

2015 Annual Report

Setting the Stage

GROWTH | INNOVATION | TRANSFORMATION



Tuberous Sclerosis Alliance

A blue-toned illustration of a stage lighting rig. A truss system at the top holds five spotlights. Two more spotlights are on the floor at the bottom corners. All spotlights are directed towards a central rectangular area, creating a bright, glowing effect. The background is a solid blue color.

Growth | Innovation | Transformation

*“There are no dreams too large,
no innovation unimaginable and
no frontiers beyond our reach.”*

– John S. Herrington

Throughout 2015, the Tuberous Sclerosis Alliance (TS Alliance) began setting the stage for future growth, innovation, and transformation. While 2014 focused on honoring the past 40 years, 2015 meant looking forward with a renewed determination to grow our outreach efforts, innovate with new collaborative research projects incorporating the TSC community voice, and transform lives through an aggressive plan for new clinical trials and partnerships.

Some 2015 highlights included:

- TS Alliance maintained its 4 Star Rating from Charity Navigator and Gold Level rating from Guidestar and earned the GreatNonProfits Top-Rated Award for fourth year in a row.
- A new Junior Leader Program was developed and put into place.
- The National Institutes of Health and TS Alliance sponsored a workshop in March entitled “Unlocking Treatments for TSC: 2015 Strategic Plan,” bringing together 82 participants to update research recommendations and priorities for the TSC field for the next 5 to 10 years.
- In September, the Tuberous Sclerosis Association (UK) and TS Alliance co-hosted the International Tuberous Sclerosis Complex Research Conference: From Treatment to Prevention in Windsor, UK, attended by 261 researchers, clinicians, constituents, and partners from 30 countries.

- The TSC Clinical Research Consortium published interim results from the EEG Biomarker Study in *Pediatric Neurology*. The data showed that abnormalities in EEG of infants with TSC who have never had seizures are predictive of the risk of developing epilepsy. The TS Alliance provided seed funding and was a proud supporter of this study.
- Two new TSC Clinics were recognized by the TS Alliance, increasing the total number from 16 to 49 in the past decade.
- The new #IAMTSC campaign launched with a micro-website featuring public service announcements from Julianne Moore, Mo Collins, Kate Flannery, Chris Hawkey, Jim O’Heir and Alex Skuby to heighten awareness of TSC.
- The 50K Research Challenge let the TSC community vote on which innovative project would receive seed funding.
- For the first time, the TS Alliance partnered with the Child Neurology Foundation to co-sponsor Infantile Spasms Awareness Week, December 1-7.
- The TS Alliance and The LAM Foundation held a joint meeting with nearly 70 individuals, family members, LAM and TSC researchers, clinicians and Board members to discuss ways to collaborate moving forward.



- To address a critical gap in services for transitioning young adults, the TS Alliance began discussions with The Arc about ways to work collaboratively.

This annual report provides an overview of the organization’s efforts and achievements in 2015, and while much work remains in our quest to better the lives of everyone affected by tuberous sclerosis complex – like you, **we’ll give everything. But up.**

About the Tuberous Sclerosis Alliance

The Tuberous Sclerosis Alliance is dedicated to finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected by:

- Developing programs, support services and resource information;
- Stimulating and sponsoring research; and
- Creating and implementing public and professional educational programs designed to heighten awareness of the disease.

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 where no one has to endure the devastating effects of TSC.

What is Tuberous Sclerosis Complex?

Tuberous sclerosis complex-or TSC-is a genetic disorder that causes tumors to form in vital organs, primarily the brain, eyes, heart, kidney, liver, skin and lungs. TSC is a highly variable disease. Some people with TSC live independent, healthy lives and enjoy challenging professions such as doctors, lawyers, educators and researchers. Others with the disease often experience uncontrollable seizures, autism, heart disease, learning and behavioral problems, facial disfigurement, kidney failure and, sometimes, even death. Approximately 80 percent of those with TSC develop kidney lesions.

...so much hope is on the horizon for anyone touched by TSC.

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.

While there is currently no cure, this annual report shows why so much hope is on the horizon for anyone touched by TSC.

Expanding TSC Research

The TS Alliance's Research Program stimulates and supports basic, translational, and clinical research on the various manifestations of tuberous sclerosis complex (TSC) to further the development of clinical therapies and, ultimately, a cure for TSC. The TS Alliance has funded \$18.8 million in research on TSC since 1984. Directed by Steven L. Roberds, PhD, Chief Scientific Officer, the TS Alliance **Research Grants Program** funds research focused on TSC proposed by researchers and aligned with the priorities of the TS Alliance. Collaborations between basic and clinical researchers are encouraged and fostered, for example, through biennial International TSC Research Conferences.

In 2015, the TS Alliance Research Grants Program funded a total of 11 research awards for \$486,198. The TS Alliance continued to support eight

research grants from previous years and three new research awards were funded beginning in 2015 to:

- Dr. Brendan Manning (Harvard School of Public Health) to study the repurposing of inhibitors of purine synthesis for TSC treatment,
- Dr. Polina Kosillo (University of California, Berkeley) for a postdoctoral fellowship to study the impact of TSC1 gene deletion on dopamine neurons, and
- Dr. Mustafa Sahin (Boston Children's Hospital) to study the "hedgehog" gene and ciliary signaling 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 2015, 1,849 people with tuberous sclerosis complex 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 2015, the TS Alliance invested \$467,608 in the database and implemented an investigator-initiated sub-project to address detailed questions about epilepsy in TSC. A contract with Novartis executed in November 2012 continued to provide TS Alliance with funding to enhance and grow the TSC Natural History Database through 2015.





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. Such samples are currently unavailable, and the TS Alliance's Science and Medical Committee identified this as a gap that can best be filled effectively with leadership of the TS Alliance, guided by a steering committee of clinicians and researchers. The TS Alliance contracted with the Van Andel Research Institute in Grand Rapids, Michigan, to host and distribute biosamples. Samples in the repository will be available to qualified researchers worldwide and will be associated with detailed clinical data, such as that found in our existing TSC Natural History Database. The Biosample Repository also houses samples collected as part of the TSC Clinical Research Consortium's Rare Disease Clinical Research Network project that launched in 2015.

In addition, the TS Alliance launched a new **TSC Preclinical Consortium** in 2015, which will enable 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 negotiated a license with Brigham and Women's



Hospital to use specific mice developed at that institution for experiments done by the TSC Preclinical Consortium. The TS Alliance is also finalizing agreements for use of other TSC mouse models from other institutions and has solicited proposals for breeding of mice and performing epilepsy-related experiments. These proposals will be reviewed to select laboratories best suited for conducting breeding and experiments. Several small and large pharmaceutical companies have expressed interest in the consortium, and all mouse license agreements include the rights for the TS Alliance to perform experiments under contract for commercial entities.

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. The five clinics comprising this consortium—Boston Children's Hospital, Cincinnati Children's Hospital Medical Center, the University of Alabama at Birmingham, the University of California Los Angeles, and the University of Texas Health Science Center at Houston—received NIH grants to conduct two clinical studies initiated in 2013. These two clinical studies will: (1) determine what early signs or tests can identify infants with TSC at highest risk of developing autism by age three, and (2) measure the ability of EEG and brain imaging to assess the risk of newly diagnosed infants with TSC to develop infantile spasms. The biomarkers resulting from these studies will have a major impact on our ability to intervene very early to prevent some of the most devastating manifestations of TSC. An interim analysis of the EEG study demonstrated that, indeed, specific abnormal EEG findings can predict that an infant will progress to develop clinical seizures. Additionally, the coordinated



work to execute both of these studies has developed infrastructure and processes to form the basis of an ongoing and growing TSC Clinical Research Network. The TS Alliance continued supporting Dr. Mustafa Sahin (Boston Children's Hospital) and his research of image analysis in the Rare Diseases Clinical Research Network. The consortium submitted an additional NIH grant application that, if funded, will add two additional clinical sites and enable the first clinical trial to prevent the development of epilepsy in infants diagnosed with TSC. As the TSC Preclinical Consortium and translational research in TSC produces additional ideas for clinical studies, the efficient initiation and conduct of future clinical trials will benefit from having this infrastructure in place to enable investigators to quickly and affordably execute studies. The TS Alliance's Chief Scientific Officer is on the leadership team of the consortium.

Along with the Tuberous Sclerosis Association in the United Kingdom, the TS Alliance co-sponsored the 2015 International TSC Research Conference: From Treatment to Prevention, held in Windsor, UK. Approximately 260 attendees from 30 countries participated in the conference featuring oral presentations, a poster session, and ancillary meetings including TSC International and TSCure, a working group of clinical researchers tackling issues necessary to plan clinical trials of very early treatments to prevent manifestations of TSC and lymphangioleiomyomatosis (LAM). This conference was supported by a grant from Novartis, while the Rothberg Institute for Childhood Diseases was a presenting sponsor. Support was also provided by the Brian O'Brien Family, GW Pharmaceuticals, Bcureful, Castle Hotel Windsor, National Institutes of Health, National Institute of Neurological Disorders and Stroke, and National Center for Advancing Translational Sciences.

Providing Outreach and Support

Our Outreach 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 Outreach Department provided support and resources to 2,905 individuals and families dealing with TSC throughout 2015. The Vice President of Outreach attended 39 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. In 2015, 24 Educational Liaison volunteers worked in 24 states to connect families to free educational advocacy trainings in collaboration with the states' Parent Training and Information Centers. As a result, more than 1,885 free parent trainings/webinars on educational advocacy were offered to families dealing with educational issues for their children. In addition, the Educator Mentor Program supported 89 school systems in understanding the learning needs of children with TSC.

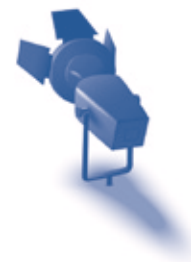
Through a network of 35 volunteer branches of the organization, called Community Alliances, local education and support group meetings were held throughout the country. Through these Community Alliances, the TS Alliance hosted 76 educational meetings and gatherings, including a 13-meeting Town Hall educational series called New Clinical Research in Epilepsy and Infantile Spasms. These Town Hall meetings were hosted in TSC clinics and other venues across the United States to educate TSC individuals and families about new research in epilepsy and infantile spasms with 160 people



attending. One new Community Alliance, the TS Alliance of Kentucky/West Virginia, was added in 2015.

The TS Alliance facilitated 7,413 peer-to-peer supports from Adult Regional Coordinators, Clinic Ambassadors and Dependent Adult Transition Resource Coordinators and through Community Alliance meetings.

In 2015, the TS Alliance hosted three Regional TSC Conferences held in St. Paul, MN; Stanford, CA; and Winston-Salem, NC with 180 combined attendees. These conferences 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 can make informed decisions when evaluating treatment options. These one-day symposiums offered educational outreach, information on the latest treatments in TSC, research updates, and support options. They featured the region's top experts and provided attendees the opportunity to have one-on-one meetings with these experts in a nurturing, supportive environment. Regional TSC Conferences provide much-needed forums for the growing number of people facing the daily challenges of TSC.

Increasing Awareness

The TS Alliance diligently works to heighten awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families. During 2015, the TS Alliance produced three issues of its national magazine, *Perspective*, which is mailed to 15,000-plus constituents as well as posted on the website. The TS Alliance's website increases awareness and provides extensive education via 1 million-plus hits monthly from an average of more than 38,000 unique visitors. The TS Alliance also relies heavily on social media to educate constituents and promote new resources and events. Our Facebook Group boasts more than 7,000 participants, while our Twitter account has 1,400-plus followers.



To increase public awareness, the TS Alliance introduced a new public awareness campaign called #IAMTSC. This effort includes a dedicated website at IAMTSC.org, which garnered 21,912 page views from 10,788 unique visitors through December 31. Public service announcements were also filmed and throughout 2015 played 3,807

times on TV stations across the United States, reaching a potential audience of more than 21 million. The TS Alliance once again participated in TSC Global Awareness Day on May 15, where the #IAMTSC theme was leveraged heavily on social media and in a satellite media tour, sponsored by Novartis, featuring TS Alliance President & CEO Kari Luther Rosbeck and the #IAMTSC campaign's creator—Eric D'Amario, a dad whose daughter has TSC. This media tour reached 4.8 million people.

In 2015, the TS Alliance also heavily promoted Infantile Spasms Awareness by producing four new videos for parents whose children with TSC experience these types of seizures; these videos were viewed 1,879 times by December 31. The TS Alliance, in partnership with the Child Neurology Foundation, planned and executed Infantile Spasms Awareness Week, December 1-7. This public awareness campaign included social media, advertising to first line physicians and a media tour. Facebook advertising to reach misdiagnosed or those seeking a diagnosis reached 31,547 people. Advertising to first line physicians included an American College of Emergency Physicians (ACEP) Now website banner ad with 5,279 impressions, ACEP online newsletter with 21,061 subscribers, and the American Academy of Pediatrics Gateway with 50,000 impressions. An accompanying satellite media tour reached a total audience of 2.7 million.

Educating Healthcare Professionals

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

The TS Alliance also participated in and presented at 32 professional meetings including: The Child Neurology Society Meeting; LAMposium-The LAM Foundation Conference; Congressional Showcase with the Coalition for Imaging and Bioengineering Research (CIBR); Association of Clinical Research Professionals Conference; Interagency Collaborative To Advance Research In Epilepsy (ICARE); Clinical Trials Transformation Initiative; Rare Disease Day at NIH; The NINDS Nonprofit Forum; NORD Annual Conference on Rare Diseases and Orphan Products; DIA Rare Diseases Workshop; ExL's 2nd Rare Disease Collaboration Summit; CBI's Evidence for Value-Based Programs; Society for the Study of Behavioral Phenotypes; 2015 BIO Patient and Health Advocacy Summit; NORD Summit; Translational Neuroscience Symposium; and the American Thoracic Society. In addition, at the American Epilepsy Society (AES) annual meeting, the TS Alliance hosted an Infantile Spasms Awareness Innovation Pavilion exhibit and a TSC reception for more than 100 researchers, clinicians, and community members. The TS Alliance also participated in two Special Interest Group scientific sessions, one on TSC and another on research resources made available by non-profit organizations advocating for rare disorders that involve epilepsy.

Further, the Vice President of Outreach has ongoing collaboration with national educational networks, such as the Association for Middle Level Education (AMLE). She also collaborates with Parent Training Information Centers (PTIs) throughout the country. Providing children with appropriate education is one key to individuals having a good quality of life.

Advocating at the Federal and State Level



Rep. Mike Fitzpatrick receiving the TSC Champion Award from Julie Blum, TS Alliance Government Relations Committee.

The organization's government advocacy efforts focus 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 2015. More than 80 members of the TSC community participated, asking their Senators and Representatives to sign Dear Colleague letters in support of TSC research. In the House, 27% or 117 Democratic and Republican Representatives signed onto a bipartisan Dear Colleague letter of support from Representatives Loretta Sanchez (D-CA) and Mike Fitzpatrick (R-PA).

The number of signatures secured for the Sanchez-Fitzpatrick letter greatly exceeds the numbers set in previous years. The Senate letter, sponsored by Senators Chris Murphy (D-CT) and Johnny Isakson (R-GA), included 22 signatures. In FY2016, the TSC Research Program at the CDMRP received a \$6 million appropriation, bringing the cumulative funding to \$65 million since 2002 as a result of our successful grassroots efforts.

Research done 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, 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 LAM leading to a clinical trial funded in FY2012. Building upon FY2010-funded research on glutamate receptors (mGluR5), several companies are now looking into developing drugs to 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. In 2013 an industry-sponsored clinical trial began to test mTOR inhibitors to treat epilepsy in 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 on Capitol Hill to commemorate TSC Global Awareness Day on May 15, 2015. Congressional staff and key members of the TSC research and grassroots communities attended the event.

In 2015, Missouri State Senator Eric Schmitt led an effort for research funding on the state level. Due to his leadership and advocacy the state's Department of Mental Health bill included \$250,000 to establish a comprehensive Washington University Tuberous Sclerosis Center of Missouri, promoting a three-fold mission of basic scientific research, clinical patient research, and patient care for TSC. The new center integrates all aspects of research and patient care in TSC, spanning basic drug discovery in the laboratory, clinical drug trials, and comprehensive clinical care of TSC patients.

Raising Funds to Support Our Mission

The heart of the TS Alliance has always been the TSC community—a dedicated group of people across the country who come together each year to raise significant funding that allows the TS Alliance to offer valuable community programs and invest in research. Events, large and small, make an incredible impact in the fight against TSC—whether it’s Comedy for a Cure®, Step Forward to Cure TSC® walks, Four Decades | One Community performances, or the many other community-based events such as Rock 4 Riley, Crashin’ for the Cause, golf tournaments, garage sales, marathons and other community-inspired fundraisers. These events are successful because of the dedication and creativity of the TSC community and our shared goal to raise awareness of TSC while improving the lives of those affected.

In 2015, special events netted \$1,435,897, representing 36% of the organization’s overall revenue. A few highlights include:

Comedy for a Cure® Hollywood celebrated its 14th anniversary in 2015 at the Globe Theatre in Universal Studios Hollywood, and raised \$183,000 for the TS Alliance! The evening featured hilarious performances by Mark Eddie, Craig Shoemaker and a return to the Comedy for a Cure stage by TS Alliance supporter Larry Miller. We were also joined by our gracious Honorary Chair Jim O’Heir, Emcee Mo Collins, and Host Alex Skuby, who each continue to champion our cause. We were humbled to present the Courage in Leadership Award to the Heffron Family, and everyone in the room was charmed by 10-year-old Bao’s speech. An Honoree Tribute was also given to Helena Foulkes, Executive Vice President of CVS Health

and President of CVS/pharmacy, for her years of commitment to TSC. The event was dedicated to the Goff Family in honor of Tiara Goff, who lost her battle with TSC earlier in the year. Tiara’s mom, Tiffani, gave an extraordinary and inspiring memorial speech. We thank all our partners for making the evening possible including the fabulous Comedy for a Cure planning committee, auctioneer Damon Casatico, Ingram Design Studio, Traci Hoffberg Events and Tom Bercu Presents, and our incredible major sponsors including CVS Health, Mallinckrodt, MarketCast, Variety, Emily’s Hope—the Szilagyi Family, Glacier Design Systems, Inc., Lundbeck, Maginn Family, Novartis, Twentieth Century Fox, and WNC & Associates Inc.

The Step Forward to Cure TSC® national walks took place in 32 cities across the United States and collectively raised \$1,095,151. 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. Julianne Moore once again served as our National Honorary Chair with support provided by national sponsors Novartis, LIDS, Lundbeck, Cyberonics, MetLife Center for Special Needs Planning and Pillar Hotels & Resorts.

The Step Forward to Cure TSC® National Walk on the Mall took place at Constitution Gardens raising more than \$80,000 while also increasing awareness of TSC in our nation’s capital. This walk was a great success thanks to the TSC community and the generous support from Lundbeck, Novartis, Scitor, Cyberonics, LIDS, Mallinckrodt, The Law Office of Joseph P. Smith III, Fraternal Order of Detention Officers and Personnel, CWA Local 2911, Anne Arundel County, MD, Buffalo Wild Wings, and Caribou Coffee.

Four Decades | One Community Encore Performances were held in Minneapolis and Washington, DC as the TS Alliance took our original play written by John Morogiello on tour. Both events were accompanied by live and silent auctions and proved a great success, raising a combined \$110,000 to fund future breakthroughs in the fight against TSC and creating greater awareness. Our wonderfully talented celebrity supporters brought these plays to life while providing a beautiful living history of the triumphs and challenges that are ever present in the TSC community. In Minneapolis we were pleased to present the Courage in Leadership Award to the Hable Family and to honor Judy Shoulak, Executive Vice President, President North America Buffalo Wild Wings, for their years of commitment to the TS Alliance. In DC, we recognized the tremendously courageous Evan Moss just weeks after his second brain surgery and paid tribute to one of our strongest government advocates, Congressman Mike Fitzpatrick, co-sponsor of the House Dear Colleague Letter in Support of the TSC Research Program in the Department of Defense. Both events were dedicated to Dee Carpenter Triemer.

Unlock the Cure: ACT Now, launched as the second phase of the Unlock the Cure fundraising campaign, raised \$665,145. The Unlock the Cure campaign helped the TS Alliance develop a Drug Screening Program, identify biomarkers, develop a Clinical Research Consortium, expand the TSC Natural History Database, and increased support for the TS Alliance Research Grants Program. The next phase will expand on these efforts and add additional focus to developing a Biosample Repository, Preclinical Consortium and preventative treatments for TSC.

Events Raising More Than \$10,000

Signature National Events

- Comedy for a Cure®
- Four Decades | One Community, Minneapolis
- Four Decades | One Community, Washington, DC

Step Forward to Cure TSC® Walks

- Alabama - Carole Pitard and Margaret Cox
- Arizona - Debora Moritz
- Atlanta/North Georgia - Reiko Donato
- Chicago (Westmont) - Geri Greenberg
- Connecticut - Rebecca Thereault
- Dallas - Joy Graydon
- DC Metro National Walk on the Mall - Brooke Carpenter
- Delaware/Lehigh Valley - Shelly Meitzler and Bridget Simmons
- Delta Region - Katie Christensen
- Houston - Bill and Taska Fields
- Indiana - Pat Schmutte
- Michigan - Treasa Bolger-Dunlap
- Memphis - Brittany Schwaigert
- New England - Stacie Verrill
- New York (Long Island) - Rob and Denise Spear
- New Jersey - Tresha Bisang
- Rocky Mt. Region - Leslie Byers and Caroline Clough
- Seattle/Pacific Northwest - Devon McCollum
- Southern California - Barbara O'Neill and Dawn Redfield
- St. Louis - Gwen Montaigne
- Upper Midwest - Judy Prudhomme and Maria Gibbons

Community Events

- 10th Annual Friends and Family BBQ for TSC - Bill and Nancy Youmans
- Crashin' for the Cause - Joe and Abby Kopf
- The 9th Annual Heather Joy Memorial TS Alliance/LAM Foundation Golf Outing
- Rock 4 Riley - Melanie Vogel
- Strikeout TSC Softball Tournament - Laura Laramie
- TSC Fundraiser in Honor of Christine Ritchie - Victoria Goodman
- Raleigh City of Oaks Marathon - Lindsey Miller



Annual Fund - Major Donors

Fiscal Year 2015: January 1 to December 31

President's Circle (\$100,000 and Above)

The Cowlin Family Fund
Harold Simmons Foundation
Lundbeck Pharmaceuticals, Inc.
Novartis Pharmaceuticals Corporation
Tuberous Sclerosis Alliance Endowment Fund

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

James and Andrea Maginn
Mallinckrodt Pharmaceuticals
OPL Charities
Jonathan and Bonnie Gould Rothberg, The Rothberg
Institute for Childhood Diseases
William and Kristina Watts

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

Cyberonics, Inc.
Crashin' for the Cause, Eldorado Lions Club
Harold B. Belfer Trust
Victoria Goodman
The Laclede Group, Inc.
LIDS Foundation, Inc.
The MetLife Center for Special Needs Planning
Julianne Moore and Bart Freundlich
Pillar Hotels & Resorts
Jack D. Scott
The Winifred M. Gordon Foundation, Inc.

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

America's Charities
Chad and Alicia Austin
Will and Kay Cooper, WNC & Associates, Inc.
CVS Health
Richard and Lori Day
Conrad and Judy Duprez
Estate of Claire A. Baten
Genesco
Louis Berkowitz Family Foundation, Inc.
MarketCast
Scott and Kasandra Merrill
David and Nancy Michaels
Minnesota Epilepsy Group, P.A.
The National Institutes of Health, the National Institute of
Neurological Disorders and Stroke and the National
Center for Advancing Translational Sciences

Ned Neely
Brian and Sandra O'Brien, Brian E. O'Brien Oil & Gas
Allan and Carla Price
Research Triangle Institute
Irene Rothberg
Kevin and Melanie Vogel
Karen White and Julie Geissman
Whittingham Foundation

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

Steve and Lynn Aguiar
ARMATURE Corporation
The Arnold Foundation, Inc.
The Bayless Family Foundation
Bcureful
David and April Bennett
Jim and Debora Moritz, Cake Arts, Inc.
Henry Casillas
Ray Chan
Charles & Mildred Schnurmacher Foundation, Inc.
Scott Clarkson, Glacier Design Systems
Craig and Cindy Cunningham, C&C Market Research
Cornelius and Linda Denharder
Michael and Rita DiDomenico, DiDomenico Packaging Co., Inc.
Digital Millennium Wireless, Inc.
Tim and Kathi Dills
Pamela Edstrom
Scott and Jill Feinstein
John Geraghty
The Gertrude and Philip Hoffman Philanthropic Fund of the
Jewish Federation of Greater Pittsburgh
Indiana Oxygen Co., Inc.
William and Debra Joseph
Ken and Beth Kocher
Mark and Dawn Koers
David and Cathy Krinsky
Laura Laramie
Herbert and Carol Marton
Theodore and Peggy Mastroianni
Robert and Staciellen Mischel, The Mischel Family Foundation
John and Carol Nicholson
Jim O'Heir
The Pediatric Epilepsy Research Foundation
John Pietrolungo
Clark and Temple Poche
Matthew and Rebecca Anhang Price
Robinson Foundation
Christopher and Kari Luther Rosbeck
Schneider Electric North America Foundation
Scitor Corporation
Shawn Gaffney Memorial Fund, Inc.
James and Judy Shoulak, The Shoulak Family Fund
Scott and Lori Shoup
Susan Smith
Annie Szilagyi
Transgenomic, Inc.

Twentieth Century Fox Film Corporation
Upsher-Smith Laboratories, Inc.
Variety - The Children's Charity
Jack and Jeanne Whitaker
Cliff and Deborah White, The Cliff and Deborah White
Family Foundation
Lois Whitman
Joseph and Deborah Yohn

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

A Cure for Cauty
A. Sturm & Sons Foundation, Inc.
Joel and Kelly Abramson
Earl Abramson and Sheila Schlaggar
Arlene Bandstra Achterhof and James Achterhof
Howell and Madeline Adams
James and Lee Ann Addison
Adobe Systems Incorporated
Janice Akridge
Farid and Faranza Ali
Amazon Smile Foundation
Anonymous
Adam and Laura Antoyan
Frances Ardolf
Arlington Lexus in Palatine
AXA Foundation
Baker Hughes Foundation
Bank of North Georgia
Adrian Banner
Geoff Bauer
Thomas and Elizabeth Beattie
Martina Bebin
Matthew and Kelley Beck
Benevity Community Impact Fund
Tom Bercu
Larry and Judy Best
Roger and Diane Bevans
Biotechnology Industry Organization
BJ Restaurant, Inc.
Cynthia Black
John Blake
BlueCross BlueShield of Massachusetts
Booster
Mark Borman and Karen Hermelin
Tyler and Alison Brainard
George and Laura Braunstein
Bristol Myers Squibb Foundation
Brooks Sports, Inc.
Victor and Diane Brown
Scott and Renee Brown
Linda Buchman
Andrew and Elizabeth Buchsbaum
Buffalo Wild Wings
Henry Buhl
Pablo Burbridge
Linda Cain

Joe and Sharon Cappadona
 Caribou Coffee Charitable Foundation
 Cavarocchi Ruscio Dennis Associates
 Brad Charles
 Chris Cheadle
 Chicago Title of Texas, LLC
 William and Sue Clark
 Cleveland Clinic
 Richard Cockerham
 Jessica Cohen
 Larry and Terry Coil
 County of Los Angeles
 Phillip and Ann Marie Cole
 Colten Cowell Foundation
 Larry and Cynthia Comeaux
 Wilfred and Jennifer Cooper
 County of Los Angeles
 Jared and Margaret Cox
 Cullman Savings Bank Foundation
 Customer Engineering Services, LLC
 Donelle Dadigan
 Michael and Beth Dean
 Joseph and Pamela Delpino
 Leonard and Lisa Dick
 Gloria Dinsdale
 Discavage Family Foundation, Inc.
 DoTopia
 Blake and Mindy Douet
 Denise Dowling
 Darian Downs
 Joey and Linda Dugas
 Stuart Dunlap
 Andre Duplantis
 Robin Edwards
 Dennis Ehrler
 Richard and Athena Eitel
 Henry and Kathy Elsesser
 Moise and Carol Emquies, Emquies Family Fund
 Jay Erb
 Kenneth and Linda Escobar
 Chris Evans, Independent Rebuild Specialist, LLC
 Tom and Kathy Ewald
 Fidelity Charitable Gift Fund
 Peter and Joyce Filosi
 Firstgiving, Inc.
 Kasey and Jami Flicker
 William and Helena Foulkes
 Jesus Frausto
 Liliana Frausto
 Fraternal Order of Detention Center Officers and Personnel,
 CWA Local 2911, Anne Arundel County, MD
 Gap, Inc.
 The GE Foundation
 Jennifer Geetter
 Gail Levitt Gershon
 Todd and Jill Giannoble
 Gillian's Wonderland Pier
 Global Impact

Larry Gohmert
 Goldman, Sachs & Co. Matching Gift Program
 Joshua Gordon
 William Grabb and Jean Leonard
 Robert and Nancy Graham
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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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Neurodevelopmental Disabilities

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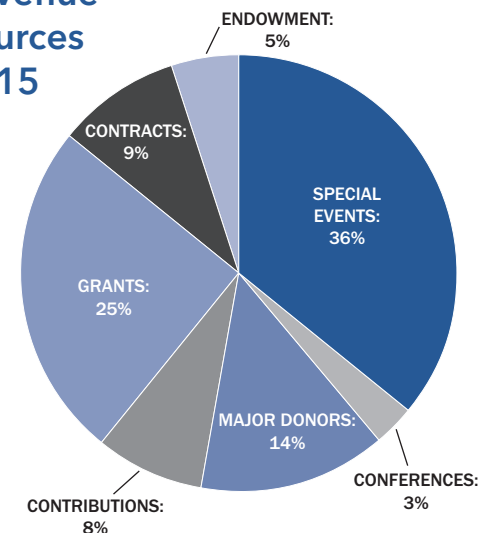
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National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Financial Position • 12-31-15

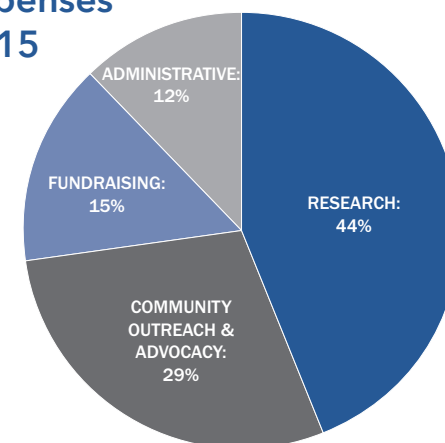
As of December 31,	2015	2014
Assets		
Current Assets		
Cash and cash equivalents	\$ 2,767,106	\$ 2,149,653
Short-term investments	762,809	838,562
Accounts receivable	2,548	274,463
Promises to give, current portion	242,500	417,226
Prepaid expenses and other assets	110,268	75,260
Total current assets	3,885,231	3,755,164
Long-term investments	4,689,245	5,082,040
Property and equipment	146,437	185,887
Promises to give, less current portion	73,697	-
Total Assets	\$ 8,794,610	\$ 9,023,091
Liabilities and Net Assets		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	\$ 37,692	\$ 30,557
Accrued compensation	148,301	163,779
Deferred rent and lease incentive, current portion	19,525	16,781
Gift annuity obligations, current portion	12,530	12,530
Total current liabilities	218,048	223,647
Deferred rent and lease incentive, less current portion	82,903	101,986
Gift annuity obligations, less current portion	73,048	76,912
Total liabilities	373,999	402,545
Net assets		
Unrestricted		
Undesignated	1,002,282	1,220,131
Designated	4,641,486	4,864,263
Total unrestricted	5,643,768	6,084,394
Temporarily restricted	1,897,399	1,656,708
Permanently restricted	879,444	879,444
Total net assets	8,420,611	8,620,546
Total liabilities and net assets	\$ 8,794,610	\$ 9,023,091

Operating Revenue Sources 2015



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

Operating Expenses 2015



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

The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year's auditors completed their 2015 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. 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 both the TS Alliance and the TS Alliance Endowment Fund. The TS Alliance Endowment fund incurred a net loss on its investments in 2015, contributing to the (\$199,935) negative change in net assets on a consolidated basis. On a stand alone basis, operations of the TS Alliance generated a positive change in net assets of \$97,846 in 2015.

National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Activities

	Unrestricted	Temporarily Restricted	Permanently Restricted	2015 Total	2014 Total
Revenue and Support					
Special Events	\$ 1,460,839	\$ 122,133	\$ -	\$ 1,582,972	\$ 1,671,191
Cost of direct benefits to donors	(147,075)			(147,075)	(206,047)
Special events, net	1,313,764	122,133	-	1,435,897	1,465,144
Contributions	621,066	1,142,158		1,763,224	1,479,852
Contracts	380,405			380,405	550,887
Interest and dividends	271,643	56,197		327,840	384,270
Conferences	98,408			98,408	657,556
Memorials and honoraria	93,003	4,215		97,218	72,410
Federated funding	49,688			49,688	79,771
Other income	1,404			1,404	9,351
	2,829,381	1,324,703	-	4,154,084	4,699,241
Net assets from restrictions	1,013,888	(1,013,888)		-	-
Total revenue and support	3,843,269	310,815	-	4,154,084	4,699,241
Expenses					
Program services					
Research	1,706,805			1,706,805	1,508,138
Family services	608,533			608,533	629,770
Public health education	364,102			364,102	284,172
Government relations	126,441			126,441	178,975
Professional education	40,042			40,042	39,012
World TSC Conference				-	651,254
Total Program Services	2,845,923	-	-	2,845,923	3,291,321
Supporting Services					
Fundraising	593,713			593,713	705,401
Management and general	506,928			506,928	334,737
Total supporting services	1,100,641	-	-	1,100,641	1,040,138
Total expense	3,946,564	-	-	3,946,564	4,331,459
Change in net assets from operations	(103,295)	310,815	-	207,520	367,782
Net loss on investments	(337,331)	(70,124)		(407,455)	(194,079)
Change in net assets	(440,626)	240,691	-	(199,935)	173,703
Net assets, beginning of year	6,084,394	1,656,708	879,444	8,620,546	8,446,843
Net assets, end of year	\$ 5,643,768	\$ 1,897,399	\$ 879,444	\$ 8,420,611	\$ 8,620,546



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

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