



# knowledge inspiration unity

ANNUAL  
REPORT  
2018





# Knowledge. Inspiration. Unity.

When the Tuberous Sclerosis Alliance (TS Alliance) began planning the 2018 World TSC Conference, the staff came together to brainstorm a theme for the conference and framed the discussion around this question: What do we want attendees to have gained by attending? After much discussion, we kept coming back to three words: knowledge, inspiration and unity.

If by the end of those four days families and individuals affected by tuberous sclerosis complex (TSC) left empowered with the knowledge needed to receive the highest quality of care available, if they were struck by inspiration because they can see the breakthroughs on the horizon, and if they feel a sense of unity because they realize they do not have to fight this disease alone, but rather are part of a global community, then we have made a tangible difference in their lives. By those standards the conference was a resounding success.

But these aims extend well beyond this one conference – they are foundational to our strategic vision for how to improve the lives of everyone affected by TSC and are reflected in many of the accomplishments throughout 2018. We invested in research to expand our **knowledge** of the disease and accelerate new treatments. We sought **inspiration** from others, continuing to collaborate and form new partnerships that extend our ability to offer support. And we fostered **unity** amongst our incredible corps of volunteers who make everything we do possible.

## Some 2018 highlights include:

- In May, the TS Alliance signed a global agreement with the TS Alliance of India. The TS Alliance now has six global partnerships, including TS Alliance of Israel, TS Canada ST, TS Alliance of Mexico, TS Alliance Foundation (in Thailand), Hungarian Foundation for Tuberous Sclerosis, and TS Alliance of India.
- Three pharmaceutical companies joined the Preclinical Consortium in 2018, bringing the total since inception to nine industry partners, seven of whom remain active members. The TSC Preclinical Research Consortium ran 12 studies to test 10 compounds in 2018, compared to 10 studies and 8 compounds in 2017.
- Over the course of the year, the TS Alliance facilitated 24,852 peer-to-peer supports from Adult Regional Coordinators, Clinic Ambassadors, Dependent Adult Transition Resource Coordinators, Education Parent Mentors, and Community Alliances through the TSC Connect Program.
- The TS Alliance participated in and presented at 38 professional meetings and 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.
- More than 100 members of the TSC community came together for our annual March on the Hill to advocate for continued funding for the Tuberous Sclerosis Complex Research Program (TSCR), securing a \$6 million appropriation for FY2019 and bringing the cumulative funding to \$83 million since 2002.

- In partnership with the Infantile Spasms Action Network the TS Alliance again heavily promoted Infantile Spasms Awareness Week. This awareness campaign included targeted social media outreach and a satellite radio tour, which gained coverage reaching a potential audience of 1.8 million. Additional news releases reached another 76.1 million people.

This report provides an overview of the organization's efforts and achievements in 2018. With the incredible support from our partners and community we continue to redefine what is possible. We have set even more ambitious goals because we know that together we can positively change the lives of those affected, we are inspired by a community who reflect the mantra "give everything, but up" every day, and we are united behind our ultimate goal of finding a cure for TSC.

## What is Tuberous Sclerosis Complex?

Tuberous sclerosis complex (TSC) is a genetic disorder that causes tumors to form in vital organs, primarily in the brain, eyes, heart, kidneys, skin and lungs. TSC is also the leading genetic cause of both autism and epilepsy.

The aspects of TSC that most strongly impact quality of life are generally associated with the brain: seizures, developmental delay, intellectual disability and autism. However, many people with TSC are living independent, healthy lives and enjoying challenging professions such as doctors, lawyers, educators and researchers. The incidence and severity of the various aspects of TSC can vary widely between individuals—even between identical twins.

As a genetic disorder, TSC can be inherited from one parent with the disease or can result from a spontaneous genetic mutation. Children have a 50 percent chance of inheriting TSC if one of their parents has this condition. At this point, only one-third of TSC cases are known to be inherited. The other two-thirds result from a spontaneous and unpredictable mutation occurring during conception or very early development of the human embryo.

At least two children born each day in the United States will have tuberous sclerosis complex. Current estimates place TSC-affected births at one in 6,000. Nearly 1 million people worldwide are estimated to have TSC, with approximately 50,000 in the United States. Many cases may remain undiagnosed for years or decades due to the relative obscurity of the disease and the mild form symptoms may take in some people.

While there is no cure, ongoing research into the TSC may lead to a better understanding of other diseases like cancer, autism and epilepsy. Because of TSC's genetic pathway, it is considered a linchpin disease, meaning every dollar spent funding cures and treatments for TSC may also bring about leaps in our understanding of these other diseases as well.

## About the Tuberous Sclerosis Alliance

The Tuberous Sclerosis Alliance (TS Alliance) is the only national organization dedicated to finding a cure for tuberous sclerosis complex while improving the lives of those affected. Founded in 1974, the organization has since become an international leader in providing support services and resource information; creating and implementing public and professional educational programs to increase awareness of the disease; and funding and driving research.

Our story is one of determination and devotion—an unyielding determination to help bring about better treatments and a cure for TSC and an intense devotion to all those who share this battle with us. Individuals and families. Health care professionals. Medical researchers. Friends and family. Everyone who has a stake in this fight can multiply his or her impact by linking arms and working together to bring this disease to the brink of a breakthrough.

The TS Alliance was founded on the core belief that community is a sustaining strength in the face of difficult challenges. In 1974 four mothers who shared the common bond of tuberous sclerosis complex came together to provide fellowship, generate awareness, pursue more knowledge and offer hope to each other. That was the birth of the Tuberous Sclerosis Alliance, and the spirit and intention of those founders permeate everything we do to this day.

## 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, the TS Alliance research program funds research focused on TSC proposed by researchers and aligned with the organization's mission. The TS Alliance builds and fosters collaborations between basic and clinical researchers by collecting and distributing TSC natural history data and biosamples, through collaborative preclinical and clinical research programs, and by hosting biennial International TSC Research Conferences.



The TS Alliance has funded more than \$20.7 million in research grants on TSC since 1984. Through the **research grants program**, applications can be submitted for postdoctoral fellowships and research grants. Grants are reviewed in a three-step process: (1) all grant applications are reviewed by a committee comprised of scientists knowledgeable about the topic area for scientific merit and of adults affected by TSC for potential impact on the lives of those affected by TSC; (2) the Science and Medical Committee of the Board of Directors evaluates the grant review committee's recommendations and the relevance of the applications to the TS Alliance's funding priorities; and (3) the Board of Directors then reviews the recommendations of the Science and Medical Committee and makes final approval for funding.

A total of 13 research awards were funded during 2018. The Board of Directors approved funding to begin in 2018 for four major research projects: (1) Dr. You Feng (Brigham and Women's Hospital) to study dysregulated phosphatidylcholine metabolism in TSC and LAM pathogenesis and therapy; (2) Dr. Christine Ochoa Escamilla (University of Texas Southwestern Medical School) for a postdoctoral fellowship to study neural circuits underlying autism-related behaviors in TSC;



(3) Dr. Angélique Bordey (Yale University) to study non-cell autonomous effects in TSC brain malformations; and (4) Dr. Alan Dombkowski (Wayne State University) to study the role of exosomes in epilepsy of TSC.

The TS Alliance also funded four seed grants in response to a call for proposals to utilize biosamples and data in the TSC Biosample Repository and Natural History Database: (1) Dr. Laura Farach (University of Texas Health Science Center at Houston) for developing a genetic risk prediction model for epilepsy in patients with TSC; (2) Dr. Hilaire Lam (Brigham and Women's Hospital) to study mitochondrial DNA heteroplasmy in the pathogenesis and therapy of TSC; (3) Dr. Joana Marques (University of Porto Faculty of Medicine) to study epigenetic and transcriptional analysis of TSC2 in leukocyte DNA from TSC patients; and (4) Dr. Jane Yu (University of Cincinnati) for quantification of plasma levels of sphingolipids and ceramides in patients with TSC.

Also in 2018, we continued to support five research grants awarded in previous years: (1) Dr. Heng-jia Liu (Brigham and Women's Hospital) for a postdoctoral fellowship to study T-cell dysfunction in TSC; (2) Dr. Peter Tsai (University of Texas Southwestern Medical Center) to study the impact of cerebellar-medial prefrontal cortical circuits in TSC; (3) Dr. Brendan Manning (Harvard School of Public Health) to study the repurposing of inhibitors of purine synthesis for TSC treatment; (4) Dr. Mustafa Sahin (Boston Children's Hospital) for administrative core support for developmental synaptopathies associated with TSC, PTEN and SHANK3 mutations; and (5) Drs. Mark Thomas and Rosemary Ekong (University College London) to curate additional mutations in TSC1 and TSC2 genes and make them openly available to the public in a database that is highly utilized by genetic researchers in TSC.



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 2018, 2,179 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 2018, the TS Alliance invested \$170,893 in the TSC Natural History Database, including sub-projects on TAND, epilepsy, 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 10 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 2018 with 756 biosamples: 524 blood, buccal cell, or tissue samples from individuals with TSC enrolled in the TSC Natural History Database, and an additional 232 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 further in 2019 and beyond, the TS Alliance in November 2018 hired Dean J. Aguiar, PhD, as the Director of Preclinical Research. Dean has more than 17 years of research and development (R&D) leadership in biopharmaceutical and medical device industries, leading teams and technologies from discovery to investigational new drug (IND) and investigational device exemption (IDE), a pre-requisite for clinical trial evaluation. 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 2018, bringing the total since inception to nine industry partners, seven of whom remain active members. The TSC Preclinical Research Consortium ran 12 studies to test 10 compounds in 2018, compared to 10 studies and 8 compounds in 2017. Some of the consortium's results were shared by PIQUR at the Epilepsy Pipeline Conference and by Dr. Angélique Bordey at the American Epilepsy Society annual meeting.



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 NIH funding. Now

consisting of ten sites with another five sites to be added in early 2019, the consortium has received \$29 million in competitive grant funding from the National Institutes of Health (NIH) to support clinical studies in TSC. The Clinical Research Consortium is making history with the PREVeNT clinical trial. PREVeNT is the first preventative trial for any form of epilepsy in the United States and expects to complete enrolling participants in December 2019. 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 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.





## 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.

In 2018 the TS Alliance facilitated 24,852 peer-to-peer supports from Adult Regional Coordinators, Clinic Ambassadors, Dependent Adult Transition Resource Coordinators, Education Parent Mentors, and Community Alliances through the TSC Connect program.

The Support Services Department, directed by Dena Hook, provided direct support and resources to 4,083 individuals and families dealing with TSC throughout 2018. The Vice President, Support Services and Education Parent Mentors attended 83 school meetings (IEPs, Evaluation Team Meetings, 504 Plan Meetings, Resolution Meetings, and Mediations) in person, through SKYPE/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 2018, 4,473 free parent trainings/webinars on educational advocacy were offered to families in 36 states dealing with educational issues for their children. In addition, 110 school systems were offered the support of the Educator Mentor Program in 2018. Twelve school systems provided training on “TSC 101” in an effort to help them understand the complexities of TSC and learning.

Through a network of 37 volunteer branches of the organization, called Community Alliances, local education and support group meetings were held throughout the country educating and supporting 1,500 families/individuals living with TSC. Overseen by April Cooper, the Community Programs team was developed in 2018 when the Community Alliances were divided into three regions, with a Community Programs Manager assigned to each region to manage the day-to-day activities within their communities. In 2018, 16 of 75 leadership positions (37 Community Alliance Chairs and 38 Walk Chairs) were filled, and three remained open as of December 31, 2018.



The hugely successful 2018 World TSC Conference was held in Dallas, Texas from July 26-29, 2018. This event attracted more than 900 participants from 26 countries and 41 states for three days packed with educational sessions, social activities and time to make lifelong connections. The 2018 World TSC Conference was co-hosted by the TS Alliance and TSC International (TSCi), supported by Title Sponsor Novartis and Presenting Sponsor The Rothberg Institute for Childhood Diseases. The five general sessions featured world-renowned TSC expert physicians, TSC family members, and the State Treasurer of Missouri Eric Schmitt. For the first time, the TS Alliance offered these sessions via livestream to include any conference participants from around the world who could not be in Dallas. This successful endeavor resulted in more than 200 viewers who were able to participate in our general sessions through live viewing and Q&A. The opening session alone had 34 countries tune in.

The 29 breakout sessions were recorded and are also available for viewing at [www.tsalliance.org/2018WTSC](http://www.tsalliance.org/2018WTSC). Topics included a TAND workshop, alternative therapies, seizure management, autism and behavior issues, kidney involvement, and much more. Every session included presentations and ample time for questions and answers to encourage audience participation.

The group sessions promoted active discussion and sharing by allowing participants to focus on topics such as women's health, family planning, relationships, and appealing insurance denials. There was also a dedicated workshop for siblings ages 7-17, which was primarily hosted in the conference day camp managed by Corporate Kids Events (CKE).

CKE hosted the day camp at the 2006, 2014, and 2018 World TSC Conferences. Their services allow families to bring dependents of all ages and abilities to the conference and trust they are well-cared for during conference sessions. Campers enjoyed a myriad of activities – a magician, an animal show, and an onsite fire truck to name a few. The camp hosted more than 140 TSC individuals and siblings who left with new friends and connections of their own.



Two of the most popular conference sessions were not formal activities with specified topics and presentations. These Meet-the-Experts sessions were simply two time slots allotted for strictly free-form questions and answers with a panel of six TSC expert physicians with specialties in neurology, nephrology, genetics, and more.

The 2018 World TSC Conference also included the first-ever TSC Clinic Nurses meeting, which allowed a collaboration of nurses from across the United States to share ideas and best practices at TSC clinics. In addition, hours were poured into updating the TSC Consensus Guidelines allowing for nearly real-time updates at the conference opening session. In addition, TSCi hosted a workshop the day before the 2018 World TSC Conference. Representatives from associations in Australia, Belgium, Brazil, Canada, China, Denmark, Greece, Hong Kong, Hungary, Israel, Italy, Mexico, New Zealand, Norway, Portugal, Sweden, United Kingdom, United States, and Wales participated. The workshop focused on what TSC care looks like around the world and how TSC organizations can work together to improve health care available to individuals with TSC worldwide.

## Public Health Education

Public Health Education focuses on increasing awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families. The Communications team is led by Jaye Isham, Vice President, Communications Strategy. During 2018, the TS Alliance produced two issues of our national magazine, *Perspective*, which is mailed to approximately 14,000 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 35,000 unique visitors each month. The TS Alliance also relies heavily on social media to educate constituents and promote new resources and events. Our Facebook TSC Discussion Group boasts more than 9,200 members, while our Twitter and Instagram accounts have 2,000-plus and 1,300-plus followers respectively.

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 15.7 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 radio tour, which gained coverage reaching a potential of 1.8 million. Additional news releases reached another 76.1 million. Educational session videos from the organization's 2018 World TSC Conference were viewed 4,510 times

## Professional Education

The TS Alliance's Professional Education efforts expand 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 TS Alliance participated in and presented at 38 professional meetings including: American Thoracic Society and the ATS Leadership Summit; Society for Neuroscience; Global Genes; NINDS Antiepileptogenesis and Disease Modification Workshop; the Epilepsy Pipeline Conference; two Health Research Alliance members meetings; International Society for Autism Research; Research Roundtable in Epilepsy; Association of Clinical Research Professionals; International Research Conference on TSC (Japan); ICARE (Inter-agency Collaborative to Advance Research in Epilepsy); NINDS Nonprofit Forum; FDA CDER Public Workshop: Draft Guidance Relating to Patient Experience; World Orphan Drug Congress; NORD Orphan Products and Breakthrough Summit; Open Research Funders Group; NCATS Rare Diseases Clinical Research Network (RD-CRN) meeting; Partners Against Mortality in Epilepsy (PAME); Drug Information Association Annual Meeting; BIO International Convention; BIO Patient Health and Advocacy Summit; the Arc National Convention;





Infantile Spasms Action Network; American Academy of Pediatrics; The LAM Foundation's Rare Lung Diseases Conference and LAMposium; International Autism Conference Pathways to an Inclusive Life in Mumbai, India; 7 Reunion Nacional de Esclerosis Tuberosa; CBI Rare Disease Innovation Summit; 2018 World TSC Conference; and Nonprofit Funder-Research Forum. In addition, at the American Epilepsy Society meeting the TS Alliance presented in the Discovery Center and the poster session, and we 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.

In addition, 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.

## Government Advocacy

Our Government Relations Program 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 early March 2018. 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 not able 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, 200 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 29 signatures. In FY2019, the TSC Research Program at the

CDMRP received a \$6 million appropriation, bringing the cumulative funding to \$83 million since 2002 as a result of our successful grassroots efforts.

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 lymphangio-leio-myomatosis (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. Data obtained from an FY2010 TSCRP clinical research award to define early autism predictors in TSC and an FY2014 TSCRP award for a pilot clinical trial is being tested in a large, NIH-funded clinical trial looking at the effectiveness of a behavioral intervention strategy, JASPER, to improve outcomes in children with autism.

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.



## Global Outreach

The TS Alliance works to address unmet needs within the global TSC community through our Global Alliance Program. This effort provides the opportunity for the TS Alliance to share experiences and assist in the start-up of 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 and raise revenue and awareness while supporting the mission of the organization.

In 2018, the TS Alliance signed a global agreement with the TS Alliance of India. The TS Alliance now has six global partnerships, including: TS Alliance of Israel, TS Canada ST, TS Alliance of Mexico, TS Alliance Foundation (in Thailand), Hungarian Foundation for Tuberous Sclerosis, and TS Alliance of India.

## Fund Development

2018 was a tremendous year of collaboration for the TS Alliance and TSC community, culminating in the World TSC Conference in Dallas. It was wonderful to have so many opportunities for our community to gather together and incredible to witness the drive, dedication and support of the TSC community. While attending the World TSC Conference, supporting TS Alliance national events, raising awareness at walks across the country and holding community fundraisers, the TSC community truly embodied the mission to find a cure for TSC while improving the lives of those affected. The incredible generosity of the TSC community continues to be an inspiration.

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. President's Council members 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:

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

## Unlock the Cure

In 2018 the *Unlock the Cure* campaign raised more than \$1.2 million and completed this phase of the campaign, procuring more than \$6 million cumulatively from private sources. This funding has been instrumental in helping the TS Alliance establish a Preclinical Consortium, create a Biosample Repository, support the Natural History Database, expand the Clinical Research Consortium and continue to fund important research through the TS Alliance research grants program. The goal through these endeavors is to identify more treatments for TSC and ultimately identify preventative treatments for TSC that will change the course of the disease. Major gift fundraising, corporate partnerships and appeals are led by Senior Director of Donor Relations Lisa Moss.



## Special Events

**In 2018, special events netted \$1,519,508 representing 25% of the organization's overall revenue.**

Held April 8 at The Globe Theatre at Universal Studios, Hollywood, CA, the **17th Annual Comedy for a Cure®** was filled with magic, music, laughter and much hope while raising \$265,000 and invaluable awareness for the TS Alliance. The spectacular evening was sprinkled with a variety of acts, including magicians Shane Brady and Mark Furey, mixed with musical entertainment by The Von Krappe Family Singers and Kate Flannery and the Tony Guerrero Quintet. The headliner for the evening was the hilarious Jimmy Shubert. And we are thankful to emcee Melissa Peterman, co-hosts Jim O'Heir and Alex Skuby and auctioneer extraordinaire Damon Casatico, who helped make the night extra special.

We were thrilled to present the much-deserved Leadership in Courage Award to the Grandia Family, who have turned their challenge of having four of their five family members affected by TSC into action for the TS Alliance. As Adult Regional Coordinators, Rob and Shannon have made it their mission to represent the adult community. We were also humbled to honor Cathy Jackson, Director of Advocacy Relations at Mallinckrodt Pharmaceuticals, who leads its efforts to increase awareness about infantile spasms, a devastating type of seizure that impacts one third of newborns with TSC.



Thank you to our generous event sponsors: Mallinckrodt Pharmaceuticals, MarketCast, Novartis, The Szilagyi Family, Variety, C&C Market Research, CVS Health, FusionStorm, Greenwich Biosciences, Lundbeck, The Maginn Family, WNC & Associates, Lauren & Richard Packard and Upsher-Smith. We also would like to thank all of our partners for making the evening possible, including the fabulous Comedy for a Cure planning committee, Ingram Design Studio, Traci Hoffberg Events and Tom Bercu Presents.

**Step Forward to Cure TSC®** walks took place in 35 cities across the United States and collectively raised \$940,123. 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 with incredible news coverage in some areas. Support was provided by national sponsors Novartis, Greenwich Biosciences, LivaNova, Upsher-Smith and MassMutual. The **Step Forward to Cure TSC® National Walk on the Mall** took place at Constitution Gardens raising \$66,448 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, Upsher-Smith and Inspire.



Team TSC participated in two marathons in 2018. The TS Alliance, supported by Team TSC, was proud to be an official charity partner at the **2018 Marine Corps Marathon**, held in Washington, DC, with 19 registered runners, who raised \$50,000! The team was led and motivated by Team TSC Ambassadors Jill Woodworth and Ryan Novotny. Special thanks to our 2018 Team TSC members: Kerilyn Amedio, Ali Blanchette, Dave

Carpenter, Rob Carpenter, Kate Carter, Rob Cronin, Seamus Donoghue, Dana Imperatore, Olivia Imperatore, Ryan Novotny, Kalia Parrott, George Petty, Kay Rawlings, Casey Ryan, Taylor Ryan, Beth Wilson, Jill Woodworth and Eugene Zebrowski, Jr.

For the second year, the TS Alliance had a dedicated group of 11 individuals running in the **TCS New York City Marathon**. Special thanks to our 2018 Team TSC members: Wendy Anderson, Rob Bendini, Joseph Cervantez, Susan Cohen, Brianah DoedeFaria, Justin Largent, Allen Newbauer, Stephen Presley, Ashley Roth and Kiran Thomas. These runners actively fundraised and trained for the largest marathons in the country. The team raised more than \$60,000 to advance the mission of the TS Alliance. We were grateful to have Celia Mastbaum and Liz Buchsbaum host what has become an annual Rooftop Celebration the day before the marathon, where a small group of local TSC family members came together to eat, make signs and celebrate Team TSC.



## Events Raising More Than \$10,000

### SIGNATURE NATIONAL EVENTS

- Comedy for a Cure® – Planning Committee
- Art for a Cure – Planning Committee

### STEP FORWARD TO CURE TSC® WALKS

- Alabama – Jessica White
- Arizona – Debora Moritz and Terri Butler
- Atlanta – Lauren and Jeff Perry and Jeff Triemer
- Carolina – Heather Morris
- Chicago – Scott Brown
- Cincinnati – Nathalie Mortine
- Connecticut – Jennifer Waldron
- Dallas/Fort Worth – Sylvia Sparby and Cassie Jimenez
- Delaware/Lehigh Valley – Shelly Meitzler
- Houston – Rachael Jackson
- Indiana – Pat Schmutte
- Intermountain West – Rob Thurston
- Michigan – Treasa Bolger-Dunlap
- Mississippi (Delta Region) – Chelsea Lamb
- Nashville, TN – Gail Saunders
- National Walk on the Mall (Metro DC) – Lauren Shillinger
- New England – Stacie Verrill
- New Jersey – Tresha Bisang
- New York (Long Island) – Carol Ann White and Lori DiStefano
- Northern California – Bridgett Britt
- Oklahoma – Heather Lens
- Seattle (Pacific NW) – Gloria Triebenbach and Debbie Rothweiler
- Southern California – Shannon and Rob Grandia
- Tampa Bay – Amy Hightower and Jamie Jodoin
- Upper Midwest – Angela Wiltschek
- Wisconsin – Scott Brown and Geri Greenberg

### COMMUNITY EVENTS

- 10th Annual Western Pennsylvania Tournament of Champions – Lori Shoup
- A Birthday Celebration – Brad Ruback
- Brewing for a Cure – Heather Harden and Chelsea Lamb
- Crashin' for the Cause – Joe and Abby Kopf
- RaboBank Dinner and Auction – Haydn Scarr
- Strikeout for TSC Softball Tournament – Laura Laramie and Kristen Chico

## Annual Fund – Major Donors and Contract Revenue

Fiscal Year 2018: January 1 to December 31

### CHAIRMAN'S CIRCLE

(\$100,000 and Above)

Aeonian Pharmaceuticals  
Anonymous  
Gerry and Bill Cowlin Foundation  
Christopher and Joy Dinsdale  
Engles Family Foundation on Behalf of Engles Collaborative Research Fund  
Facebook Community Donations  
Greenwich Biosciences  
Novartis Pharmaceuticals Corporation  
OPL Charities  
Ovid Therapeutics  
Jonathan Rothberg and Bonnie Gould Rothberg.  
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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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UC San Diego School of Medicine  
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Neurodevelopmental Disabilities

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Safra Children's Hospital  
Sheba Medical Center  
Tel Hashomer, ISRAEL  
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Specialty: Pediatric hematology-oncology

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Children's Hospital  
Department of Neurology  
Pittsburgh, PA  
Specialty: Pediatric Neurology & Epilepsy

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Children's Healthcare of Atlanta/Emory  
University  
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Specialty: Pediatric Neurology &  
Neuro-oncology

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Mount Sinai Beth Israel Roosevelt  
New York, NY  
Specialty: Pediatric Neurology & Epilepsy

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Specialty: Neurology, Clinical  
Neurophysiology, Epilepsy

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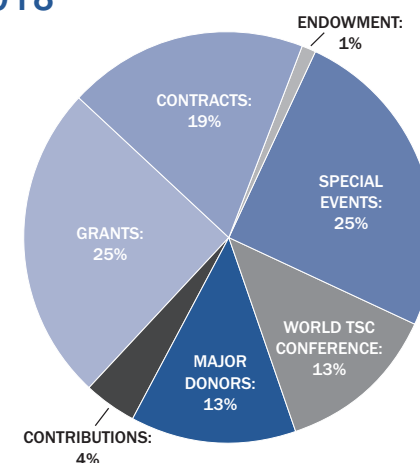
## National Tuberous Sclerosis Association & Affiliate

### Consolidated Statement of Financial Position

As of December 31,	2018
<b>Assets</b>	
Cash and cash equivalents	\$ 1,304,824
Investments	6,209,943
Accounts receivable	158,782
Promises to give	1,249,706
Prepaid expenses and other assets	263,093
Property and equipment	169,346
<b>Total assets</b>	<b>\$ 9,355,694</b>
<b>Liabilities and Net Assets</b>	
<b>Liabilities</b>	
Accounts payable and accrued expenses	\$ 196,626
Accrued compensation	255,560
Deferred revenue	114,499
Deferred rent and lease incentive	35,378
Gift annuity obligations	73,943
<b>Total liabilities</b>	<b>676,006</b>
<b>Net assets</b>	
Without donor restrictions	
Undesignated	235,336
Board-designated	4,789,541
<b>Total without donor restrictions</b>	<b>5,024,877</b>
With donor restrictions	3,654,811
<b>Total net assets</b>	<b>8,679,688</b>
<b>Total liabilities and net assets</b>	<b>\$ 9,355,694</b>

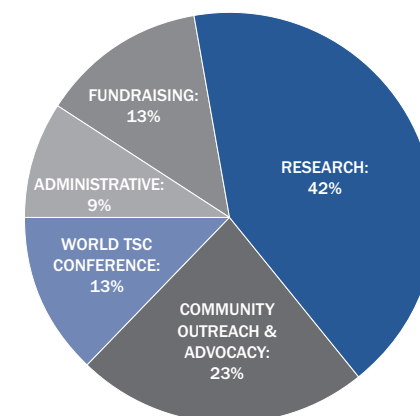
The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year's auditors completed their 2018 audit and submitted an unmodified opinion to the TS Alliance Board of Directors. The complete audited financials are on file with the TS Alliance or 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 2018 there was a net loss, contributing to the total change in net assets on a consolidated basis for the year. On a stand alone basis, excluding investment losses from the TS Alliance Endowment Fund, the change in net assets of the TS Alliance was a positive \$84,529 for the year. The TS Alliance finance team is directed by Chief Financial Officer Richard Gollub.

## Operating Revenue Sources 2018



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

## Operating Expenses 2018



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

## National Tuberous Sclerosis Association & Affiliate

### Consolidated Statement of Activities

	Without Donor Restrictions	With Donor Restrictions	2018 Total
<b>Revenue and Support</b>			
Special Events	\$ 1,660,285		\$ 1,660,285
Cost of direct benefits to donors	(141,001)		(141,001)
Special events, net	1,519,284		1,519,284
Contributions	735,203	\$ 1,728,528	2,463,731
Contracts	1,126,302		1,126,302
World TSC Conference	743,427		743,427
Interest and dividends	122,186	19,960	142,146
Memorials and honoraria	77,552		77,552
Federated funding	44,107		44,107
Other income	15,118		15,118
	4,383,179	1,748,488	6,131,667
Net assets released from restrictions	1,585,118	(1,585,118)	-
Total revenue and support	5,968,297	163,370	6,131,667
<b>Expenses</b>			
Program services			
Research	2,463,285		2,463,285
Family services	770,313		770,313
World TSC Conference	767,575		767,575
Public health education	322,973		322,973
Government relations	149,340		149,340
Professional education	128,621		128,621
Total program services	4,602,107		4,602,107
Supporting services			
Fundraising	781,502		781,502
Management and general	528,655		528,655
Total supporting services	1,310,157	-	1,310,157
Total expenses	5,912,264	-	5,912,264
Change in net assets from operations	56,033	163,370	219,403
Net investment loss	(508,220)	(88,275)	(596,495)
<b>Change in net assets</b>	(452,187)	75,095	(377,092)
Net assets, January 1, 2018 as restated	5,477,064	3,579,716	9,056,780
<b>Net assets, December 31, 2018</b>	\$ 5,024,877	\$ 3,654,811	\$ 8,679,688



WE'LL GIVE EVERYTHING. BUT UP.



Tuberous Sclerosis Alliance

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