



ANNUAL REPORT 2017

Unity is strength...

when there is **TEAMWORK**

and

**COLLABORATION**

wonderful things

can be achieved.

MATTIE STEPANEK





In 2017, the Tuberous Sclerosis Alliance (TS Alliance) sought partners to further advance our mission of finding a cure for tuberous sclerosis complex (TSC) while improving the lives of all those affected. In doing so, we were able to bring together a consortium of researchers to accelerate the development of new treatment options, develop new support programs to help people throughout their lifetimes, and increase awareness of TSC worldwide. We're grateful to the many incredible partners who continue to propel us further than we can go alone.

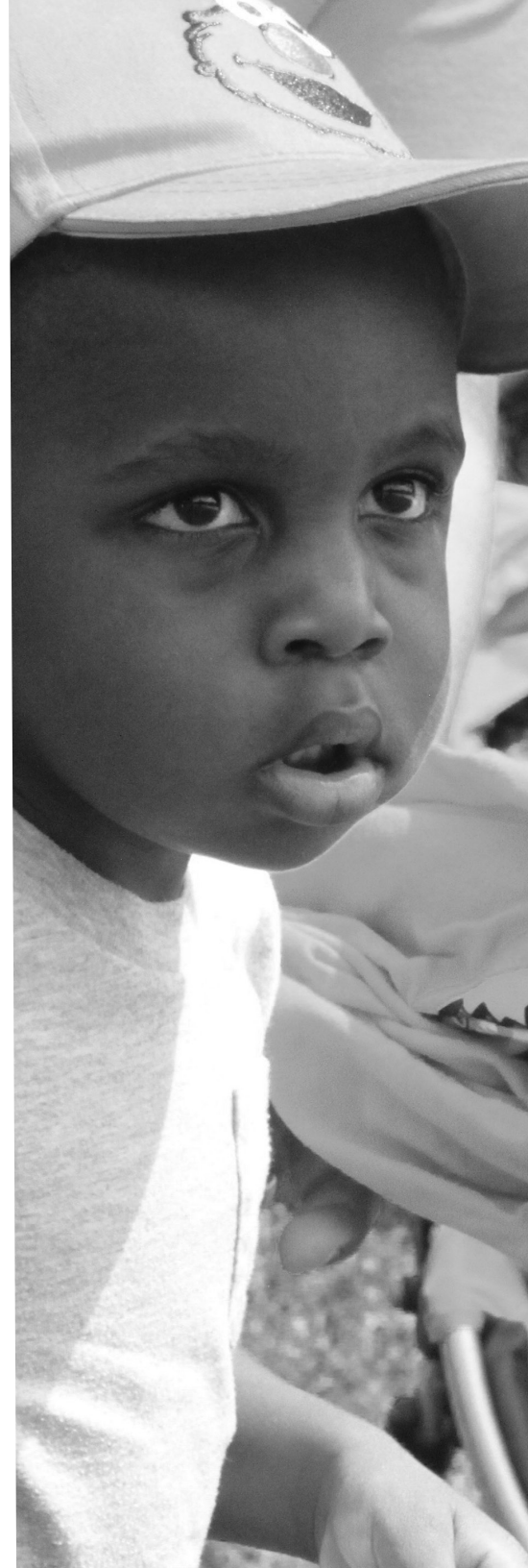
The ongoing recruitment for the first-ever preventative clinical trial in both TSC and epilepsy in the United States serves as an ongoing reminder of the amazing things we can accomplish together, but it is only the beginning. We know future breakthroughs, and ultimately a world without TSC are achievable, because we have the unwavering support of dedicated allies, including you.

#### Some 2017 highlights include:

- In June, the TS Alliance sponsored an Externally-Led Patient-Focused Drug Development Meeting on TSC and LAM with the Food and Drug Administration (FDA). Testimony from the meeting was compiled in our *Voice of the Patient* report, which was submitted to the FDA in October. This report communicates needs and improvements the TSC community wants and hopes to see in their daily lives and illustrates a framework for how our community weighs risk and benefit in new drug development.
- Three pharmaceutical companies joined the Preclinical Consortium in 2017, bringing the total to six industry partners. The TSC Preclinical Research Consortium ran ten studies in 2017, compared to just four in 2016.

- Thanks to our dedicated March on Capitol Hill volunteers, in 2017 the TSC Research Program at the Congressionally Directed Medical Research Program received a \$6 million appropriation, bringing the cumulative funding to \$71 million since 2002 as a result of our successful grassroots efforts.
- The TS Alliance and The LAM Foundation jointly sponsored the 2017 International Research Conference on TSC and LAM: Innovating through Partnerships, held June 22-24, 2017, at the Hyatt Regency Capitol Hill in Washington, DC, with more than 200 people from 27 countries attending.
- In partnership with The Arc USA, Child Neurology Foundation and MassMutual, the TS Alliance held two Transition Workshops in New York, NY and San Diego, CA. These workshops gave parents and caregivers tangible resources to empower them with clear timelines and next steps to develop an effective transition plan for their children into adulthood.
- The TS Alliance signed a global agreement with the Hungarian Foundation for Tuberous Sclerosis. We now have five formal global partnerships, including: TS Alliance of Israel, TS Canada ST, TS Alliance of Mexico, TS Alliance Foundation (in Thailand) and the Hungarian Foundation for Tuberous Sclerosis.
- The TS Alliance facilitated 20,247 peer-to-peer supports from Adult Regional Coordinators, Clinic Ambassadors, Dependent Adult Transition Resource Coordinators, and Community Alliances.

This annual report provides an overview of the organization's efforts and achievements in 2017, and while much work remains in our quest to better the lives of everyone affected by tuberous sclerosis complex, we know that with the continued collaboration between our community and partners, we will achieve so much more together.





## About the Tuberous Sclerosis Alliance

Founded in 1974, the TS Alliance has become an international leader in providing support services and resource information; creating and implementing public and professional educational programs that heighten awareness of the disease; and funding and driving research.

With these goals in mind, the TS Alliance is the only organization able to rally the financial resources, the research, the partnerships and the sheer will of TSC-affected families and individuals to work toward a future in which no one has to endure the devastating effects of TSC.

## About Tuberous Sclerosis Complex

Tuberous sclerosis complex—or TSC—is a genetic disorder that causes tumors to form in vital organs, primarily the brain, eyes, heart, kidney, liver, skin and lungs. TSC is a highly variable disease. Some people with TSC live independent, healthy lives and enjoy challenging professions such as doctors, lawyers, educators and researchers. Others with the disease often experience uncontrollable seizures, autism, heart disease, learning and behavioral problems, facial disfigurement, kidney failure and, sometimes, even death. TSC strikes every 1 in 6,000 live births, impacting 50,000 Americans and more than 1 million people worldwide.

In addition, TSC is the leading genetic cause of both autism spectrum disorder and epilepsy. Up to 50 percent of people with TSC develop autism, while about 85 percent experience seizures at some point during their lives and 50 percent of those individuals are challenged with intractable epilepsy. Approximately 80 percent of those with TSC develop kidney lesions.

Moreover, TSC is considered a linchpin disease. Because of TSC's genetic pathway, every dollar spent finding cures and treatments for TSC may also bring about quantum leaps in our understanding of autism, cancer and epilepsy.

While there is currently no cure, this annual report explains why current research, support programs and other TS Alliance efforts are creating real hope for everyone touched by tuberous sclerosis complex.

## Research

The TS Alliance's Research Program stimulates and supports basic, translational, and clinical research on the various manifestations of tuberous sclerosis complex to further the development of clinical therapies and, ultimately, a cure for TSC. Directed by Steven L. Roberds, PhD, Chief Scientific Officer, this program funds research focused on TSC proposed by researchers and aligned with the research priorities of the TS Alliance. Collaborations between basic and clinical researchers are encouraged and fostered, for example, by biennial International TSC Research Conferences.

The TS Alliance has funded more than \$20.3 million in **research grants** on TSC since 1984. Eight research awards were funded during 2017. In 2016, Dr. Peter Davis (Boston Children's Hospital) was awarded one year of funding to study brain network biomarkers of epilepsy in TSC to identify those at highest risk of developing seizures. In 2017, he applied for and was granted an additional year of funding to extend his work to correlate EEG network biomarkers with epilepsy severity and treatment response. The Board of Directors approved funding to begin in 2018 for three additional projects, including one co-funded with The LAM Foundation.

Implemented in 2006, the **TSC Natural History Database** captures clinical data to document the impact of the disease on a person's health over their lifetime. As of December 2017, 2,124 people with TSC were enrolled in the project from among 18 U.S.-based sites. The TS Alliance provides funding to participating clinics to perform data entry, monitors the integrity of the database, and makes data available to investigators to answer specific research questions and identify potential participants for clinical trials and studies. In 2017, the TS Alliance invested \$222,524 in the

*Greenwich Biosciences has been excited to partner with the TS Alliance on multiple fronts. We are thrilled to be a member of the TSC Preclinical Consortium, a unique model that brings together academic researchers, pharmaceutical/biotech companies and the TS Alliance to move candidate therapies forward faster. This partnership provides companies the animal models and expertise to evaluate all aspects of this linchpin condition, while giving tuberous sclerosis complex a heightened attention for drug development. It is a unique model for a unique condition.*

**KATHRYN NICHOL, SENIOR DIRECTOR, MEDICAL AFFAIRS, GREENWICH BIOSCIENCES**

TSC Natural History Database and implemented sub-projects on TSC-associated neuropsychiatric disorders (TAND) and epilepsy while continuing sub-projects on renal angiomyolipomas and subependymal giant cell astrocytomas to address detailed questions about these life-threatening manifestations of TSC. A contract with Novartis executed in November 2012 provided TS Alliance with funding to enhance and grow the depth of data in the TSC Natural History Database through 2018.

The **TSC Biosample Repository** is a TS Alliance-directed project initiated in 2014 that will impact research over the next ten years or more. High-quality biosamples such as blood, DNA, and tissues linked to detailed clinical data are required for researchers to understand why TSC is so different from person to person. The TS Alliance's Science and Medical Committee identified this as a gap that can only be filled effectively with leadership of the TS Alliance, guided by a steering committee of clinicians and researchers. The TSC Biosample Repository ended 2017 with 397 biosamples: 251 blood, buccal cell, or tissue samples from individuals with TSC enrolled in the TSC Natural History Database, and an additional 146 samples from the Rare Disease Clinical Research Network's Developmental Synaptopathies Consortium and the Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT) clinical trial. Samples in the repository are linked to detailed clinical data in our existing TSC Natural History Database and are available to qualified researchers worldwide. Samples are housed at and distributed from the Van Andel Institute in Grand Rapids, Michigan, under control of the TS Alliance.

The TS Alliance launched the **TSC Preclinical Consortium** in 2015, which enables prioritization of candidate treatments based on comparing head-to-head data using consistent animal models and rigorous testing procedures. The TS Alliance is ideally positioned to drive this collaboration—with input from academic, regulatory, and industry stakeholders—by maintaining constant focus on the needs of people with TSC. To drive this project, the TS Alliance contracted with Dr. Daniela Brunner, who has more than 20 years of experience validating in vivo experimental protocols and testing drugs in many animal models of developmental, psychiatric, and neurodegenerative diseases. The TS Alliance has licenses to use specific TSC mouse models for experiments carried out by the Preclinical Consortium, and all mouse license agreements include the rights for the TS Alliance to perform experiments under contract for commercial entities. This ensures data generated by the Preclinical Consortium can be used to accelerate the development of new treatments by commercial entities as well as academic



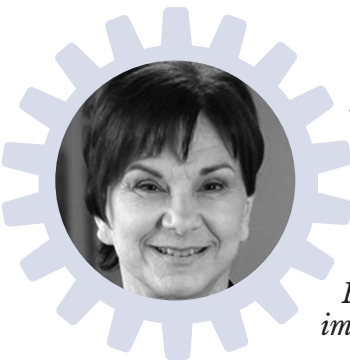
*This is a very exciting time for TSC research, and the PREVeNT Trial is a critical collaborative effort aiming to determine the impact of prevention therapy for epilepsy in TSC. The success of the PREVeNT trial would not have been possible without the unrelenting commitment of the clinical investigators involved in the TSC Consortium, including the TS Alliance and Bcureful. This partnership, along with the grant support of NINDS, has provided all the necessary elements to complete this important research effort.*

**MARTINA BEBIN, MD, MPA, CO-DIRECTOR, TSC CLINIC, UNIVERSITY OF ALABAMA AT BIRMINGHAM (UAB), AND PROFESSOR OF NEUROLOGY AND PEDIATRICS, UAB EPILEPSY CENTER**

investigators. The consortium began running epilepsy experiments in August 2016 at PsychoGenics, a contract research organization. Tumor experiments began in August 2017 at Porsolt, another contract research organization. Three pharmaceutical companies joined the Preclinical Consortium in 2017, bringing the total to six industry partners. The TSC Preclinical Research Consortium ran ten studies in 2017, compared to just four in 2016. Some of the consortium's early results were shared by TS Alliance and PsychoGenics scientists at the National Organization for Rare Disorders conference, the Society for Neuroscience annual meeting, and the American Epilepsy Society annual meeting in Washington, DC.

The TS Alliance continued to be a key part of the **TSC Clinical Research Consortium** although only a small amount of TS Alliance financial support was required because of the consortium's success in obtaining National Institutes of Health (NIH) funding. Now consisting of seven sites—Boston Children's Hospital, Cincinnati Children's Hospital, the University of Alabama at Birmingham, the University of Texas Health Science Center at Houston, UCLA, Stanford University, and Minnesota Epilepsy Group—the consortium has received \$29 million in competitive grant funding from the NIH to support clinical studies in TSC. The Clinical Research Consortium is making history with the PREVeNT trial (Preventing epilepsy using vigabatrin in infants with tuberous sclerosis complex).





*Externally-Led Patient-Focused Drug Development Meetings, like the one hosted by the Tuberous Sclerosis Alliance, allow the FDA to receive authentic patient input about the symptoms that matter most to them, the impact the disease has on patients' daily lives, and patients' experiences with currently available treatments. By listening to and documenting these experiences, we ensure FDA incorporates patient input into our decisions about new therapies. FDA wants to thank the TS Alliance for helping to amplify our efforts in improving drug development in tuberous sclerosis complex.*

**JANET WOODCOCK, MD, DIRECTOR, CENTER FOR DRUG EVALUATION AND RESEARCH,  
US FOOD AND DRUG ADMINISTRATION**



The TS Alliance and The LAM Foundation jointly sponsored the **2017 International Research Conference on TSC and LAM: Innovating through Partnerships**, held June 22-24, 2017, at the Hyatt Regency Capitol Hill in Washington, DC. More than 200 people, including 183 professional attendees from 27 countries, participated in scientific sessions featuring oral presentations, a poster session, and working groups of researchers tackling specific issues related to genetic, multidisciplinary clinical care,

and translational research strategies. The conference concluded with a joint session including individuals and families affected by TSC and lymphangioleiomyomatosis (LAM). This session highlighted how quickly the fields of TSC and LAM treatment are moving and emphasized the need for further collaboration between individuals with TSC or LAM and their families, clinicians and researchers to accelerate the development of greatly improved treatments for these disorders. We were also thrilled to present the Manual R. Gomez Award to

PREVeNT is the first preventative trial for any form of epilepsy in the US and began enrolling participants in December 2016. The PREVeNT trial builds directly upon the Consortium's first clinical study from which interim results have been published ([www.ncbi.nlm.nih.gov/pubmed/26498039](http://www.ncbi.nlm.nih.gov/pubmed/26498039)) showing that all infants who developed abnormal activity on EEGs went on to develop seizures. This trial will determine whether treatment with vigabatrin prior to the onset of clinical seizures in TSC is beneficial to children's developmental and neurologic outcomes. The TS Alliance's Chief Scientific Officer serves on the Consortium's leadership team.

*2017 was a banner year for our two organizations with regard to our collaborative efforts. Building upon a legacy of innovative joint programming, The LAM Foundation and the TS Alliance co-hosted the International Research Conference on TSC and LAM, testified to the FDA with a unified TSC and LAM patient voice at the Patient-Focused Drug Development Meeting and co-funded a career development scientific grant for a young scientist. The pace of scientific discovery in TSC and LAM continues to accelerate in large part due to patient and family engagement via our two organizations, and by working together, we have a measurably greater impact.*

**SUE SHERMAN, CHIEF EXECUTIVE OFFICER, THE LAM FOUNDATION**

Drs. Chris Kingswood and Julian Sampson for their extraordinary contributions to research and clinical care.

The TS Alliance sponsored a landmark **Externally-Led Patient-Focused Drug Development (PFDD) Meeting** with the FDA on June 21 in Washington, DC. The meeting's purpose was to allow individuals and caregivers affected by TSC and LAM to present their perspectives on living with these diseases to the United States Food and Drug Administration (FDA). This meeting resulted in a *Voice of the Patient* report the TS Alliance submitted to the FDA in October 2017. The report, available online at [tsalliance.org/pfdd](http://tsalliance.org/pfdd), summarizes the input provided by participants and panelists at the PFDD meeting, as well as findings from the international drug development survey and the post-event comment submission form. Participants highlighted the need to treat TSC as a whole rather than as a collection of individual manifestations. Because TSC affects many parts of the body, TSC patients see many different specialists who may not always be aware of treatments other physicians have prescribed. Epilepsy and TAND were the manifestations of TSC most disruptive to daily living in children and least likely to be adequately controlled by existing treatments. Adults with TSC and/or LAM often must limit their physical activities in ways that impact everyday living due to a number of manifestations that vary from person to person, and existing treatments are not curative and often expensive. The TS Alliance asks the FDA to utilize the *Voice of the Patient* report in its benefit-risk analysis when evaluating new or repurposed treatments for TSC.



## Support Services

Our Support Services Department develops programs and services that provide individuals with TSC direct access to information, resources, and specialists experienced in the diagnosis, treatment and management of TSC.

The Support Services Department provided support and resources to 3,547 individuals and families dealing with TSC throughout 2017. Dena Hook, Vice President, Support Services, attended 74 school meetings (IEPs, Evaluation Team Meetings, 504 Plan Meetings, Resolution Meetings, and Mediations) in person, through SKYPE or Facetime, and via conference calls to support families in attaining educational services for their children throughout the country. Through collaborations with the Parent Training and Information Centers in 2017, 3,005 free parent trainings/webinars on educational advocacy were offered to families in 32 states dealing with educational issues for their children. In addition, 128 school systems offered the support of the Educator Mentor Program in 2017. The Vice President, Support Services provided four school systems with training on “TSC and Learning” to help provide better educational outcomes for students with TSC.

Through a network of 37 volunteer branches of the organization, called Community Alliances, 57 local education and support group meetings were held throughout the country. In 2017, the TS Alliance of Maryland was launched, and the TS Alliance of DC Metro and TS Alliance of Virginia merged to reflect the overlapping constituencies.

The TS Alliance facilitated 20,247 peer-to-peer supports from Adult Regional Coordinators, Clinic Ambassadors, Dependent Adult Transition Resource Coordinators, and Community Alliances.

In 2017, the TS Alliance hosted two Regional TSC and LAM Conferences in Houston, TX and Washington, DC with 118 combined attendees. These conferences, co-hosted by The LAM Foundation, brought together



**AMY BRIN MILLER, MSN, MA, APRN-BC, ACHPN, EXECUTIVE DIRECTOR,  
CHILD NEUROLOGY FOUNDATION**

*Collaboration guards against individual intent while facilitating the advancement of the shared community's larger need. The TS Alliance has been a tremendous partner to the Child Neurology Foundation's efforts in the infantile spasms space. This partnership was the initial model that has since led to 24 other national and international organization joining the Infantile Spasms Action Network, whose awareness-building efforts reached 195 million people worldwide in 2017.*

individuals, parents, caregivers and members of the medical community to provide the most up-to-date information so parents and adults with TSC and LAM can make informed decisions when evaluating treatment options. These one-day symposiums offered educational outreach, information on the latest treatments in TSC and LAM, research updates, and support options. Regional TSC and LAM Conferences provide much-needed forums for the growing number of people facing the daily challenges of TSC and LAM.

The TS Alliance also held two Transition Workshops in New York, NY and San Diego, CA. The combined attendance at these workshops was 58. The goal of these all-day transition workshops was to give parents and caregivers tangible resources to empower them with clear timelines and next steps to develop an effective transition plan for their children. The TS Alliance partnered with The Arc USA, Child Neurology Foundation (CNF) and Mass Mutual because these organizations have pre-existing tools and best practices to assist through different aspects of the transition plan, and their expertise was vital to families in attendance.

## Public Health Education

Public Health Education heightens awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families. During 2017, the TS Alliance produced three issues of its national magazine, *Perspective*, which is mailed to almost 17,000 constituents as well as posted on the website.

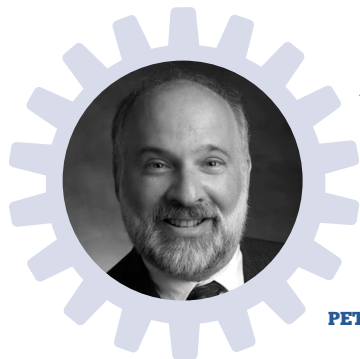
The TS Alliance's website increases awareness and provides extensive education through an average of more than 30,000 unique visitors each month. The TS Alliance also relies heavily on social media to educate constituents and promote new resources and events. Our Facebook Group boasts more than 8,600 members, while our Twitter account has 1,800-plus followers.

To increase public awareness, the TS Alliance once again participated in TSC Global Awareness Day on May 15 as well as TSC Awareness Month throughout May; a TSC Global Awareness Day news release garnered 12.1 million impressions.

The TS Alliance again heavily promoted Infantile Spasms Awareness Week, December 1 to 7. This awareness campaign included targeted social media outreach and a satellite media tour featuring TSC Clinic Director and CNF Board Member Dr. Mary Zupanc, which gained coverage from 16 media outlets reaching a potential of 1.2 million. A news release about the TS Alliance's *Voice of the Patient* report being submitted to the FDA resulted in 18.8 million media impressions.

## Professional Education

Professional Education expands programs to target researchers and healthcare providers caring for individuals with TSC, medical students, genetic counselors and educators to minimize the consequences of ignorance and misinformation.



*The Arc is thrilled with the partnership we've built with the TS Alliance over the past two years. Clearly, we are stronger together. By marshalling our resources and sharing our strengths, we are able to have much greater impact than either organization could achieve on its own. In these times, when so much is at stake for people with disabilities and their families, collaboration is essential.*

**PETER BURNS, CEO, THE ARC OF THE UNITED STATES**

The TS Alliance participated in and presented at 36 professional meetings including: American Thoracic Society and the ATS Leadership Summit; Child Neurology Society; Society for Neuroscience; Disability Policy Seminar; Global Genes; NINDS Biomarkers Workshop; NICHD workshop "Looking to the Future: The Next 50 Years of Intellectual and Developmental Disabilities Research"; Trans-NIH TSC meeting; Health Research Alliance members meetings; Research Roundtable in Epilepsy; Association of Clinical Research Professionals; Externally-Led Patient Focused Drug Development Meeting on TSC and LAM; International Research Conference on TSC and LAM; TSC/LAM Regional Conference in Houston; PKD Foundation; ICARE (Interagency Collaborative to Advance Research in Epilepsy); NINDS Nonprofit Forum; NCATS Toolkit for Patient-Focused Therapy Development; FDA CDER Public Workshop: Strategies, Tools, and Best Practices for Effective Advocacy in Rare Diseases Drug Development; Children's Tumor Foundation Research Consortium; Epilepsy Foundation's Cannabinoid Signaling in Epilepsy workshop; World Orphan Drug Congress; NORD Orphan Products and Breakthrough Summit; Simons Foundation workshop on patient registries for neurodevelopmental disorders; Open Research Funders Group; BIO Patient Health and Advocacy Summit; the Arc National Convention; Infantile Spasms Action Network; REN Outcomes in Epilepsy Workshop; Refractory Epilepsy in Children

at Sourasky Medical Center in Israel; LGS Family Conference; and The LAM Foundation Patient Benefit Conference and LAMposium LA. In addition, at the American Epilepsy Society meeting the TS Alliance presented in the Discovery Center and the poster session, and hosted more than 100 guests at a reception for TSC researchers. At the conference the TS Alliance also participated in a Special Interest Group meeting on TSC.

Finally, the Vice President, Support Services continues to collaborate with national educational networks, including The Arc USA, Parent Training Information Centers across the country and the Association for Middle Level Education.

*Each year our grassroots advocates spend countless hours calling, emailing and meeting with hundreds of Congressional offices to maintain funding for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense. Last year this funding was in grave jeopardy. Tenacious targeted personal appeals were needed to continue funding. Our advocates also had to remain vigilant for proposed health care legislation that would cut Medicaid and critical coverage protections for those with pre-existing health conditions. When the TS Alliance issued calls to action, our community responded in force to ensure continued funding for the TSCRP and other Congressionally-Directed Medical Research Programs in partnership with the Defense Health Research Consortium. We also joined other national advocacy efforts to successfully challenge threats that would cut access to healthcare. The extraordinary passion and dedication of our volunteers made this possible.*

**DEBORA MORITZ, 2017 TS ALLIANCE BOARD MEMBER, CHAIR OF THE GOVERNMENT RELATIONS COMMITTEE AND PARENT OF A CHILD WITH TSC**

## Advocacy

Government Relations focuses on educating members of Congress about TSC to further TSC research, awareness and clinical care. The annual TS Alliance March on Capitol Hill to advocate for federal funding for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense's (DoD) Congressionally Directed Medical Research Program (CDMRP) took place in late February 2017. More than 100 members of the TSC community participated and asked their Senators and Representatives to sign onto Dear Colleague letters in support of the TSCRP. Many other advocates who were unable to travel to Washington, DC met with their Senators and Representatives in their home states to make the case for continued funding. In the House, 160 Democratic and Republican Representatives signed a bipartisan Dear Colleague letter of support from Representatives Dave Loebsack (D-IA) and Ileana Ros-Lehtinen (R-FL). The Senate letter was sponsored by Senators Chris Murphy (D-CT) and Johnny Isakson (R-GA) and ended with 24 signatures. In FY2017, the TSC Research Program at the CDMRP received a \$6 million appropriation, bringing the cumulative funding to \$71 million since 2002 as a result of our successful grassroots efforts. Funding for FY2018 is pending on Congress passing the FY2018 budget but is currently included in the House's 2018 Defense Appropriations Act at \$6 million.





*Being a global affiliate of the TS Alliance is a great honor and opportunity for us to build up a strong, visible and good advocacy community. We look forward to collaborating on educational resources, research and care for individuals with TSC.*

**IMOLA DANKAHÁZI, PRESIDENT OF THE HUNGARIAN FOUNDATION FOR TUBEROUS SCLEROSIS**



Research performed through this program has recently led to additional clinical trials including determining if imatinib, a drug FDA-approved for cancer, can safely improve levels of VEGF-D, a biomarker of LAM, a life-threatening lung manifestation of TSC, funded in FY2013; testing a combination of two drugs to treat LAM funded in FY2012; a multi-site clinical trial testing the efficacy of an experimental topical rapamycin cream to treat the disfiguring facial tumors, called facial angiofibromas, caused by TSC funded in FY2010; a clinical research network was created to test potential new therapies, to validate biomarkers, and to learn the natural history of leading to a clinical trial funded in FY2012. Building upon FY2010-funded research on glutamate receptors (mGluR5), several companies are now looking at the link between cognitive impairments in TSC to autism, anxiety, and other mental disorders. The TSCRP has also funded research to develop animal models of TSC that have seizures, enabling a better understanding of the etiology of TSC. Based on data from TSCRP-funded animal models of TSC that have seizures and share pathology related to that of traumatic brain injury, an industry-sponsored clinical trial demonstrated the effectiveness the mTOR inhibitor, everolimus, at treating epilepsy in many individuals with TSC. None of this progress would have been possible without the critical support provided through the TSCRP.

Additional Government Relations efforts included a Congressional Briefing, in partnership with the Infantile Spasms Action Network, on Capitol Hill on December 5, 2017. Congressional staff and key members of the TSC research and grassroots communities attended the event.

## Global Outreach

The TS Alliance's Global Alliance Program was created as a way to address unmet needs within the global TSC community at the country level. This program facilitates knowledge transfer for the TS Alliance to share experiences and assist in the start-up or support of TSC-related organizations in other countries.

A Global Alliance is a structured group of empowered and caring volunteers who work closely with the TS Alliance to facilitate local connections for individuals and families affected by TSC, initiate fundraising and increase awareness all while supporting the mission of the organization. The Global Alliance program also fosters stronger links between the TS Alliance, communities and individuals around the world.

In celebration of TSC Global Awareness Day on May 15, the TS Alliance announced the establishment of a new Global Alliance, the TS Alliance of Mexico. This new international partnership will enhance community support, clinical care, and education and research efforts in both countries.

Through the Global Alliance Program, the TS Alliance also recognized its first TSC Clinic in Mexico in 2017. The Neural Clinic in Mérida directed by Dr. Joao Garcia joins the three TSC Clinics recognized in Israel as part of the TS Alliance international TSC Clinic network.

In 2017, the TS Alliance signed a Global Alliance agreement with the Hungarian Foundation for Tuberous Sclerosis. Since 2014, the TS Alliance's Global Alliance Program has grown from one global partnership to five, including: TS Alliance of Israel, TS Canada ST, TS Alliance of Mexico, TS Alliance Foundation (in Thailand) and the Hungarian Foundation for Tuberous Sclerosis.

In addition, as part of the global TSC community, the TS Alliance works in close coordination with Tuberous Sclerosis Complex International (TSCi). TSCi is a world-wide consortium of existing tuberous sclerosis complex associations and organizations, serving as an avenue to empower those affected by TSC, including individuals, families, caregivers, educators and health care providers. In addition, TSCi provides a forum to share information, exchange ideas and methods. In 2017 using unrestricted educational support from Novartis, TSCi focused on an Improving Care Project, promoting TSC Global Awareness Day and providing mentoring resources to new TSC organizations.





*I am always interested in driving research forward to address seizure control through drug discovery and developing personalized treatment options. Awareness and collaboration blend monetary resources and enable all involved to focus on achieving like results, which for me is to treat and defeat TSC.*

**JOY DINSDALE, TS ALLIANCE PRESIDENT'S COUNCIL MEMBER**



## Fund Development

The TS Alliance's most prominent partner for collaborating is the TSC community. Everything is made possible because of the drive, dedication and support of the TSC community—whether supporting TS Alliance national events, raising awareness at walks across the country or holding community fundraisers. The incredible generosity of the TSC community continues to inspire the TS Alliance to provide more resources and support and create new initiatives to accelerate current research efforts.

**THE TS ALLIANCE PRESIDENT'S COUNCIL** was introduced in 2016 and is comprised of members of families impacted by TSC who work with the President & CEO and Board of Directors to drive research forward through significant contributions given and/or solicited to the **Unlock the Cure – Accelerate, Collaborate, Target (ACT) Now!** campaign. The President's Council differs from the TS Alliance Board of Directors in that members have no fiduciary responsibility for the organization and advice is non-binding. However, their counsel and assistance in raising substantial capital for the organization will have a profound impact on exceeding Unlock the Cure aims.

The President's Council exists to dramatically advance scientific progress by ensuring resources exist to make strategic results possible, thereby improving the quality of life for those living with the disease today and in future generations. Members of the President's Council are tasked with the following:

- Give or get a minimum gift of \$100,000 per year to fuel Unlock the Cure – ACT Now!
- Identify potential individual, corporate or foundation donors.
- As needed/necessary make introductions or schedule appointments with contacts to discuss research opportunities.
- Review Unlock the Cure ACT Now! fundraising materials.
- Work with TS Alliance Staff in generating tailored requests based on donor interests or requirements.

- Help to identify other potential sources or strategies effective in obtaining federal or state research funds and making personal calls and introductions.

Current TS Alliance President's Council Members include:

- Christopher and Joy Dinsdale
- Gregg and Molly Engles, Engles Family Foundation on behalf of Engles Collaborative Research Fund
- Jonathan Rothberg and Bonnie Gould Rothberg, Rothberg Institute for Childhood Diseases
- William Watts



The Tuberous Sclerosis Alliance Board of Directors established the **KEITH HALL MEMORIAL FUND** to honor and pay tribute to Keith Hall. Keith passed away July 23, 2017 after a battle with cancer and left behind an incredible legacy of caring for others and inspiring hundreds of children, teens and adults with TSC to embrace life and live it to the fullest, despite any challenges they may face. As

an adult with TSC, Keith served on the TS Alliance's Adult Task Force and Outreach Committee, and he chaired the board's Strategic Planning Committee. In 2014 during the TS Alliance's 40th anniversary, Keith served as Chair of the TS Alliance Board of Directors. He lived in East Lyme, Connecticut with his devoted wife Andrea and two beautiful children, Brandon and Marissa. Due to the generosity of friends, families, supporters and with an extraordinary challenge matching grant of \$100,000 from the TSC Exploration Fund, \$221,649 was raised for the Keith Hall Memorial Fund from more than 300 donors in 2017. The TS Alliance of Board of Directors approved the first Keith Hall Research Grant Award for a two-year grant to Michael Evans at University of California, San Francisco, Developing New Ablative Therapies to Treat TSC, as well as partial funding for a two-year grant to You Feng at Brigham & Women's, Dysregulated Phosphatidylcholine Metabolism in TSC Pathogenesis and Therapy, and a two-year grant to support the TSC1 and TSC2 Variant Databases.



In 2017, special events netted \$1,323,959 representing 28 percent of the organization's overall revenue. A few highlights include:



### COMEDY FOR A CURE® HOLLYWOOD

16th Annual Comedy for a Cure – April 2, 2017

The Globe Theatre at Universal Studios, Hollywood, CA

The night was filled with laughter and hope, while raising \$200,000 and invaluable awareness for the TS Alliance. This year's hilarious comedians were Bryan Callen and Wendy Liebman, who were joined by magician Shane Brady with musical entertainment provided by Jane Lynch, Kate Flannery, Tim Davis and the Tony Guerrero Quintet. We're also thankful to our friends and returning Emcees Mo Collins and Alex Skuby and auctioneer extraordinaire Damon Casatico.

We were thrilled to present the much-deserved Leadership in Courage Award to the Michael Augustine Family, who were instrumental in development of the TS Alliance's Endowment Fund on behalf of their daughter, Megan, who has TSC. We were also humbled to honor Jim O'Heir, a long-time supporter of both the TS Alliance and Comedy for a Cure.

Thank you to our generous event sponsors: C&C Market Research, Mallinckrodt, MarketCast, Novartis, Michael Augustine Family, CVS Health, Lundbeck, Jim and Andrea Maginn, Upsher-Smith, WNC & Associates, Annie Szilagyi, Kathi and Tim Dills, Lauren and Richard Packard. We also would like to thank all of our partners for making the evening possible, including the fabulous Comedy for a Cure planning committee, Ballast Point Brewery, Ingram Design Studio, My

Cup Counts, Traci Hoffberg Events, Tom Bercu Presents and William Grant & Sons.

### DC SOUND BITES

March 1, 2017

National Press Club, Washington DC

This fabulous night was filled with great food, wine, music and hope, raising \$110,000 to fund future breakthroughs in the fight against TSC while creating greater awareness with moving speeches surrounded with entertainment provided by the Golden Gup and the Rhythmhancers and our gracious Emcee Chris Hawkey.

Jordan and John Richards received the Leadership in Courage Award for their government advocacy efforts on behalf of their son, Thorpe, who has TSC. We were also pleased to present an Honoree Tribute to Eric Schmitt, Missouri State Treasurer, who brought the room to tears with a moving speech about his son, Stephen, who was having brain surgery the following morning.

Thank you to our generous event sponsors: Nancy G. Richards, Mallinckrodt, Novartis, Rebecca Anhang Price and Matthew Price, Bogorad & Richards PLLC, Julie Blum and Greg Linsin, CRD Associates, Kathi and Tim Dills, Andrea and Keith Hall, Lundbeck, Peggy and Ted Mastroianni, NVG, Nita and Tad Blundon, Neet and Bill Ford, The Winifred M. Gordon Foundation, Carol and Jim Herscot, Katie and Richard Horan,



Inspire, Barbara and Jocelyn Nichols, Laureen and Les Nicholson, Katten Muchin Rosenman LLP, The RMR Group, Gigi and Garret Rasmussen, Rosemont Strategies, Seizure Tracker, Robert Trout and Janet Studley, Liz and Tim Cullen.

### SOUND BITES MINNESOTA

Second Annual – November 9, 2017

The Metropolitan in Golden Valley

The evening was a smashing success, raising more \$75,000. We presented another Leadership in Courage Award to The Hulbert Family, who have provided years of service to the Minnesota and national TSC community on behalf of their son, Trevor, who has TSC.

Honoree Tributes were given to Chris Hawkey and the KFAN "Power Trip" Morning Show for the awareness they have brought to the Minnesota community. We also honored Darren Miles, who has become an influential TS Alliance Board member as the TS Alliance expands our global footprint. Entertainment was provided by Chris Hawkey, Kat Perkins, Eric Warner and Shane Martin together with our gracious and hilarious Emcee Melissa Peterman.

**STEP FORWARD TO CURE TSC®** walks were held in 35 cities across the United States and collectively raised \$926,266. The walks are both fundraisers and community gatherings and it is inspiring to see the TSC community support these events and share their experiences on social media and through incredible news coverage locally. Support was provided by national sponsors Novartis, Greenwich Biosciences, LivaNova, MassMutual and LIDS Foundation.

### THE STEP FORWARD TO CURE TSC® NATIONAL WALK ON THE MALL

took place at Constitution Gardens raising \$63,124 while also increasing awareness in our nation's capital. This walk was a great success thanks to the TSC community and the generous support from Novartis, Greenwich Biosciences, LivaNova, Mallinckrodt, MassMutual, UCB and LIDS Foundation.

## Events Raising More Than \$10,000

### SIGNATURE NATIONAL EVENTS

- Comedy for a Cure® - Planning Committee
- DC Sound Bites - Planning Committee
- Minnesota Sound Bites - Kari Ihle and Planning Committee

### STEP FORWARD TO CURE TSC® WALKS

- Alabama - Margaret Cox
- Arizona - Debora Moritz
- Atlanta - Jeff Triemer
- Chicago - Scott Brown
- Connecticut - Jennifer Waldron
- Dallas/Ft Worth, TX - Sylvia Sparby and Cassie Jimenez
- Delaware/Lehigh Valley - Shelly Meitzler
- Indiana - Pat Schmutte
- Kansas City, MO - Laurisa Ballew
- Lansing, MI - Treasa Bolger-Dunlap
- Metro DC - Brooke Carpenter
- Tennessee - Scott Brown and Planning Committee
- New England - Stacie Verrill
- New Jersey - Tresha Bisang
- New York (Long Island) - Carol Ann White and Lori DiStefano
- Northern California - Bridgett Britt and Shannon Hackley
- Rocky Mountain Region (Colorado) - Alison Brainard
- Seattle, WA - Gloria Triebenbach
- Southern California - Barb O'Neill and Dawn O'Neill-Redfield
- St. Louis, MO - Ashley Fasciola
- Tampa Bay, FL - Amy Hightower
- Upper Midwest (Minnesota) - Maria Gibbons and Jody Prudhomme



### COMMUNITY EVENTS

- The 9th Annual Tuberous Sclerosis Alliance Fundraiser - Robert and Denise Spear
- 2017 Team TSC: TCS New York City Marathon - Sarah Blyth
- 2017 Team TSC: TCS New York City Marathon - Brianah Doeden
- Team TSC: 2017 Ironman World Championships - Reiko Donato
- 2017 Team TSC: TCS New York City Marathon - Lindsey Miller
- Crashin' for the Cause - Joe and Abby Kopf
- Strikeout for TSC - Laura Laramie and Kristen Chico
- 9th Annual Dinner to Benefit the TS Alliance - Temple Poche'

### Annual Fund - Major Donors and Contract Revenue

Fiscal Year 2017: January 1 to December 31

#### CHAIRMAN'S CIRCLE

(\$100,000 and Above)

Christopher and Joy Dinsdale  
Engles Family Foundation on Behalf of Engles Collaborative Research Fund  
Gerry and Bill Cowlin Foundation  
Novartis Pharmaceuticals Corporation  
OPL Charities  
Piquir Therapeutics AG  
Jonathan Rothberg and Bonnie Gould Rothberg, Rothberg Family Charitable Foundation for Children's Disease  
Takeda  
TSC Exploration Fund  
Tuberous Sclerosis Alliance Endowment Fund  
UCB, Inc.  
William Watts

#### BENEFACTOR

(\$50,000 - \$99,999)

Greenwich Biosciences, Inc.  
Harold Simmons Foundation  
James and Andrea Maginn  
Mallinckrodt Pharmaceuticals  
Estate of Robert McBride

#### SPONSOR

(\$20,000 - \$49,999)

Anavex Life Sciences Corp.  
Anonymous  
Anonymous  
Robert Baker  
Will and Kay Cooper, WNC & Associates, Inc.  
Crashin' for the Cause, Eldorado Lions Club  
Craig and Cindy Cunningham, C&C Market Research  
Richard and Lori Day  
Haag Family Foundation  
LivaNova  
MassMutual Financial Group  
Barbara McNeal  
The National Institutes of Health, the National Institute of Neurological Disorders and Stroke, the National Center for Advancing Translational Sciences, The National Heart, Lung & Blood Institute and the National Institute of Arthritis and Musculoskeletal and Skin Diseases  
RTI International  
The Winifred M. Gordon Foundation  
Laura Wasserman

#### PROTECTOR

(\$10,000 - \$19,999)

America's Charities  
Bcureful  
Jefferson Hall  
David and Cathy Krinsky  
Mary Ann Lamb  
The Louis Berkowitz Family Foundation, Inc.  
MarketCast  
David and Nancy Michaels  
Julianne Moore and Bart Freundlich  
Ned Neely  
Brian and Sandra O'Brien, Brian E. O'Brien Oil & Gas  
Allan and Carla Price  
The QBE Foundation  
Irene Rothberg  
Judy and James Shoulak  
Rob and Denise Spear, The 9th Annual Tuberous Sclerosis Alliance Fundraiser  
Strikeout TSC  
Upsher-Smith Laboratories, Inc.  
Karen White and Julie Geissman  
Whittingham Foundation





*Bcureful brings together TSC patients, families and medical professionals by raising funds to help with travel costs for testing, treatment, research and community. Bcureful provided seed money to help plan an upcoming TS Alliance TSC Nurse Coordinator Meeting. We are finding ways to work in a collaborative effort with the TS Alliance because together we are stronger, and each mile traveled is one step closer to a cure.*

**ELIZABETH GRANT AND DIANE MCSWAIN, CO-CHAIRS, BCUREFUL**

## DEFENDER

(\$5,000 - \$9,999)

Steve and Lynn Aguiar  
Rebecca Anhang Price and Matthew Price  
Anonymous  
Michael and Milly Augustine  
Ray Chan  
Charles & Mildred Schnurmacher Foundation, Inc.  
Scott Clarkson, Glacier Design Systems, Inc.  
David and Margaret Coit  
CVS Health  
Cornelius and Linda DenHarder  
Tim and Kathi Dills  
Tony and Linda Ellrod  
Facebook  
Michael and Janie Frost  
The Gertrude and Philip Hoffman Philanthropic Fund of the  
Jewish Federation of Greater Pittsburgh  
Kevin and Pam Hawkesworth  
Christy Hobart and Henry Shapiro  
Carol Hoffman  
Indiana Oxygen  
Ken and Beth Kocher  
Alan Koenigsberg  
KSM Business Services, Inc.  
Lundbeck Pharmaceuticals, Inc.  
Jane Lynch  
John and Frances Lyons  
Al Marshall  
Stuart and Carina Marton  
Herbert and Carol Marton  
Theodore and Peggy Mastroianni  
David and Lindsey Miller  
Minnesota Epilepsy Group, P.A.  
Robert and Staciellen Mischel, Mischel Family Charitable Fund  
Jon and Patricia Myers  
Network for Good  
Jim O'Heir

Roy Pfautch  
Clark and Temple Poché  
George and Susie Polsky  
Psychogenics, Inc.  
Ralph Vecchio Family Foundation  
Chris and Leslie Russell  
Michele Smith  
Susan Smith  
Brad and Jonna Stromberger  
Annie Szilagyi  
Tuberous Sclerosis Alliance of Israel  
Tuberous Sclerosis Canada Sclérose Tubéreuse  
Valero Energy Foundation  
Variety - The Children's Charity  
Lorne and Heidi Waxlax  
Cliff and Deborah White, Cliff and Deborah White Family  
Foundation  
Patrick Whitehead and Christine Page  
Kevin and Sarah Wright

## ADVOCATE

(\$1,000 - \$4,999)

A. Sturm & Sons Foundation, Inc.  
Aaron's, Inc.  
Earl Abramson and Sheila Schlaggar  
Accurate Healthcare, Inc.  
Howell and Madeline Adams  
James and Lee Ann Addison  
Farid and Faranza Ali  
The Allstate Foundation  
Amazon Smile Foundation  
Paul and Patricia Anderson  
Anonymous  
Arborscapes, LLC  
Frank Auman  
Chad and Alicia Austin  
Axis Medical Education, Inc.  
Daniel and Laurisa Ballew

Arlene Bandstra and James Achterhof  
Adrian Banner  
Rick Barrett  
Edmund and Mary Bartlett  
Geoff Bauer  
Thomas and Elizabeth Beattie  
Benevity Community Impact Fund  
Daniel Benninghoff  
The Berkshire Heights Fire Co. Small Games of Chance  
BF Clyde's Cider Mill  
Biotechnology Innovation Organization  
John Bissler  
Eileen Black  
Stephanie Black  
Stacey Black  
Daniel Bloomstein and Kirscha Burgess  
Bogorad & Richards, LLC  
Booster  
Jason and Alison Brainard  
Bristol-Myers Squibb Foundation  
Scott and Renee Brown  
Victor and Diane Brown  
Emerson Bruns and Benedict McCaffree  
Linda Buchman  
Andrew and Elizabeth Buchsbaum  
Pablo Burbridge  
Business Knowledge Services, Inc.  
Aaron Butler  
Linda Cain  
Elizabeth Cannon  
David and Brooke Carpenter  
Daniel and Ingrid Carroll  
James and Diane Caserta  
Patrick Casey  
Cavarocchi Ruscio Dennis Associates, LLC  
Charter Oak Federal Credit Union  
Marcia Chatfield  
Chemistry Rx, LLC  
Chevrolet Cadillac of Bellevue, Inc.  
Sara Chieffo and David Skillman  
Mardel Chinburg  
Makel Church  
William and Sue Clark  
Margie Colby  
Mark Colby  
Columbian Charities of Missouri, Inc.  
John and Mary Conner  
Steve and Kathleen Conrad  
Constellation  
Jared and Margaret Cox

Jason and Michelle Cox  
 Mark Craig  
 Greg Cronkhite  
 Cruisin Cajun Country, Inc.  
 Donelle Dadigan  
 Deborah D'Alfonso  
 The Daniel and Adrienne Wasserman Charitable Fund  
 Mary Rose Davis  
 Kathleen Dawson  
 Rachel Depew  
 Roy and Gloria Dinsdale  
 Tyler Docking  
 Brianah Doeden  
 Darian Downs  
 Scott Dragos  
 Tony Dunlap and Treasa Bolger-Dunlap  
 Andre Duplantis  
 Robin Edwards  
 Barbara Egolf  
 Nick Eitel, NMS LLC  
 Richard and Athena Eitel  
 Denny Erhler  
 Kenneth Escobar  
 Exelon Foundation  
 Pamela Farr  
 Scott and Jill Feinstein  
 Greg Ferland  
 Joseph and Hilary Feshbach  
 Fifth Third Bank  
 Michael and Jacqueline Flaherty  
 Kasey and Jami Flicker  
 FOCUSED Marketing Research, Inc.  
 Frictionless Solutions, Inc.  
 Sam and Wendy Frieder  
 Gap, Inc.  
 Gerhardt & Berry Construction, Inc.  
 Gail and Andrew Gershon  
 Shayla Gifford, Guild Mortgage Company  
 Larry Gohmert  
 Lauren and Dennis Goldasich  
 Goldman, Sachs & Co. Matching Gift Program  
 Joan Gomez  
 Dianne Gordon  
 William Grabb and Jean Leonard  
 Charles and Suzanne Graham  
 Robert and Nancy Graham  
 Ritchey Graham  
 Donn and Julie Gray  
 Miriam Green  
 Tim Griffin

Martin and Dorothea Grolnic  
 Patrick Gross  
 Robert and Kathryn Groves  
 Christopher Growe  
 Shannon Hackley  
 Andrea Hall and the late Keith Hall  
 Pete and Nancy Hall  
 Jennifer Hall and Eric Anderson  
 John Hanifin  
 John and Candice Handley  
 Neil Harlan  
 David Harper  
 Marcia Hecht  
 Dennis and Lynn Heieie  
 Henry Sullivan Campaign Committee  
 Elizabeth Henske  
 Herbst Foundation  
 James and Carol Herscot  
 Amy Hightower  
 Daniel and Melanie Hileman  
 Garrick Hodge  
 Jay and Lesley Hoffarth  
 Traci Hoffberg  
 Tyler and Cynthia Hoffman  
 Jeffrey and Linda Hoffman  
 Patrick and Mary Holmay  
 John and Alice Hulbert  
 Sandra Hyde-Swanson  
 Hyman Family Charitable Foundation  
 Leon and Pam Ihle  
 Ann Jacques  
 Linda Jackson  
 Jean A. Panther Estate  
 John Garlinger Hazlett Fund of the Licking County Foundation  
 Ken and Shonnie Johnson  
 Johnson & Johnson  
 Scott Johnston  
 Joseph M. Levine Foundation  
 Arnold and Carol Kamm  
 Michael Keating  
 Keiser Family Foundation  
 Richard and Linda Keister  
 Kendra Scott, LLC  
 David and Maureen Kenna  
 Kenvo Foundation  
 Corey Kluber  
 Kohl's  
 Koni Hospitality, Inc.  
 Scott Koppendrayner  
 Katherine Krenning  
 Todd and Debi Kronebusch

Kutztown Rod & Gun Club, Inc.  
 David Kwiatkowski  
 Lise Lagace  
 Justin and Carey Largent  
 Steven Laufer  
 LDK Homes and Home Cellar Group  
 William and Barbara Lee  
 Christopher and Heather Lens  
 Rodney and Caroline Lenz  
 Matt Leone  
 Steven and Charla Lerman  
 Mary Lestak  
 Lexus of Arlington  
 Linda G. Porter Fund of Waccamaw Community Foundation  
 Greg Linsin and Julie Blum  
 Patricia Loewen  
 Richard Lotz  
 Jason and Brandi Lowe  
 Laura Lubbers and Trent Buck  
 The MacPherson Fund, Inc.  
 Charles Maestas  
 William and Audrey Malesky  
 David and Martha Martin  
 Gregory Massad  
 Everett Maynard  
 Amy McDonald  
 Robert McNeilage  
 Cara Medeiros  
 Medtronic, Inc.  
 Matthew and Shelly Meitzler  
 Barbara Meitzler  
 Michael and Janell Meredith  
 Karen Meredith  
 Harry and Donna Meyer  
 Michael Bill Avner Memorial Fund of The Pittsburgh Foundation  
 Michael P Wilson, Inc.  
 Margaret Middleton  
 Edward Miguel  
 Tim Missey  
 William Mitchell  
 Holly Myers and E. Kirk Neely  
 Jo Anne Nakagawa  
 Nissrine Nakib  
 National Association of Theatre Owners of California/Nevada  
 National Centers for Pain Management and Research, LLC  
 James Nelson and Nan Martin  
 Thu-Trinh Nguyen  
 Norgren Family Fund  
 The Norman and Susan Abazoris Foundation  
 Northern Louisiana Medical Center  
 Hope Northrup and Ed Bonura



Nueva Vista Group, LLC  
 David O'Brien  
 Dennis and Agnes O'Leary  
 Office Insights, Inc.  
 Thomas and Laurel Olear  
 Mary Oliver  
 Michael and Diane Oravec  
 Adolfo Orive and Camila Uribe  
 Amy Overby  
 Richard and Lauren Packard  
 George and Joy Pantelis  
 Nikolas Pappas, International Association of Fire Fighters  
 Pat and Pete Schenkel Charitable Fund  
 Muriel Pattis  
 Steve and Kate Peer  
 Lillie Peery  
 PepsiCo Foundation  
 Steven Peters  
 Christopher and LeAnn Peterson  
 Dave and Colleen Pfeiffer  
 John Pietrolungo  
 Andrew and Maureen Piotrowski  
 PNC Foundation  
 Karen Pope  
 Prevention Genetics  
 Proverbs 3:9 Foundation  
 PTC Therapeutics  
 Quest Diagnostics  
 Brian Rabben  
 Jeremy Radisich  
 Peter and Bitty Rapaport  
 Ilana Horowitz Ratner  
 David and Kathy Rausch  
 Raymond James Financial, Inc.  
 Scott Reinker  
 Vic Reyes, Jr.  
 John and Jordan Richards  
 Stephanie Ricke  
 Robinson Management, LLC  
 John and Debbie Roeser  
 Christopher and Kari Luther Rosbeck  
 Rotonda Golf Partners, LLC  
 John and Peggy Ruckauf  
 Terry and Cynthia Rust  
 San Francisco Spice Company  
 James and Nicole Schmidt  
 Schwab Charitable Fund  
 Robert and Mary Ellen Scott  
 Douglas and Lacinda Scott  
 David and Karen Senger  
 Paul and Mary Seward

Seyfarth Shaw Charitable Foundation  
 Thomas and Elysa Seymour  
 Shamrock Capital Advisors  
 Shawn Gaffney Memorial Fund  
 Tess Shreffler  
 Julie Silcock  
 Daniel Silverberg  
 Brittany Smith  
 Don and Mary Smith  
 Johnny and Vianne Smith  
 Ralph and Isabel Smith  
 Trevar Smith  
 Barbara Snider  
 Kiran Somani  
 Mark and Alanna Spotts  
 Jerrill and Heidi Sprinkle  
 Loretta Stanton  
 Kate Staples  
 David M. Stefanoni  
 Stifel Nicolaus  
 Charles Strangfeld  
 Neal Suares  
 Swift Fund Management, LLC  
 Pam Sztukowski and Chris Holubwicz  
 Stephen and Winifred Tart, Stephen Tart Associates  
 TD Ameritrade  
 Sean and Kelly Thomann  
 Jacob Thomas  
 Thomas H. Louder Family Foundation  
 James Tolley  
 Steven and Sarah Towne  
 Michelle Trombetta  
 Truist  
 Albert Tseng  
 Uline  
 United Way of Central & Northeastern Connecticut  
 United Way of Orange County  
 United Way of The National Capital Area  
 The University of Alabama at Birmingham  
 US Bank  
 Jasper Van Schaik  
 Sasha Varghese  
 Airi Veimer  
 Cathy Villegas  
 Christine Viola-Weiss  
 Barbara Wahl  
 Joseph Walsh  
 Victor Wang  
 Gary and Ann Wasserman  
 Rebecca Webber  
 David Weigel

Westbury Fire Dept Hook & Ladder  
 Jane Wiggins  
 Brian Williamson  
 Wintrust Commercial  
 Wonderland Pier  
 Michael Wong and Cecilia Hsien-Tsing Wu  
 WPT Administrator  
 John Wyskiel  
 Joseph and Deborah Yohn  
 YourCause, LLC  
 Youtech & Associates  
 Zimmco Equipment, Inc.  
 Zimmer Biomet  
 Tara Zimmerman  
 Evan Zuckerman and Andy Bernstein

## CHAMPION

(\$500 - \$999)

Leonard Abruzzo  
 All Out Companies, LLC  
 Christina Alvarado  
 Arthur and Kimberly Anderson  
 Jason Anderson  
 William Anderson  
 Mark and Becky Annen  
 Robert and Dorothy Apple  
 ARC Thrift Stores  
 Arkansas Elder Outreach of Littlerock DBA Southwind Nursing  
 Gordon and Pauline Arndt  
 Kandiah Arulmoli  
 Charles and Lucille Asensio  
 John and Patricia Badorf  
 Karsten Bartels  
 Claire Beadle  
 Sally Bell  
 Debra Bell  
 Joel Bernheim  
 Robert and Kelly Best  
 David Beyenhof  
 Kevin Bittel  
 Michael Bixiones  
 Cynthia Black  
 David Blake  
 Bluffton Electric, LLC  
 Tad and Nita Blundon  
 Kathleen Blyth  
 BMR Investment  
 Brian and Jamie Boesiger  
 James and Betty Bolger  
 John Bonnes

Nancy Boriack  
 Bev Bradley  
 Walter and Mary Bradley  
 Ruth Brainard  
 David Breihan  
 Megan Brewster  
 Bridgewater Knights of Columbus Council 488  
 Connie Briones  
 Bridget Britt  
 Harry and Karen Broome  
 Pheobe Brown  
 Dennis Brown  
 Joe and Donna Bryant  
 Jeremy Buchman and Laura Marks  
 Bycorp Builders, LLC  
 Capital Advisors  
 Frank and Barbara Capone  
 Joe and Sharon Cappadona  
 Carle Place Fire Department  
 Robert Carpenter  
 Joe and Margaret Carrillo  
 Damon Casatico  
 Mary Sue Catlett  
 Lisa Catto  
 Laura Cheek  
 Cherokee Nation  
 Children's of Alabama  
 Nathan and Whitney Chisholm  
 Tim and Glenda Christenson  
 John and Teresa Christian  
 Michael Coburn  
 James Coburn  
 Paul Collins  
 Community Shares of Colorado  
 George and Susan Conlon  
 Connecticut Hotel Group, LLC  
 Linda Connors  
 Lee Coogan  
 Mike and Mary Cook  
 William Cook  
 Wilfred and Jennifer Cooper  
 Alfred and April Cooper  
 Brian Corcoran  
 Council of Colts Corrals, Inc.  
 William Cowlin  
 Elizabeth Cullen  
 The David Pattis Memorial Foundation  
 Beth and Michael Dean  
 Lori DeLuca  
 Ron Devalle

Charles Dohn  
 Rick Douglas  
 Jack and Agnes Dover  
 Cornelia Drees  
 Neil and Amy Dublinske  
 Bonnie Hogue Duffy and Charles Duffy  
 Dugas, Soileau & Breaux, LLC  
 Dynamic Earth Lawn Landscape  
 East Penn Mfg. Co. Inc.  
 Guy Edwards  
 Mona El-Sherif  
 Sidney Burr Ellis  
 Derek Embody  
 Entertainment Works  
 Jay Erb  
 Linda Fairchild  
 Christina Fernandez  
 Steve Ferrarese  
 The Florence Mauboules Charitable Trust  
 Steven Foley  
 William and Anita Ford  
 Taylor Foxwell  
 Kim Franklin  
 Franklin Street Financial Partners  
 Bernard and Damaris Friel  
 Laura Furey  
 Elizabeth Gardner  
 Alfred and Johanna Garzino  
 Don and Nancy Germano  
 Gertiebells, LLC  
 Eric and Tricia Gerum  
 Matt and Jennifer Geyso  
 Matt Gilder  
 Global Gutter Screens, Inc.  
 Robert and Shirley Goble  
 Louis and Tiffani Goff  
 Pat Goldsberry and Kenneth Brown  
 Goodin Company Foundation  
 Joan Grabe  
 Jane Greenberg  
 Shannon Griffin  
 Bernard Grimm  
 Erin Grisanti  
 Joseph and Margaret Griscti  
 Michael and Kathleen Gutto  
 Patricia Hagins  
 Ben and Faith Hall  
 Raymond and Nancy Hall  
 Linda Hamilton  
 William and Bridget Hamilton  
 Hansen Project Management, Inc.

Michael Harden  
 Jonathan and Heather Harden  
 Harry Braswell, Inc.  
 Donald and Florence Hauge  
 Chris and Kimberly Hawkey  
 Tom and Linda Heathman  
 Todd and Toni Heino  
 Michelle Hennessey  
 Here's Wings Vernon Hill, LLC  
 Michael Hicks and Megan Big John  
 Lisa Hiday-Baca  
 Sandra Hightower  
 Daniel and Melanie Hileman  
 Paul Hinz  
 Don Hissam  
 James and Amy Hobbs  
 Jonathan Hyman and Susan Hoffman  
 David and Jennifer Hoffman  
 William and Charlene Holmes  
 Teresa Home  
 Dena Hook and Santo Pino  
 Hope Christian Reformed Church  
 Richard and Katherine Horan  
 Ann Huber  
 Curtis and Carolyn Hull  
 Mark Hyman and Sheryl Neuman  
 Justin and Kari Ihle  
 Jaye Isham and Larry Rocha  
 Cathy Jackson  
 Kathy Johanson  
 Scott and Emily Johnson  
 Adelta Johnston  
 Debbie Johnston  
 Sheri Jones  
 William and Debra Joseph  
 Jim and Nancy Joyce  
 Jay and Deborah Julow  
 Kaempfer Crowell Attorney  
 Keith and Janet Kappes  
 Donna and Darrin Keibel  
 Kelsch Associates Inc.  
 Danielle Kennedy  
 Scott Kesten  
 Knight and Ann Kiplinger  
 Kiwanis Club of Lost Mountain  
 Daniel Klein  
 Ann Kliethermes  
 Matthew Knapp  
 Russell and Merry Kraft  
 Todd and Stephanie Krauser  
 Melanie Krinsky and Charles Luke

Andrew Kunian  
 Young and Hee Kwak  
 Jessica Kyj  
 Linda Kyle  
 Robert and Brenda Kay Laird  
 Shamsuddin and Ezmina Lalani  
 Tammy LaMantia  
 James Lamb  
 James and Chelsea Lamb  
 Thomas and Mary Ellen Langbein  
 Bev LaSota  
 The Lasota Family Fund for Charitable Giving  
 Ann Lauterbach  
 Scott Lehman  
 Robert LeMoine  
 Lois Leuthold  
 Greg Linder  
 LLR, Inc.  
 Ernest Lockridge and Laurel Richardson  
 Kenneth Londoner  
 Nicole Longino  
 Mitchell and Cyndy Lovic, Mitchell Lovic Transport, Inc.  
 Christopher Mahony  
 Robert and Barbara Malatesta  
 Arien Malec and Kristin Barr  
 Edward and Judith Malecki  
 Kondala Rao Mantri  
 William Markel  
 Lawrence and Joya Marks  
 Kren Marsalko  
 Andrea Marshall  
 Stephen and Barbara Martin  
 Angela Martinez  
 Raymond and Charlene McFadden  
 Ryan McFadden  
 Virginia McKiernan  
 Diane McSwain  
 Linda Meints  
 Meitu Corporation  
 Robert and Mary Melcher  
 Members Give  
 Yaron Mendelovici  
 Merck Foundation  
 Carol Michael  
 Margarete Michel  
 The Michelle & David Fries Charitable Fund  
 Shawnalee Miller  
 Annette Miner  
 Missouri General Insurance Agency, Inc.  
 William Moncure  
 Ted and Barbara Montgomery

Clark Moore  
 Kacie Moulos  
 Charlotte Myers  
 Phillip Myhra  
 Naperville North Huskies Hockey Club  
 National Christian Foundation Alabama  
 NBC Universal  
 NeuroPace, Inc.  
 Maureen Nichols  
 O-Ring Sales & Service, Inc.  
 Leon and Sharon Oberlander  
 Ryusuke Ohori  
 John and Jennifer Ortiz  
 Paint Nite  
 Ann Parker  
 Kyle Parker  
 Dunia Pasternak  
 Gary and Cynthia Paxton  
 PDI  
 Donald and Jean Pearson  
 Preston and Deborah Pelkey  
 Hal Pennington  
 Perciballi Container Service, Inc.  
 Kat Perkins  
 David Peterman  
 William and Linda Pfeiffer  
 Anthony Phillips  
 Jane Phillips  
 Kathy Piasta  
 Kevin and Anastasia Pike  
 Tracy Pones  
 John Poutasse and Mara Flynn  
 Charles Preston  
 Elizabeth Pulick  
 Gregory and Nancy Putz  
 Lori Weingarten, Quick Test/Heakin  
 Alan and Billi Rakov  
 Jesse and Allison Rangel  
 Donald Ray  
 RE/MAX of Cerritos  
 Frank Reagoso  
 Paul and Jennifer Recinos  
 Red Men Club, Inc.  
 Gary Reiner  
 Elizabeth Reinhardt  
 Paul Richards  
 Gustavo Rivas  
 Lauren Rivera  
 Nilsa Roberts  
 Alice Robin  
 Christie Robinson

Thomas and Joanne Roche  
 Heather Roche  
 Jim and Jennifer Rooney  
 Diane Rose  
 Nancy Rosenbach  
 Susan Royles  
 Allen and Gayle Ruplinger  
 Abel Sanchez  
 Mildred Sanders  
 Raman and Oonagh Sankar  
 Sam and Tina Sansone  
 Willie Sarver  
 John Satter  
 Thomas and Deborah Schaefer  
 Paul and Kathryn Schoenle  
 Erin Schor  
 Martha Schumacher  
 Jay Sciortino and Christina Dremousis  
 Benjamin Scott  
 Jeffrey and Lesley Seymour  
 Stanley Shapiro  
 Brian and Dawn Sharp  
 Garland Sharp  
 Cheryl Shaw  
 Margaret Sheehan  
 Sean and Lauren Shillinger  
 Carol Sidell  
 Steven and Amy Silver  
 Bruce Simmons  
 Edward Sims  
 Ann Skillman  
 Alice Skinner  
 Lisa Slocum  
 Lynda Smith  
 Melvin Smith  
 Betty Smith  
 David and Gloria Solomon  
 Timothy and Samantha Soule  
 Eric and Adelynn Spiecker  
 Hans and Joanne Spiecker  
 Rocco and Carmela Spinoso  
 Barbara Spotts  
 Doris Stachelek  
 John and Janine Steenman  
 Mark and Alyson Steil  
 Tammy Sullivan  
 James and Mabel Tarlton  
 Team Hannah, Inc.  
 Sam Teske  
 Kiran Thomas  
 Mark and Nadine Thorn



Daniel and Ellen Tobin  
 Armen and Vicky Tororian  
 Sheila G. Tortorici  
 Lee and Gloria Triebenbach  
 Harvey Triebwasser  
 Andrew and Helen Triemer  
 James and Heather Trimm  
 Amanda Truax  
 Tuberous Sclerosis Clinic - Ohio  
 Kelly Tufts  
 James and Cynthia Tuite  
 William Tuttle  
 United Way of Central Indiana  
 United Way of Greater Philadelphia  
 United Way of San Antonio  
 United Way of Sheboygan County, Inc.  
 United Way of the Bay Area  
 Thomas Varghese  
 Alan and Nancy Vogel  
 Barbara Wachter-Regello  
 Waitr Inc.  
 Neila Walsh  
 Christina Waxlax  
 Vanessa Wear  
 Katherine Wegner  
 Yoda and Cordelia Wegner  
 Jerry Wells  
 Edward Wes  
 West Chicago Garden Club  
 Jack and Jeanne Whitaker  
 Steve Widdoss  
 Carl and Sheila Wiezalis  
 Elaine Wilder  
 Hayes Williams  
 Karen Womack  
 David and Goldy Wood  
 Ann Woodford  
 Thomas and Eleanor Woods  
 Joanna Wright  
 Stephen Wright  
 John and Laurel Wrynn  
 David Yeamans  
 Cece Yorke  
 Shari Yoshimitsu  
 Bill and Nancy Youmans  
 Dave Zimmerman

## MAJOR GIFTS IN KIND

(Value of \$500 or more, as identified on received in-kind forms)

Anonymous  
 Aziz Ansari  
 Laura Antoyan  
 Art the DJ  
 Attract, LLC  
 Baba's Catering by Mediterranean Cruise Cafe  
 Ballast Point Brewery  
 Tom Bercu  
 Bob's Watches  
 Shane Brady  
 Buffalo Wild Wings  
 Bryan Callen  
 Cara Irish Pubs, Coopers Restaurant and Pub  
 Caribou Coffee  
 Chick-Fil-A  
 Contours  
 Mo Collins  
 Julie Conway  
 April Cooper  
 Tim Davis  
 DigitalEra Group, LLC  
 Kathi and Tim Dills  
 Amy Dublinske  
 Edina Kiss Jewelry  
 English Benji  
 Fabio Trabocchi Restaurants  
 Family Adventure Drone Video  
 Kate Flannery  
 Janie and Michael Frost  
 Tabitha Goff  
 Tiffani Goff  
 The Grand Casino  
 Harry Braswell, Inc. dba Concierge Homes Services  
 Chris Hawkey  
 Chris Hawkey Band  
 Eric D'Amario  
 Golden Gup and the Rhythmhancers  
 Heart-Field Productions  
 Christy Hobart and Henry Shapiro  
 The Hess Collection  
 Hudson Whiskey  
 Justin, Kari and William Ihle  
 Jennifer Jacobs  
 William Harold Jewelers  
 Jorgenson & Salberg Attorneys at Law  
 Wendy Liebman  
 Jane Lynch

JPL Inc.  
 Kent Kahlen  
 KFAN Power Trip Morning Show  
 Kripalani Hong Kong Tailors  
 Lisa and Rod Lawrence  
 Lazy Dog  
 LDK Homes and Home Cellar Group  
 Lela Restaurant  
 Doug Loftus  
 Loop Bar + Restaurant  
 Lucille's BBQ  
 Jim Maginn  
 Everette McCarthy  
 McCoy's Public House  
 Mehrnough Architecture  
 Norma Meyers  
 Milagro Tequila  
 Patrick L. Mills  
 Julianne Moore  
 MSB Properties, LLC  
 My Cup Counts  
 Ocean Properties Hotels, Resorts and Affiliates  
 Nick Offerman  
 Jim O'Heir  
 Pacific Coast Audio  
 Pepsi Company  
 Kat Perkins  
 David Peterman  
 Melissa Peterman  
 Peter Pepper Products  
 Amy Poehler  
 Chris Pratt  
 Allan and Carla Price  
 Proctor & Gamble  
 Rainforest café  
 The Red Cow and The Red Rabbit  
 Redtree Productions  
 Retta  
 Reyka Vodka  
 John and Jordan Richards  
 Ritz-Carlton  
 Jennifer Rolfes  
 Rosie Rae's Toffee  
 Salerno's  
 Adam Scott  
 Sally Shae  
 Chris Sheffield  
 Sheila Kelley S Factor  
 Alex Skuby  
 Southwest Airlines  
 Alanna Spotts

Stapleton CrossFit  
 Strike Promo  
 Suzanne Sus  
 Mabel Tarlton  
 Benjamin Taylor  
 Tesla  
 T-Rex Cookies  
 Tony Guerrero Quintet  
 True Boutique  
 Ty, Inc.  
 Erica Valdez  
 Vina Zaco  
 Volunteer Clowns of Orange County  
 Doug and Carol Wateron  
 Jerry Wells  
 Williams Ski & Patio  
 William Grant and Sons  
 Yoga Fit  
 Jason Zucker

*The TS Alliance strives to correctly recognize all our donors. We apologize in advance for any errors, omissions or misspellings in this annual report. Please call our office at (800) 225-6872 with any corrections.*

## Endowment Fund

The TS Alliance Endowment Fund is a separate fiduciary organization specifically chartered to receive gifts that will be invested to generate an income stream to help fulfill the mission of the TS Alliance. The Endowment Fund ensures the TS Alliance has an ongoing source of funding to better serve those touched by TSC through education, support services and research.

### ADVANCEMENT SOCIETY (\$25,000 - \$99,999)

Andrea Hall and the late Keith Hall  
 Ken and Shonnie Johnson  
 Magdalena Lutsky  
 Philip and Marion Winsor

### ENRICHMENT SOCIETY (\$5,000 - \$9,999)

Donald and Betsy Ellis  
 Doug and Linda Loftus  
 Robert and Joan Appleby Foundation  
 William and Corinne Ward

### INVESTMENT SOCIETY (\$500 - \$4,999)

Anonymous  
 Farrar Family Charitable Fund  
 Mark and Judy Fox  
 Todd and Toni Heino  
 Linda Meints  
 Network For Good  
 Kimberly Osborn  
 Truist  
 Waxlax Family Foundation  
 YourCause, LLC

## The Eternal Flame Society

When individuals and families inform the TS Alliance of a designated planned gift through a will or estate plan to the TS Alliance Endowment Fund or the TS Alliance they become part of the Eternal Flame Society. If you or a loved one has designated the TS Alliance through a planned gift and are currently not listed on The Eternal Flame Society, please let us know so that we can add you. We are pleased to honor the following distinguished members of the Eternal Flame Society:

Anonymous  
 David Armijo  
 Michael and Millicent Augustine  
 Jeffery and Gloria\* Benham  
 Matt Bolger  
 Treasa Bolger-Dunlap  
 Alice Brossart\*  
 Scott and Jan Burton  
 Marguerite Cleveland  
 John and Katherine Conrad  
 Will and Kay Cooper  
 Richard and Reiko Donato  
 Cindy Fowler  
 Jeffrey Ross Goldstein  
 David and Laura Grimes  
 Robert W. and Kathryn A. Groves  
 Shannon Hackley  
 Keith Hall\*  
 Jeffrey and Lisa Hargreaves  
 Clara Harwell  
 Anne Heilman\*  
 James and Amy Hobbs  
 Jaye Isham  
 Ken and Shonnie Johnson

Arnold and Carol Kamm  
 Steve and Laura Kozisek  
 David and Cathy Krinsky  
 Mark Leal  
 Craig T. Lewis\*  
 Doug and Linda Loftus  
 Magdalena Lutskey  
 James Lynch  
 Robert McBride\*  
 Donna McGaha  
 David and Jan Mintz  
 Maria Sharon Munoz-Chargoy  
 David and Penney Parkes  
 Jeffrey and Bonnie Rickert  
 Pat and Jennifer Rolfes  
 Kari Luther Rosbeck  
 Dave and Nancy Scott  
 Robert and Mary Ellen Scott  
 Fred and Ilse Smith  
 John and Janine Steenman  
 Rob Thurston  
 Kathy Trapp  
 Alma A. Tutrone\*  
 Jim and Nancy Weir  
 Philip and Marion Winsor  
 Barbara Witten and William Bradley  
 Frieda Zimmerman\*

\*Deceased

## Endowment Named Funds

On gifts of \$25,000 or more (with a pledge payable over five years), a donor has the opportunity to name a fund in honor of someone. We are deeply grateful for the following named funds:

Megan Augustine Fund  
 Augustine Family Fund  
 John A. Conrad Jr. Memorial Fund  
 Carrie Cooper Memorial Fund  
 Matthew J. Fox Fund  
 Lauren E. Krinsky Fund  
 The Lawler Fund  
 Cade Scott Fund  
 Jeb Ward Legacy Fund

*Please remember the TS Alliance Endowment Fund when planning for the future by designating a gift to the organization.*

## Leadership

### BOARD OF DIRECTORS

Timothy Dills, Chair  
Great Falls, VA

Beth Dean, Vice Chair  
Grayslake, IL

Rebecca Anhang Price, PhD, Secretary  
Chevy Chase, MD

Jim Maginn, Treasurer  
Manhattan Beach, CA

David Fitzmaurice, Immediate Past Chair  
Wyckoff, NJ

Martina Bebin, MD, MPA  
Athens, AL

John Bissler, MD  
Memphis, TN

Michael Caggiano  
McLean, VA

Cassandra Carroll  
Oakland, CA

Sara Chieffo  
Washington, DC

Margaret Cox  
Vestavia, AL

Andrew Duffy, Ex-Officio  
Toronto, ON

Bonnie Hogue Duffy  
Chevy Chase, MD

Tom Gwinn  
Parkland, FL

Laura Lubbers, PhD  
Perkasie, PA

Brendan Manning, PhD  
Boston, MA

David Michaels  
Scarsdale, NY

Darren Miles  
Edina, MN

Debora Moritz  
Scottsdale, AZ

Julie Scroggins  
Beach Park, IL

Matthew Simonian  
Humble, TX

### ENDOWMENT FUND BOARD OF DIRECTORS

Doug Loftus, Chair  
Cincinnati, OH

David Michaels, Secretary  
Scarsdale, NY

Rita DiDomenico, Treasurer  
Staten Island, NY

James Achterhof  
Palos Park, IL

Mark Carroll  
Saratoga, CA

### CORPORATE ADVISORY BOARD

Wilfred Cooper, Sr., Honorary Chair  
Chairman  
WNC & Associates

Julianne Moore, Honorary Chair

Orrin Devinsky, MD  
Director  
NYU Epilepsy Center

Gail Gershon  
Director, Employee Engagement  
Gap Foundation, Gap Inc.

Ken Kocher  
Former President  
LIDS Sports Group

Alan Marshall  
Director, Customer Engagement  
Greenwich Biosciences

Ted Mastroianni

MaryJane Mudd  
Principal  
MJM Communications

Sean C. Nolan  
President & CEO  
AveXis, Inc.

Henry Shapiro  
Chief Executive Officer  
MarketCast

John Thorpe Richards, Jr.  
Bogorad and Richards, PLLC

James S. Richter  
Partner  
Winston & Strawn LLP

Marc Shapses  
Executive Managing Director  
Savills Studley

Judy Shoulak  
CEO & Founder  
Relatively Speaking

### STAFF

Kari Luther Rosbeck  
President & Chief Executive Officer

Richard Gollub, CPA  
Controller & Chief Financial Officer

Steven Roberds, PhD  
Chief Scientific Officer

Christen Bell  
Conference Manager

Tori Bonn  
Administrative Assistant

Dani Brunner, PhD  
Senior Scientific Advisor/Preclinical  
Research Leader

April Cooper  
Director, Community Programs

Emebet Gmichael  
Senior Accountant

Calvin Ho, PhD  
Science Project Coordinator

Tyler Hoffman  
Database Project Manager

Dena Hook  
Vice President, Support Services

Jaye Isham  
Vice President, Communications Strategy

Daniel Klein  
Manager, Donor Relations

Shelly Meitzler  
Regional Program Manager, North

Lisa Moss  
Senior Director, Donor Relations

Jo Anne Nakagawa  
Director, Clinical Projects & TSC Clinic  
Liaison

Gail Saunders  
Senior Regional Program Manager, South

Julie Scroggins (As of January 8, 2018)  
Regional Program Manager, West

Katie Smith  
Manager, Research & Global Affairs



## COMMUNITY ALLIANCES

TS Alliance of Alabama

TS Alliance of Alaska  
Rebecca Racenet, Chair  
Erica Chilla, Vice Chair

TS Alliance of Arizona  
Debora Moritz, Chair

TS Alliance of Arkansas

TS Alliance of Connecticut  
Jennifer Waldron, Chair

TS Alliance of Dallas/Fort Worth  
Joy Graydon, Co-Chair  
Leslie Russell, Co-Chair

TS Alliance of Delaware/Lehigh Valley  
Liz Saadoun, Chair

TS Alliance of the Delta Region  
Heather Harden, Chair

TS Alliance of Florida  
Amy Hightower, Co-Chair  
Vanessa Vazquez, Co-Chair

TS Alliance of Georgia  
Wendi Scheck, Chair

TS Alliance of Greater Chicago  
Geri Greenberg, Chair

TS Alliance of Greater Kansas City  
Amy Dublinske, Chair

TS Alliance of Hawaii  
Trisha Kam, Chair

TS Alliance of the Heartland

TS Alliance of Houston  
Heather Little, Chair

TS Alliance of Indiana  
Laura Marlin, Chair

TS Alliance of the Intermountain West  
Kelli Sutherland, Vice Chair

TS Alliance of Kentucky/West Virginia  
Tammy Kouns, Co-Chair  
Melissa Pennington, Co-Chair

TS Alliance of Maryland  
Lauren Shillinger, Chair  
Kandace Shortt, Vice Chair

TS Alliance of Michigan  
Carly Kaye, Chair

TS Alliance of Nevada  
Kathleen Kingston, Co-Chair  
Tara Zimmerman, Co-Chair

TS Alliance of New England  
Allyson D'Amario, Chair

TS Alliance of New York/New Jersey  
Laura Marks, Co-Chair  
Rhiannon Schade, Co-Chair

TS Alliance of North Carolina  
Lindsey Miller, Chair

TS Alliance of Northern California  
Lilian Ansari, Co-Chair  
Jennifer Yeaman, Co-Chair

TS Alliance of Ohio  
Donnie Bilbrey, Chair

TS Alliance of Oklahoma  
April Bennett, Co-Chair  
Heather Lens, Co-Chair

TS Alliance of the Pacific Northwest  
Debbie Rothweiler, Chair

TS Alliance of the Rocky Mountain Region  
Dana Holinka, Chair

TS Alliance of South Carolina  
Amy Bredeson, Chair

TS Alliance of Southern California  
Tara Palage, Chair

TS Alliance of St. Louis/Southern Illinois

TS Alliance of Tennessee  
Kelly Vigil, Co-Chair  
Sheila Dodson, Co-Chair

TS Alliance of the Upper Midwest  
Alanna Spotts, Chair

TS Alliance of Washington, DC/Virginia  
Kathi Dills, Chair  
Adrienne Cohen, Vice Chair

TS Alliance of Western Pennsylvania  
Kelsey Hudson, Chair

TS Alliance of Wisconsin  
Kristin DeGueme, Chair

## ADULT REGIONAL COORDINATORS

Region 1: Washington, Oregon, Idaho,  
Montana, Wyoming, Alaska  
Rob and Shannon Grandia

Region 2: California, Arizona, Nevada,  
New Mexico, Utah  
Rob and Shannon Grandia

Region 3: Colorado, Nebraska, South  
Dakota, North Dakota, Iowa, Minnesota,  
Wisconsin  
Seth Fritts

Region 4: Texas, Oklahoma, Kansas,  
Missouri, Arkansas, Louisiana  
Jake Irby

Region 5: Illinois, Michigan, Indiana, Ohio,  
Pennsylvania  
Brooke Simsa

Region 6: Tennessee, Kentucky, Georgia,  
Alabama, Mississippi, Florida  
Mark Martin

Region 7: Connecticut, Vermont, Maine,  
Rhode Island, New Hampshire, New York,  
New Jersey, Massachusetts  
Scott Moskowitz

Region 8: Delaware, Virginia, West Virginia,  
Maryland, North Carolina, South Carolina,  
Washington DC  
Kathy Henkel

## PROFESSIONAL ADVISORY BOARD

E. Martina Bebin, MD, MPA, Chair  
University of Alabama at Birmingham  
Department of Neurology  
Birmingham, AL  
Specialty: Pediatric Neurology, Epilepsy

Mary Elizabeth Aronow, MD  
Massachusetts Eye & Ear Infirmary  
Boston, MA  
Specialty: Ophthalmology, Ophthalmic  
Oncology, Medical Retina

Stephen Ashwal, MD  
Loma Linda School of Medicine  
Department of Pediatrics  
Loma Linda, CA  
Specialty: Pediatric Neurology

John Bissler, MD  
St. Jude Pediatrics Research Hospital and  
University of Tennessee Health Science  
Center  
Division of Nephrology  
Memphis, TN  
Specialty: Pediatric Nephrology

Deborah Briggs, MD  
Seton Brain and Spine Institute  
Dell Medical School  
Neurology  
Austin, TX  
Specialty: Neurology, Epilepsy

Anna W. Byars, PhD  
Cincinnati Children's Hospital Medical  
Center  
Cincinnati, OH  
Specialty: Neuropsychology

Kevin Chapman, MD  
Children's Hospital Colorado  
Denver, CO  
Specialty: Pediatric Neurology & Epilepsy

Pei-Lung Chen, MD, PhD  
National Taiwan University Hospital  
Taipei City, Taiwan  
Specialty: Endocrinology, Metabolism

Harry T. Chugani, MD  
Nemours/Alfred I. duPont Hospital for Children  
Pediatric Neurology  
Wilmington, DE  
Specialty: Pediatric Neurology, Epilepsy

Elizabeth Jo Coombs, BSN, RN  
Pentec Health – Renal Nurse Educator  
Specialty: TSC Nurse Educator in Nephrology

Rohini Coorg, MD  
Texas Children's Hospital/ Baylor College of Medicine  
Pediatric Neurology  
Houston, TX  
Specialty: Pediatric Neurology, Epilepsy

Peter Crino, MD, PhD  
University of Maryland School of Medicine  
Department of Neurology  
Baltimore, MD  
Specialty: Adult Neurology, Epilepsy

Daniel Curry, MD  
Texas Children's Hospital / Baylor College of Medicine  
Department of Neurosurgery  
Houston, TX  
Specialty: Pediatric Neurosurgery

Steven DeRoos, MD  
Helen DeVos Children's Hospital  
Grand Rapids, MI  
Specialty: Pediatric Neurology, Pediatrics

Orrin Devinsky, MD  
NYU Langone Comprehensive Epilepsy Center  
New York, NY  
Specialty: Neurology, Epilepsy

Kira A. Dies, ScM, CGC  
Boston Children's Hospital  
Boston, MA  
Specialty: Genetic Counselor

Francis J. DiMario, Jr., MD  
Connecticut Children's Medical Center  
Division of Pediatric Neurology  
Farmington, CT  
Specialty: Pediatric Neurology, Pediatrics

Cornelia Drees, MD  
University Hospital Colorado  
Department of Neurology  
Aurora, CO  
Specialty: Neurology, Epilepsy

Michael S. Duchowny, MD  
Miami Children's Hospital  
Department of Neurology  
Miami, FL  
Specialty: Pediatric Neurology, Epilepsy

David W. Dunn, MD  
Riley Hospital for Children  
Indiana University School of Medicine  
Department of Neurology  
Indianapolis, IN  
Specialty: Pediatric Neurology, Psychiatry

Nancy J. Elling, RN, BSN, CPN  
Children's National Medical Center  
Department of Neurology  
Fairfax, VA  
Specialty: Nursing (Neurology, Epilepsy)

Kevin C. Ess, MD, PhD  
Vanderbilt University  
Department of Neurology  
Nashville, TN  
Specialty: Pediatric Neurology, Epilepsy

David H. Ewalt, MD  
Urology Clinic of North Texas  
Dallas, TX  
Specialty: Urological Surgery

Cristina Ferrone, MD  
Massachusetts General Hospital  
Boston, MA  
Specialty: Surgical Oncology

Francis M. Filloux, MD  
Primary Children's Hospital  
Salt Lake City, UT  
Specialty: Pediatric Neurology, Pediatrics

J. Robert Flamini, MD  
PANDA Neurology  
Atlanta, GA  
Specialty: Pediatric Neurology

David Neal Franz, MD  
Children's Hospital Medical Center  
Department of Neurology  
Cincinnati, OH  
Specialty: Pediatric Neurology, Epilepsy

Michael D. Frost, MD  
The Minnesota Epilepsy Group, P.A.  
Saint Paul, MN  
Specialty: Pediatric Neurology, Epilepsy

Souheil El-Chemaly, MD, MPH  
Brigham and Women's Hospital Boston  
Boston, MA  
Specialty: Pulmonology

Joao Garcia, MD  
Neural Clinic  
Merida, Yucatan, Mexico  
Specialty: Pediatric Neurology

Patricia A. Gibson, MSSW DHL ACSW  
Wake Forest University School of Medicine  
Baptist Medical Center  
Department of Neurology  
Comprehensive Epilepsy Information Service  
Winston Salem, NC  
Specialty: Social Work

Tal Gilboa, MD  
Hadassah Medical Center  
Jerusalem, ISRAEL  
Specialty: Pediatric Neurology, Developmental Pediatrics

Tanjala T. Gipson, MD  
The Boling Center at the University of Tennessee Health Science Center and LeBoheur Children's Hospital  
Memphis, TN  
Specialty: Pediatrics, Pediatric Neurology, Neurodevelopmental disabilities

Howard P. Goodkin, MD, PhD  
University of Virginia  
Departments of Neurology and Pediatrics  
Charlottesville, VA  
Specialty: Pediatric Neurology

Elizabeth Gosnell, DMD, MS  
Division of Pediatric Dentistry and Orthodontics  
Cincinnati Children's Hospital Medical Center  
Cincinnati, OH  
Specialty: Pediatric Dentistry

Joannes (Joop) Grevelink, MD, PhD  
Boston Dermatology & Laser Center  
Boston, MA  
Specialty: Dermatology

Ajay Gupta, MD  
Cleveland Clinic  
Department of Neurology  
Cleveland, OH  
Specialty: Pediatric Neurology, Epilepsy

Daphne Hasbani, MD, PhD  
St. Christopher's Hospital for Children  
Philadelphia, PA  
Specialty: Pediatric Neurology, Epilepsy

Elizabeth P. Henske, MD  
Brigham and Women's Hospital  
Harvard Medical School  
Boston, MA  
Specialty: Oncology, LAM

Collin Hovinga, PharmD, MS, FCCP  
Dell Children's Medical Center  
University of Texas Austin  
Austin, TX  
Specialty: Pharmacology, Epidemiology, Clinical Research

John Hulbert, MD  
Urologic Physicians, P.A.  
Edina, MN  
Specialty: Urological Surgery

Monica P. Islam, MD  
Nationwide Children's Hospital  
Ohio State University  
Columbus, OH  
Specialty: Pediatric Neurology

Laura A. Jansen, MD, PhD  
University of Virginia at Charlottesville  
Charlottesville, VA  
Specialty: Pediatric Neurology, Epilepsy



Anna Jeong, MD  
Ann & Robert H. Lurie Children's Hospital  
of Chicago  
Chicago, IL  
Specialty: Pediatric Neurology, Epilepsy

Shafali Spurling Jeste, MD  
UCLA Semel Institute/Neuropsychiatric  
Institute  
Los Angeles, CA  
Specialty: Developmental Neurology,  
Autism

Karen C. Keough, MD  
Dell Children's Medical Center  
Austin, TX  
Specialty: Pediatric Neurology, Epilepsy

Bryan H. King, MD  
Children's Hospital  
Department of Psychiatry  
Seattle, WA  
Specialty: Child Psychiatry

Mary Kay Koenig, MD  
University of Texas Health Science Center  
Houston, TX  
Specialty: Pediatric Neurology

Susan Koh, MD  
University of Colorado  
Division of Pediatric Neurology  
Denver, CO  
Specialty: Pediatric Neurology, Epilepsy

Michael Kohrman, MD  
Akron Children's Hospital  
Department of Neurology  
Akron, OH  
Specialty: Pediatric Neurology, Epilepsy,  
Sleep Medicine

Bruce Korf, MD, PhD  
University of Alabama Birmingham  
Birmingham, AL  
Specialty: Genetics, Neurology

Darcy A. Krueger, MD, PhD  
Cincinnati Children's Hospital Medical  
Center  
Cincinnati, OH  
Specialty: General Neurology, Tuberous  
Sclerosis Complex

Carrie L. Krupitsky, RN, FNP  
UCSF Benioff Children's Hospital Oakland  
Department of Neurology  
Oakland, CA  
Specialty: Family Nurse Practitioner

Rachel Kuperman, MD  
UCSF Benioff Children's Hospital Oakland  
Department of Neurology  
Oakland, CA  
Specialty: Pediatric Neurology, Epilepsy

David J. Kwiatkowski, MD, PhD  
Genetics Lab, Hematology Division  
Brigham and Women's Hospital  
Harvard Medical School  
Boston, MA  
Specialty: Genetic Research

Scheherazade Le, MD  
Stanford University and Clinics  
Department of Neurology  
Stanford, CA  
Specialty: Neurology, Epilepsy

Ki Hyeong Lee, MD  
Florida Hospital for Children  
Orlando, FL  
Specialty: Pediatric Neurology, Epilepsy

Aimee Luat, MD  
Children's Hospital Michigan  
Pediatric Neurology  
Detroit, MI  
Specialty: Pediatric Neurology, Epilepsy

Fatema Malbari, MD  
Children's Hospital at Montefiore  
Bronx, NY  
Specialty: Pediatric Neurology

Miguel A. Materin, MD  
Duke University Eye Center  
Durham, NC  
Specialty: Ophthalmic Oncology

Julie A. Matsumoto, MD, FACR  
Department of Radiology and Medical  
Imaging  
University of Virginia Health System  
Charlottesville, VA  
Specialty: Neuroradiology

William McClintock, MD  
Children's National Medical Center  
Department of Neurology  
Fairfax, VA  
Specialty: Pediatric Neurology

Frank McCormack, MD  
University of Cincinnati School of  
Medicine  
Pulmonary Division  
Cincinnati, OH  
Specialty: Pulmonology

Patricia E. McGoldrick, PNP, MPA  
Mount Sinai Beth Israel Roosevelt I  
New York, NY  
Specialty: Pediatric Nurse Practitioner  
(Neurology, Developmental Disabilities)

Kimberly Parker Menzer, ANP-BC, GNP-BC  
New York University Langone Medical  
Center  
New York, NY  
Specialty: Adult Primary Care and  
Gerontological Nurse Practitioner  
(Neurology, Epilepsy)

Anne Marie Michon, MSN, RN, CPNP-PC  
Beaumont Children's Hospital  
Department of Pediatric Epilepsy  
Royal Oak, MI  
Specialty: Certified Pediatric Nurse  
Practitioner, Pediatric Epilepsy

Ian O'Neil Miller, MD  
Miami Children's Hospital  
Department of Neurology  
Miami, FL  
Specialty: Pediatric Neurology, Epilepsy

Joel Moss, MD, PhD  
National Heart, Lung, and Blood Institute,  
National Institutes of Health  
Bethesda, MD  
Specialty: Pulmonology

Srishti Nangia, MD  
New York Presbyterian/Weill Cornell  
Medical Center  
Division of Child Neurology  
New York, NY  
Specialty: Pediatric Neurology, Epilepsy

Vinodh Narayanan, MD  
APNNA- Arizona Pediatric Neurology &  
Neurogenetics Associates  
Phoenix, AZ  
Specialty: Pediatric Neurology,  
Neurogenetics

Katherine L. Nathanson, MD  
University of Pennsylvania  
Department of Medicine  
Philadelphia, PA  
Specialty: Clinical Genetics

Hope Northrup, MD  
The University of Texas Medical School  
at Houston  
Department of Pediatrics, Division of  
Medical Genetics  
Houston, TX  
Specialty: Pediatrics, Genetics

Iris Noyman, MD  
Soroka Medical Center Affiliated with  
Ben Gurion University of the Negev  
Beer Sheva, Israel  
Specialty: Pediatric Neurology, Epilepsy

Patricia (Patti) Ogden, APN, MSN  
University of Chicago  
Department of Pediatric Neurology  
Chicago, IL  
Specialty: Nurse practitioner, Epilepsy,  
Vagus Nerve Stimulation (Interrogation,  
Programming)

Neha J. Patel, MD  
American Family Children's Hospital  
Madison, WI  
Specialty: Pediatric Neuro-oncology

Elahna Paul, MD, PhD  
Massachusetts General Hospital  
Pediatric Nephrology Associates  
Boston, MA  
Specialty: Pediatric Nephrology

M. Scott Perry, MD  
Cook Children's Hospital  
Department of Neurology  
Ft. Worth, TX  
Specialty: Pediatric Neurology

Donald J. Phillips, MD, MPH  
CHOC Children's Hospital  
Orange, CA  
Specialty: Pediatric Epilepsy, Neurology,  
Clinical Neurophysiology

Brenda E. Porter, MD, PhD  
Stanford University School of Medicine  
Division of Child Neurology  
Stanford, CA  
Specialty: Pediatric Neurology, Epilepsy

Rahmin A. Rabenou, MD  
Southern Arizona VA Healthcare System &  
University of Arizona School of Medicine  
Tucson, AZ  
Specialty: Nephrology

Surya P. Redman, MD  
Texas Children's Cancer & Hematology  
Centers  
Houston, TX  
Specialty: Hematology-Oncology

James J. Riviello, Jr, MD  
Texas Children's Hospital  
Section of Neurology and Developmental  
Neuroscience  
Houston, TX  
Specialty: Pediatric Neurology, Epilepsy

E. Steve Roach, MD  
Ohio State University  
Department of Neurology  
Columbus, OH  
Specialty: Pediatric Neurology

Robb Romp, MD  
Division of Pediatric Cardiology  
University of Alabama  
Children's Alabama  
Birmingham, AL  
Specialty: Pediatric Cardiology

Mustafa Sahin, MD, PhD Boston Children's  
Hospital  
Department of Neurology  
Boston, MA  
Specialty: Pediatric Neurology

Joshua A. Samuels, MD, MPH  
University of Texas Medical School at  
Houston  
Department of Pediatrics  
Houston, TX  
Specialty: Pediatric Nephrology,  
Hypertension

Joo Hee Seo, MD, MSc  
Florida Hospital for Children  
Orlando, FL  
Specialty: Pediatric Neurology, Epilepsy

W. Donald Shields, MD  
University of California, Los Angeles  
Division of Pediatric Neurology  
Los Angeles, CA  
Specialty: Pediatric Neurology, Epilepsy

Eric B. J. Ségal, MD  
Northeast Regional Epilepsy Group  
(NEREG) Comprehensive TS Clinic  
Hackensack, NJ  
Specialty: Pediatric Neurology, Epilepsy

Mary T. Silvia, MD  
Wake Forest Baptist Medical Center  
Department of Neurology  
Winston-Salem, NC  
Specialty: Pediatric Neurology, Clinical  
Neurophysiology, Epilepsy

Marcio A. Sotero de Menezes, MD  
Swedish Neuroscience Institute  
Pediatric Neuroscience Center  
Seattle, WA  
Specialty: Pediatric Neurology, Epilepsy

Steven P. Sparagana, MD  
Texas Scottish Rite Hospital for Children  
Department of Neurology  
Dallas, TX  
Specialty: Pediatric Neurology

Suzanne M. Strickland, MD  
Medical College of Georgia  
Georgia Regents University  
Department of Child Neurology  
Specialty: Pediatric Neurology, Epilepsy

Katherine Taub, MD  
Children's Hospital of Philadelphia (CHOP)  
Philadelphia, PA  
Specialty: Pediatric Neurology, Epilepsy

Joyce Teng, MD, PhD  
Lucile Packard Children's Hospital Stanford  
Palo Alto, CA  
Specialty: Dermatology

Elizabeth A. Thiele, MD, PhD  
Massachusetts General Hospital  
Department of Neurology  
Boston, MA  
Specialty: Pediatric Neurology, Epilepsy

James H. Tonsgard, MD  
The University of Chicago Medicine  
Comer Children's Hospital  
Chicago, IL  
Specialty: Pediatric Neurology

Lily Hoang Tran, MD  
Children's Hospital Orange County  
Orange, CA  
Specialty: Pediatric Neurology, Epilepsy

Doris A. Trauner, MD  
Rady Children's Hospital San Diego  
UC San Diego School of Medicine  
Specialty: Pediatric Neurology,  
Neurodevelopmental Disabilities

Michal Tzadok, MD  
Safra Children's Hospital  
Sheba Medical Center  
Tel Hashomer, ISRAEL  
Specialty: Pediatric Neurology

Katherine Van Poppel, MD  
Carolinas Pediatric Neurology Center-  
Concord  
Concord, NC  
Specialty: Pediatric Neurology, Epilepsy

Keith K. Vaux, MD  
Rady Children's Hospital San Diego  
Division of Medical Genetics  
San Diego, CA  
Specialty: Medical Genetics,  
Dysmorphology

Petrus J. de Vries, MBChB, MRCPsych, PhD  
University of Cape Town  
Department of Psychiatry and Mental  
Health  
Child & Adolescent Psychiatry  
Rondebosch, Cape Town  
South Africa  
Specialty: Developmental Neuropsychiatry

William G. Ward, MD  
Novant Health Orthopedics & Sports  
Medicine  
Winston-Salem, NC  
Specialty: Orthopedic Surgery

James W. Wheless, MD  
LeBonheur Children's Hospital  
Pediatric Neurology  
University of Tennessee  
Memphis, TN  
Specialty: Pediatric Neurology, Epilepsy

Howard Weiner, MD  
Texas Children's Hospital  
Baylor College of Medicine  
Department of Neurosurgery  
Houston, TX  
Specialty: Neurosurgery

Jacqueline Weissman, MD, MS  
Kennedy Krieger Institute  
Baltimore, MD  
Specialty: Pediatric Neurology,  
Neurodevelopmental disabilities

Shelley Williams, MD  
Children's Hospital  
Department of Neurology  
Pittsburgh, PA  
Specialty: Pediatric Neurology, Epilepsy

David S. Wolf, MD, PhD  
Children's Healthcare of Atlanta/Emory  
University  
Atlanta, GA  
Specialty: Pediatric Neurology, Neuro-  
Oncology



Steven M. Wolf, MD  
Mount Sinai Beth Israel Roosevelt  
New York, NY  
Specialty: Pediatric Neurology, Epilepsy

Matthew Wong, MD  
Wake Forest Baptist Medical Center  
Department of Neurology  
Winston-Salem, NC  
Specialty: Neurology, Clinical Neurophysiology, Epilepsy

Michael Wong, MD, PhD  
Washington University School of Medicine  
Department of Neurology  
St. Louis, MO  
Specialty: Pediatric Neurology, Epilepsy

Joyce Y. Wu, MD  
University of California, Los Angeles  
Division of Pediatric Neurology  
Los Angeles, CA  
Specialty: Pediatric Neurology, Epilepsy

Raymond Yeung, MD  
University of Washington School of Medicine  
Division of Surgery and Medical Genetics  
Seattle, WA  
Specialty: Surgery-Oncology

Kai-Feng Xu, MD  
Peking Union Medical College Hospital  
Division of Respiratory Medicine  
Beijing, China  
Specialty: Pulmonology

Lisa R. Young, MD  
Vanderbilt University  
Nashville, TN  
Specialty: Pediatric Pulmonology

Mary L. Zupanc, MD  
Children's Hospital Orange County  
Orange, CA  
Specialty: Pediatric Neurology, Epilepsy

## INTERNATIONAL SCIENTIFIC ADVISORY BOARD

Brendan Manning, PhD, Chair  
Department of Genetics and Complex Disease  
Harvard School of Public Health  
Boston, MA

John Blenis, PhD  
Department of Pharmacology  
Weill Cornell Medical College  
New York, NY

Peter Crino, MD, PhD  
Department of Neurology  
University of Maryland School of Medicine  
Baltimore, MD

Howard Goodkin, MD, PhD  
Department of Neurology  
University of Virginia  
Charlottesville, VA

Luciana Amaral Haddad, MD, PhD  
Departamento de Genética e Biologia Evolutiva  
Universidade de São Paulo  
São Paulo, Brazil

Elizabeth Petri Henske, MD  
Brigham and Women's Hospital  
Harvard Medical School  
Boston, MA

Gregory Holmes, MD  
Chair, Department of Neurological Sciences  
University of Vermont School of Medicine  
Burlington, VT

Chris Kingswood, MD  
Brighton & Sussex University Hospitals Trust  
Renal Unit  
Brighton, UK

David Kwiatkowski, MD, PhD  
Professor of Medicine  
Brigham & Women's Hospital & Harvard Medical School  
Boston, MA

David Mowat MBBS, MRCGP, DRACOG, FRACP  
Senior Staff Specialist  
Clinical Geneticist  
Sydney Children's Hospital  
Sydney, Australia

Hope Northrup, MD  
Professor of Pediatrics  
Director, Division of Medical Genetics  
University of Texas-Houston  
Houston, TX

Mustafa Sahin, MD, PhD  
Department of Neurology  
Children's Hospital/Harvard  
Boston, MA

Julian Sampson, DM, DM, FRCP, FMedSci  
Professor and Head of Department,  
Medical Genetics  
Institute of Medical Genetics  
Wales College of Medicine  
Cardiff University  
Cardiff, Wales, UK

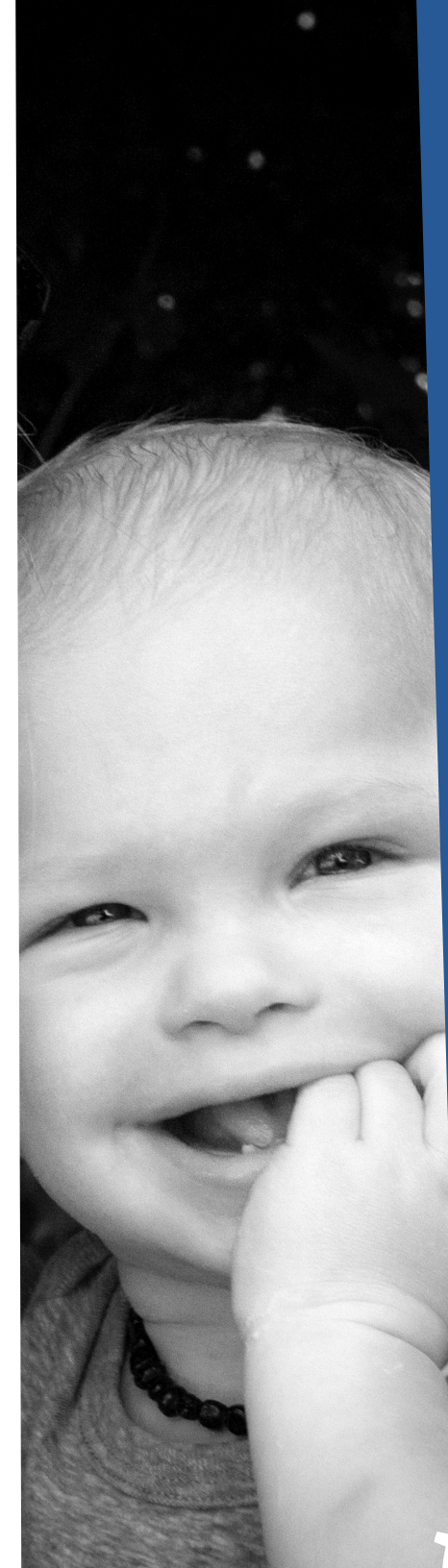
Andrew Tee, PhD  
Medical Genetics  
Institute of Medical Genetics  
Wales College of Medicine  
Cardiff University  
Cardiff, Wales, UK

Petrus J. de Vries, MBChB, MRCPsych, PhD  
Sue Struengmann Professor of Child and Adolescent Psychiatry  
University of Cape Town  
Rondebosch, Cape Town, South Africa

Michael Wong, MD, PhD  
Department of Neurology  
Washington University School of Medicine  
St. Louis, MO

Raymond Yeung, MD  
Department of Surgery  
University of Washington  
Seattle, WA

Hongbing Zhang, MD, PhD  
Institute of Basic Medical Sciences  
Chinese Academy of Medical Sciences  
Peking Union Medical College  
Beijing, China

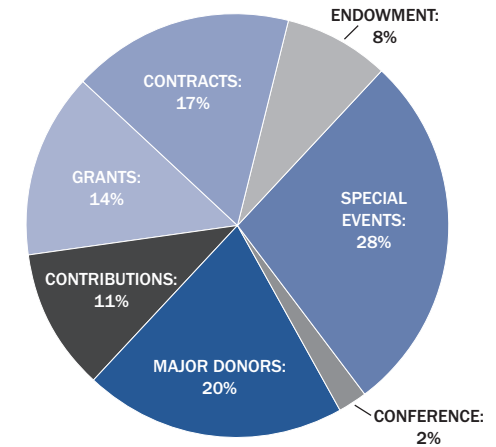


## National Tuberous Sclerosis Association & Affiliate

### Consolidated Statements of Financial Position

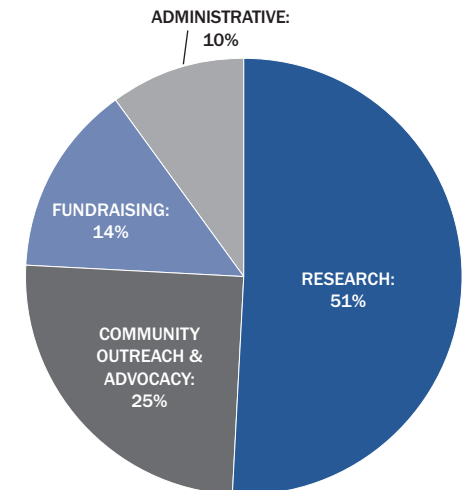
As of December 31,	2017	2016
<b>Assets</b>		
Current Assets		
Cash and cash equivalents	\$ 1,537,343	\$ 1,975,799
Short-term investments	807,688	779,808
Accounts receivable	278,373	262,025
Promises to give, current portion	746,536	683,294
Prepaid expenses and other assets	346,526	182,942
Total current assets	3,716,466	3,883,868
Long-term investments	5,689,777	5,214,829
Property and equipment (net)	186,001	190,332
Promises to give – non-current portion	242,763	797,694
<b>Total Assets</b>	<b>\$ 9,835,007</b>	<b>\$ 10,086,723</b>
<b>Liabilities and Net Assets</b>		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	\$ 258,028	\$ 320,774
Accrued compensation	214,661	203,109
Deferred rent and lease incentive – current portion	25,206	22,318
Gift annuity obligations – current portion	12,530	12,530
Deferred revenue – current portion	167,293	39,476
Total current liabilities	677,718	598,207
Deferred rent and lease incentive – non-current portion	35,378	60,584
Gift annuity obligations – non-current portion	65,131	69,228
Deferred revenue – non-current portion	–	92,500
Total liabilities	778,227	820,519
Net assets		
Unrestricted		
Undesignated	623,862	520,953
Designated	5,352,087	4,782,158
Total unrestricted	5,975,949	5,303,111
Temporarily restricted	2,201,387	3,083,649
Permanently restricted	879,444	879,444
Total net assets	9,056,780	9,266,204
<b>Total liabilities and net assets</b>	<b>\$ 9,835,007</b>	<b>\$ 10,086,723</b>

## Operating Revenue Sources 2017



NOTE: These are the stand-alone revenues of the TS Alliance.

## Operating Expenses 2017



NOTE: These are the stand-alone expenses of the TS Alliance.

The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year's auditors completed their 2017 audit and submitted an unmodified opinion to the TS Alliance Board of Directors. The complete audited financials are on file with the TS Alliance or are available on its website. To obtain a copy, please call (800) 225-6872 or download at [www.tsalliance.org](http://www.tsalliance.org). This summary was prepared from the audited consolidated statements of the TS Alliance and the TS Alliance Endowment Fund. The relationship of the organizations requires consolidation per generally accepted accounting principles in the United States. Supporting services reflected in the consolidated statement of activities include services for both the TS Alliance and the TS Alliance Endowment Fund. The Endowment Fund may experience gains or losses on its investments. In both 2017 and 2016 there was a net gain, contributing to the total change in net assets on a consolidated basis for each of those years. On a stand alone basis, operations of the TS Alliance generated a negative change in net assets of \$(570,990) in 2017 and a positive change of \$315,122 in 2016.

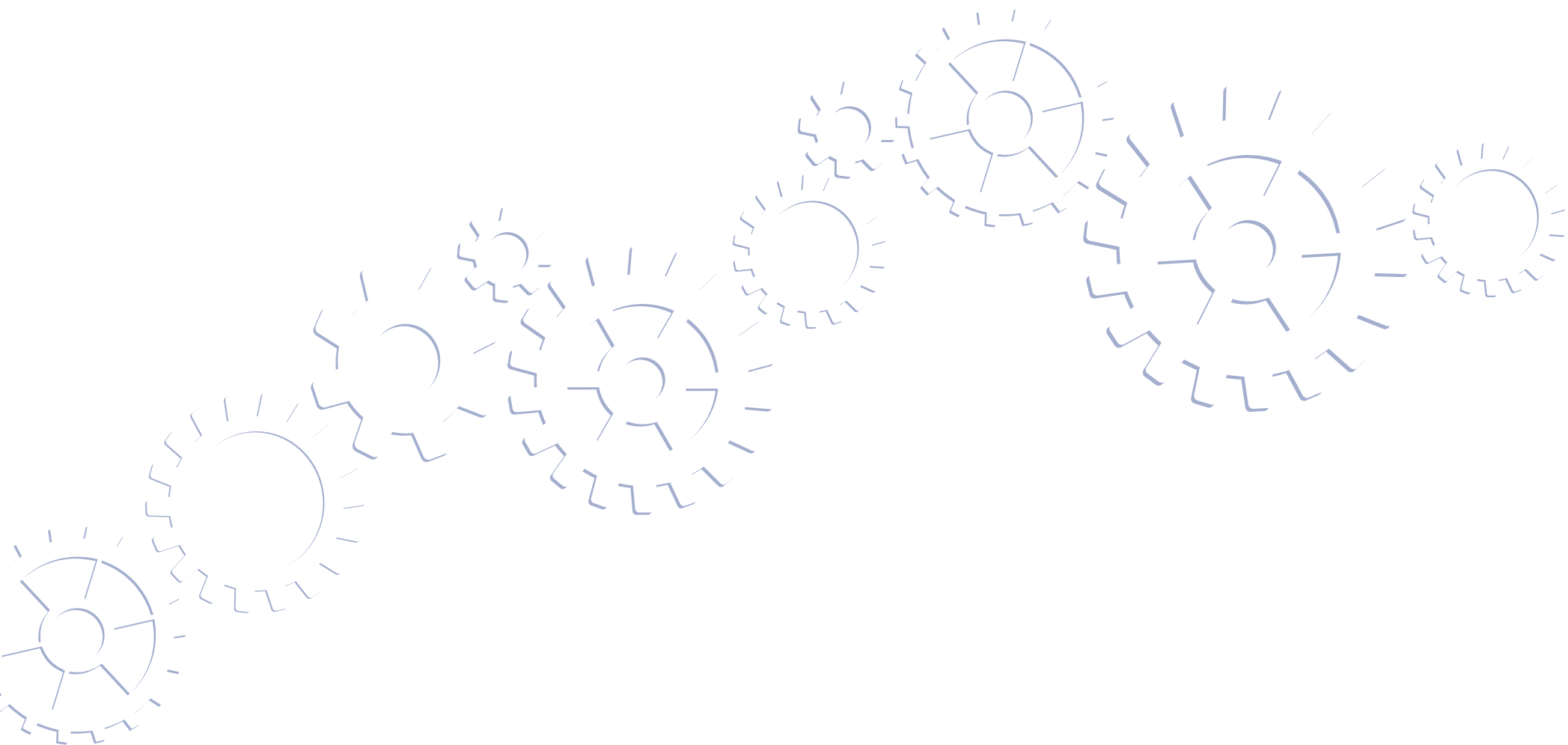
# National Tuberous Sclerosis Association & Affiliate

## Consolidated Statements of Activities

	Unrestricted	Temporarily Restricted	Permanently Restricted	2017 Total	2016 Total
<b>Revenue and Support</b>					
Special Events	\$ 1,418,146	\$ 81,429	\$ -	\$ 1,499,575	\$ 1,451,759
Cost of direct benefits to donors	(175,616)			(175,616)	(120,399)
Special events, net	1,242,530	81,429	-	1,323,959	1,331,360
Contributions	885,192	1,163,950		2,049,142	3,183,313
Contracts	824,241			824,241	629,254
Interest and dividends	152,166	27,177		179,343	117,848
Memorials and honoraria	103,914	1,815		105,729	69,384
Sponsorships	86,865			86,865	
Federated funding	45,150			45,150	39,193
Other income	885			885	2,351
Loss on disposal of fixed assets	-			-	(1,900)
Net assets released from restrictions	2,248,172	(2,248,172)		-	-
<b>Total revenue and support</b>	<b>5,589,115</b>	<b>(973,801)</b>	<b>-</b>	<b>4,615,314</b>	<b>5,370,803</b>
<b>Expenses</b>					
Program activities					
Research	2,745,515			2,745,515	2,469,977
Family services	801,081			801,081	805,022
Public health education	322,284			322,284	293,296
Government relations	147,996			147,996	146,913
Professional education	82,183			82,183	64,997
<b>Total program activities</b>	<b>4,099,059</b>	<b>-</b>	<b>-</b>	<b>4,099,059</b>	<b>3,780,205</b>
Supporting services					
Fundraising	761,427			761,427	640,458
Management and general	534,994			534,994	528,105
<b>Total supporting services</b>	<b>1,296,421</b>	<b>-</b>	<b>-</b>	<b>1,296,421</b>	<b>1,168,563</b>
<b>Total expenses</b>	<b>5,395,480</b>	<b>-</b>	<b>-</b>	<b>5,395,480</b>	<b>4,948,768</b>
Change in net assets from operations	193,635	(973,801)	-	(780,166)	422,035
Net gain (loss) on investments	479,203	91,539		570,742	423,558
<b>Change in net assets</b>	<b>672,838</b>	<b>(882,262)</b>	<b>-</b>	<b>(209,424)</b>	<b>845,593</b>
Net assets, beginning of year	5,303,111	3,083,649	879,444	9,266,204	8,420,611
<b>Net assets, end of year</b>	<b>\$ 5,975,949</b>	<b>\$ 2,201,387</b>	<b>\$ 879,444</b>	<b>\$ 9,056,780</b>	<b>\$ 9,266,204</b>



**WE'LL GIVE EVERYTHING. BUT UP.**



801 ROEDER ROAD, SUITE 750  
SILVER SPRING, MARYLAND 20910  
800.225.6872  
301.562.9890  
[WWW.TSALLIANCE.ORG](http://WWW.TSALLIANCE.ORG)