF YEAR</strong></td>
<td>$ 9,719,206</td>
<td>$ 11,009,621</td>
<td></td>
</tr>
</tbody>
</table>
Donor Recognition

What we do would not be possible without the help of so many generous supporters and members of the community. Your hard work and sacrifice have brought immeasurable light and happiness into the lives of others, and for this we thank you.

$100,000 +
Ken & Julie Moelis
The Ochsman Foundation Inc.

$50,000 - $99,999
Abide Therapeutics, Inc.
Boston Scientific Corporation
Emalex Biosciences, Inc.
Jeanette M. Clark Revocable Living Trust
Jamie Coulter
Darryl and Diane Mallah
Otsuka Pharmaceutical

$25,000 - $49,999
Ronald W. Burkle
Anne and Paul Devore
Tom Gores Family Foundation
Johnson & Johnson Medtronic
Neurocrine Biosciences
Patrick P. Lee Foundation
Johnson & Johnson
Medtronic
Neurocrine Biosciences
Patrick P. Lee Foundation

$10,000 - $24,999
Abbott Laboratories
Alfiero Family Foundation
Stephen Arcano
Reid Ashinoff
Debbie and Mark Attanasio
Judy and Ron Baron
Stephen and Carol Barron
Donna and John Barto Benevity Fund
Julie and Louis Bucksbaum
CI Capital Partners LLC
Frederic Cook
Dentons US LLP
The Draper Foundation
Fieldstead & Company Foundation for The Greatest Good
Jeanne Gnuse
Griffon Corporation
Kenneth Halaby
Debbie and Mark Henkels Herbalife International Of America, Inc.
Peter Hollenbeck, Ph.D.
Investors Bank
Joyce and Mark Jansen
The Karsh Family Foundation
Richard Kayne
Kirkland & Ellis Foundation
Kissick Family Foundation
Sidney Koch and Sheila Nevins
Brian Kwiat
Albert Lord
Sandra and Sheldon Mallah Mussafer Family Fund
Nelson Family Foundation
New Canaan Community Foundation
New York Yankees Foundation
PCORI
PS Business Management LLC
The Ressler Family Foundation
The Robinson Family Trust
Marc Rowan
Sage Foundation
Singer Family Foundation
Jane Smolik
Sheryl and Jonathan Sokoloff
David M. Solomon

Squier, Milner, Peterson, Miranela & Williamson
Jasmine Tarkoff
The Geaton & JoAnn DeCesaris Family Foundation
The Travelers Companies, Inc.
Eddie Trump
Leon Wagner

$5,000 - $9,999
Shannon Brown
Susan Courcy, Ph.D. and Mark DS Courcy, M.D.
Crescent Capital Group LP
E. Bryce & Harriet Alpern Foundation
Frank J. Antun Foundation
Jay Gellert
William Hankinson
Thomas Hopkins
HTG Investment Advisors, Inc.
Alice Kane
Laura Landau
Claude LeBlanc
Steven Lebow
Navid Mahmoodzadegan
David Mahoney
Denise Malcolm
Charles Malk
Marnie and Lloyd Mallah
Sheryl and Barry Mallah
Marges Muddance Living Rev Trust
Michael Marks
Meritage Homes
Malcolm Michael
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