Unity is strength...
when there is TEAMWORK
and
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—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 lives 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 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).

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
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) 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.

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 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, 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.

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.

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

SUE SHERMAN, CHIEF EXECUTIVE OFFICER, THE LAM FOUNDATION
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 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.

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.

Amy Brin Miller, MSN, MA, APRN-BC, ACHPN, Executive Director, Child Neurology Foundation

Child Neurology Foundation
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.

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 (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 Defense Appropriations Act at $6 million.

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.

PETER BURNS, CEO, THE ARC OF THE UNITED STATES

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

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

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
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.

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
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.


**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 – Debra 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 – Tresia 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

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($100,000 and Above)

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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

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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.

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($25,000 - $99,999)

Andrea Hall and the late Keith Hall
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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:

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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:

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

*Deceased
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Rob and Shannon Grandia

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Specialty: Pediatric Neurology

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Dell Medical School
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Cincinnati, OH
Specialty: Neuropsychology

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Denver, CO
Specialty: Pediatric Neurology & Epilepsy

Pei-Lung Chen, MD, PhD
National Taiwan University Hospital
Taipei City, Taiwan
Specialty: Endocrinology, Metabolism
<table>
<thead>
<tr>
<th>Name</th>
<th>Specialty</th>
<th>Location</th>
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<tbody>
<tr>
<td>Harry T. Chugani, MD</td>
<td>Pediatric Neurology</td>
<td>Wilmington, DE</td>
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<tr>
<td>Elizabeth Jo Coombs, BSN, RN</td>
<td>Speciality: Pediatric Neurology, Epilepsy</td>
<td>Farmington, CT</td>
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<tr>
<td>Peter Crino, MD, PhD</td>
<td>University of Maryland School of Medicine</td>
<td>Baltimore, MD</td>
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<tr>
<td>Steven DeRoos, MD</td>
<td>Department of Neurosurgery</td>
<td>Houston, TX</td>
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<tr>
<td>David W. Dunn, MD</td>
<td>Riley Hospital for Children</td>
<td>Indianapolis, IN</td>
</tr>
<tr>
<td>Nancy J. Elling, RN, BSN, CPN</td>
<td>Children's National Medical Center Department of Neurology</td>
<td>Virginia, VA</td>
</tr>
<tr>
<td>Kevin C. Ess, MD, PhD</td>
<td>Vanderbilt University Department of Neurology</td>
<td>Nashville, TN</td>
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<tr>
<td>David H. Ewalt, MD</td>
<td>Urology Clinic of North Texas</td>
<td>Dallas, TX</td>
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<tr>
<td>Cristina Ferrone, MD</td>
<td>Massachusetts General Hospital Department of Surgery</td>
<td>Boston, MA</td>
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<tr>
<td>Francis M. Filloux, MD</td>
<td>Primary Children's Hospital Salt Lake City, UT</td>
<td>Salt Lake City, UT</td>
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<tr>
<td>J. Robert Flamin, MD</td>
<td>PANDA Neurology</td>
<td>Atlanta, GA</td>
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<tr>
<td>Cornelia Drees, MD</td>
<td>University Hospital Colorado Department of Neurology</td>
<td>Aurora, CO</td>
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<tr>
<td>Michael S. Duchowny, MD</td>
<td>Miami Children's Hospital Department of Neurology</td>
<td>Miami, FL</td>
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<tr>
<td>Michael D. Frost, MD</td>
<td>The Minnesota Epilepsy Group, P.A.</td>
<td>Saint Paul, MN</td>
</tr>
<tr>
<td>Souheil El-Chemaly, MD, MPH</td>
<td>Brigham and Women's Hospital</td>
<td>Boston, MA</td>
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<tr>
<td>Joao Garcia, MD</td>
<td>Merida, Yucatan, Mexico</td>
<td>Speciality: Pediatric Neurology</td>
</tr>
<tr>
<td>Patricia A. Gibson, MSSW DHL ACSW</td>
<td>Wake Forest University School of Medicine Baptist Medical Center</td>
<td>Winston Salem, NC</td>
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<tr>
<td>Tanjala T. Gipson, MD</td>
<td>The Boling Center at the University of Tennessee Health Science Center and LeBoheur Children's Hospital Memph, TN</td>
<td>Howard P. Goodkin, MD, PhD University of Virginia Departments of Neurology and Pediatrics Charlottesville, VA</td>
</tr>
</tbody>
</table>
Anna Jeong, MD
Ann & Robert H. Lurie Children's Hospital of Chicago
Chicago, IL
Specialty: Pediatric Neurology, Epilepsy

Shafali Spurling Jeste, MD
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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

<table>
<thead>
<tr>
<th>Assets</th>
<th>2017</th>
<th>2016</th>
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<tbody>
<tr>
<td><strong>Current Assets</strong></td>
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<tr>
<td>Cash and cash equivalents</td>
<td>$1,537,343</td>
<td>$1,975,799</td>
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<td>Short-term investments</td>
<td>807,688</td>
<td>779,808</td>
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<td>Accounts receivable</td>
<td>278,373</td>
<td>262,025</td>
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<tr>
<td>Promises to give, current portion</td>
<td>746,536</td>
<td>683,294</td>
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<tr>
<td>Prepaid expenses and other assets</td>
<td>346,526</td>
<td>182,942</td>
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<tr>
<td><strong>Total current assets</strong></td>
<td>3,716,466</td>
<td>3,883,868</td>
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<td><strong>Long-term investments</strong></td>
<td>5,689,777</td>
<td>5,214,829</td>
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<tr>
<td><strong>Property and equipment (net)</strong></td>
<td>186,001</td>
<td>190,332</td>
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<tr>
<td>Promises to give — non-current portion</td>
<td>242,763</td>
<td>797,694</td>
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<tr>
<td><strong>Total Assets</strong></td>
<td>$9,835,007</td>
<td>$10,086,723</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Liabilities and Net Assets</th>
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</thead>
<tbody>
<tr>
<td><strong>Liabilities</strong></td>
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<tr>
<td>Current liabilities</td>
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<tr>
<td>Accounts payable and accrued expenses</td>
<td>$258,028</td>
<td>$320,774</td>
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<tr>
<td>Accrued compensation</td>
<td>214,661</td>
<td>203,109</td>
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<tr>
<td>Deferred rent and lease incentive – current portion</td>
<td>25,206</td>
<td>22,318</td>
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<tr>
<td>Gift annuity obligations – current portion</td>
<td>12,530</td>
<td>12,530</td>
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<td>Deferred revenue – current portion</td>
<td>167,293</td>
<td>39,476</td>
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<td><strong>Total current liabilities</strong></td>
<td>677,718</td>
<td>598,207</td>
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<tr>
<td>Deferred rent and lease incentive – non-current portion</td>
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<td>60,584</td>
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<tr>
<td>Gift annuity obligations – non-current portion</td>
<td>65,131</td>
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<td>Deferred revenue – non-current portion</td>
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<td>92,500</td>
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<td><strong>Total liabilities</strong></td>
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<td>820,519</td>
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<td><strong>Net assets</strong></td>
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<tr>
<td>Unrestricted</td>
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<td>Undesignated</td>
<td>623,862</td>
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<td>Designated</td>
<td>5,352,087</td>
<td>4,782,158</td>
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<td><strong>Total unrestricted</strong></td>
<td>5,975,949</td>
<td>5,303,111</td>
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<td>Temporarily restricted</td>
<td>2,201,387</td>
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<td>Permanently restricted</td>
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<td>879,444</td>
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<tr>
<td><strong>Total net assets</strong></td>
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<td>9,266,204</td>
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<thead>
<tr>
<th>Total liabilities and net assets</th>
<th>2017</th>
<th>2016</th>
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<tbody>
<tr>
<td></td>
<td>$9,835,007</td>
<td>$10,086,723</td>
</tr>
</tbody>
</table>

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. 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.

Operating Revenue Sources 2017

- FUNDRAISING: 14%
- COMMUNITY OUTREACH & ADVOCACY: 28%
- RESEARCH: 51%
- MAJOR DONORS: 20%
- SPECIAL EVENTS: 11%
- CONTRACTS: 17%
- ENDOWMENT: 8%
- GRANTS: 14%
- ADMINISTRATIVE: 10%
- CONFERENCES: 2%
- CONTRIBUTIONS: 11%
- FUNDRAISING: 24%

Operating Expenses 2017

- FUNDRAISING: 14%
- COMMUNITY OUTREACH & ADVOCACY: 25%
- RESEARCH: 51%
- MAJOR DONORS: 20%
- SPECIAL EVENTS: 11%
- CONTRACTS: 17%
- ENDOWMENT: 8%
- GRANTS: 14%
- ADMINISTRATIVE: 10%
- CONFERENCES: 2%
- CONTRIBUTIONS: 11%
### Consolidated Statements of Activities

#### Revenue and Support

<table>
<thead>
<tr>
<th>Source of Revenue</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>2017 Total</th>
<th>2016 Total</th>
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<tbody>
<tr>
<td>Special Events</td>
<td>$1,418,146</td>
<td>$81,429</td>
<td>-$</td>
<td>$1,499,575</td>
<td>$1,451,759</td>
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<tr>
<td>Cost of direct benefits to donors</td>
<td>(175,616)</td>
<td>(175,616)</td>
<td>(120,399)</td>
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<td>Special events, net</td>
<td>1,242,530</td>
<td>81,429</td>
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<td>1,323,959</td>
<td>1,331,360</td>
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<td>Contributions</td>
<td>885,192</td>
<td>1,163,950</td>
<td>2,049,142</td>
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<td>Contracts</td>
<td>824,241</td>
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<td>629,254</td>
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<td>Interest and dividends</td>
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<td>27,177</td>
<td>179,343</td>
<td>117,848</td>
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<tr>
<td>Memorials and honoraria</td>
<td>103,914</td>
<td>1,815</td>
<td>105,729</td>
<td>69,384</td>
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<td>Sponsorships</td>
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<td>Federated funding</td>
<td>45,150</td>
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<td>45,150</td>
<td>39,193</td>
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<tr>
<td>Other income</td>
<td>885</td>
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<td>885</td>
<td>2,351</td>
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<tr>
<td>Loss on disposal of fixed assets</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>(1,900)</td>
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<tr>
<td>Net assets released from restrictions</td>
<td>2,248,172</td>
<td>(2,248,172)</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td><strong>Total revenue and support</strong></td>
<td>5,589,115</td>
<td>(973,801)</td>
<td>-</td>
<td>4,615,314</td>
<td>5,370,803</td>
</tr>
</tbody>
</table>

#### Expenses

<table>
<thead>
<tr>
<th>Category</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>2017 Total</th>
<th>2016 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>2,745,515</td>
<td></td>
<td></td>
<td>2,745,515</td>
<td>2,469,977</td>
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<tr>
<td>Family services</td>
<td>801,081</td>
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<td></td>
<td>801,081</td>
<td>805,022</td>
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<td>Public health education</td>
<td>322,284</td>
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<td>322,284</td>
<td>293,296</td>
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<tr>
<td>Government relations</td>
<td>147,996</td>
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<td>147,996</td>
<td>146,913</td>
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<tr>
<td>Professional education</td>
<td>82,183</td>
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<td>82,183</td>
<td>64,997</td>
</tr>
<tr>
<td><strong>Total program activities</strong></td>
<td>4,099,059</td>
<td>-</td>
<td>-</td>
<td>4,099,059</td>
<td>3,780,205</td>
</tr>
<tr>
<td>Supporting services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fundraising</td>
<td>761,427</td>
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<td>761,427</td>
<td>640,458</td>
</tr>
<tr>
<td>Management and general</td>
<td>534,994</td>
<td></td>
<td></td>
<td>534,994</td>
<td>528,105</td>
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<tr>
<td><strong>Total supporting services</strong></td>
<td>1,296,421</td>
<td>-</td>
<td>-</td>
<td>1,296,421</td>
<td>1,168,563</td>
</tr>
<tr>
<td><strong>Total expenses</strong></td>
<td>5,395,480</td>
<td>-</td>
<td>-</td>
<td>5,395,480</td>
<td>4,948,768</td>
</tr>
<tr>
<td>Change in net assets from operations</td>
<td>193,635</td>
<td>(973,801)</td>
<td>-</td>
<td>(780,166)</td>
<td>422,035</td>
</tr>
<tr>
<td>Net gain (loss) on investments</td>
<td>479,203</td>
<td>91,539</td>
<td>570,742</td>
<td>423,558</td>
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</tr>
<tr>
<td><strong>Change in net assets</strong></td>
<td>672,838</td>
<td>(882,262)</td>
<td>(209,424)</td>
<td>845,593</td>
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<tr>
<td>Net assets, beginning of year</td>
<td>5,303,111</td>
<td>3,083,649</td>
<td>879,444</td>
<td>9,266,204</td>
<td>8,420,611</td>
</tr>
<tr>
<td><strong>Net assets, end of year</strong></td>
<td>$5,975,949</td>
<td>$2,201,387</td>
<td>$879,444</td>
<td>$9,056,780</td>
<td>$9,266,204</td>
</tr>
</tbody>
</table>
WE’LL GIVE EVERYTHING. BUT UP.