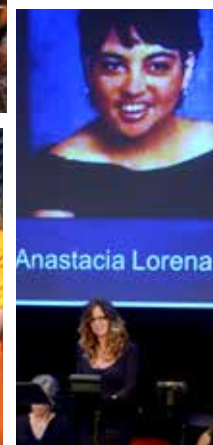
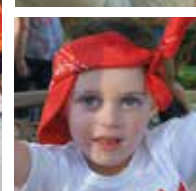




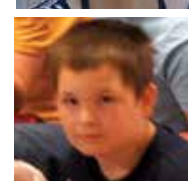
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2014 Annual Report



Tuberous Sclerosis Alliance



FORTY YEARS OF MILESTONES: 1974 - 2014

- 1974**
 - The first meeting of National Tuberous Sclerosis Association's (NTSA's) founders - Debbie Castruita, Adrienne Cohen, Susan (Diaz) McBriene and Verna Morris - is held in Southern California. Susan had previously sent a letter to *Exceptional Parent* magazine seeking other parents of children with TSC.
- 1975**
 - Federal tax exemption received from the IRS.
 - Bylaws adopted by the membership.
 - Medical advisory board established.
 - First NTSA Conference held.
- 1976**
 - First newsletter is published.
 - Manuel R. Gomez, MD, publishes new study of 150 cases of TSC.
- 1979**
 - First edition of *Tuberous Sclerosis*, edited by Manuel R. Gomez, MD, published by Raven Press.
- 1980**
 - NTSA starts regional NTSA Board teleconferences.
- 1982**
 - NTSA corporate office moves to Illinois.
- 1983**
 - Ann Landers features a column about TSC, which triggers 1,500 phone calls and 650 letters to NTSA.
 - First annual gift-wrap campaign raises \$3,246.
- 1984**
 - NTSA celebrates 10th anniversary with more than 1,800 families.
 - NTSA funds first research grant of \$5,800 to Dr. Ken Dumars, University of California, Irvine.
- 1985**
 - NTSA Board of Directors holds first face-to-face meeting in New York.
 - TS International is launched with a meeting in London; representatives from the United States, United Kingdom, Germany and the Netherlands are present.
 - NTSA funds \$23,500 in research grant awards.
- 1986**
 - First TSC clinic opens at Wyler's Children's Hospital in Chicago.
 - NTSA funds \$74,000 in research grant awards.
- 1987**
 - TSC gene localized to chromosome 9.
 - NTSA funds \$72,300 in research grant awards.
 - NTSA sponsors a research workshop in Irvine, CA.
 - NTSA approved for membership in National Voluntary Health Agencies.
- 1988**
 - NTSA headquarters moves to Washington, DC area.
 - Second edition of *Tuberous Sclerosis*, edited by Manuel R. Gomez, MD, published by Raven Press.
 - President Reagan signs a resolution declaring May 8-15 as National Tuberous Sclerosis Awareness Week.
- 1989**
 - Ice skater Scott Hamilton accepts limited role as NTSA spokesperson.
- 1990**
 - NTSA and New York Academy of Sciences present International Symposium on tuberous sclerosis in Bethesda, MD.
 - *Tuberous Sclerosis and Allied Disorders: Clinical, Cellular and Molecular Studies* is published by the New York Academy of Sciences.
- 1992**
 - Second TSC gene is linked to a region on chromosome 16.
 - NTSA funds \$156,701 in research grant awards.
 - NTSA testifies before Congress about increased research funding for TSC.
- 1993**
 - TSC2 gene on chromosome 16 is identified by European consortium.
 - Sixth International Tuberous Sclerosis Symposium held at Mayo Clinic in Rochester, MN.
- 1994**
 - 20th Anniversary International Symposium & Gala held in Crystal City, VA.
- 1995**
 - NTSA Endowment Fund and Eternal Flame Society are established.
 - NTSA approves five-year Strategic Plan.
 - NTSA funds \$210,000 in research grant awards.
- 1996**
 - Annual revenues exceed \$1 million.
 - Jonathan Taylor Thomas and Marg Helgenberger appear in NTSA public service announcements.
- 1997**
 - NTSA launches first website.
 - TSC1 gene on chromosome 9 is identified by International Consortium.
 - Public lecture held at National Institutes of Health (NIH).
- 1998**
 - NTSA launches research program and funds \$886,741 in research grant awards.
 - Historic TSC Consensus Conference held in Annapolis, MD.
 - 10th International Tuberous Sclerosis Symposium held in Goteborg, Sweden.
 - NTSA and Panasonic hold first TSC videoconference.
- 1999**
 - Third edition of *Tuberous Sclerosis Complex* published by Oxford University Press.
 - NTSA holds first National Family Conference in Washington, DC.
 - NTSA serves more than 20,000 constituents, including 11,000 family members and adults personally impacted by TSC.
 - NTSA holds 25th Anniversary Gala in Boston, MA.
- 2000**
 - NTSA adopts a new logo and begins doing business as the Tuberous Sclerosis Alliance (TS Alliance).
 - TS Alliance commits to hiring a professional fund development team to increase fundraising efforts.
- 2001**
 - TS Alliance obtains support from Congress to start TSC Program in Department of Defense Congressionally Directed Medical Research Program.
 - Community Alliance program launched.
- 2002**
 - TS Alliance partners with NIH to hold a scientific research conference "New Perspectives In Tuberous Sclerosis Research," which will produce a comprehensive research plan for TSC.
 - TS Alliance announces partnership with The Rothberg Institute for Childhood Diseases to advance drug discovery efforts specific to TSC.
 - TS Alliance announces the diagnostic genetic test for TSC has been transferred from a TS Alliance-funded research environment to a fee-for-service clinical laboratory, Athena Diagnostics.
- 2003**
 - TS Alliance and LAM Foundation award funding to sponsor a clinical trial on treatment of kidney and lung manifestations with Rapamycin.
 - Based on the success of the government advocacy program, the TS Alliance selects the firm of Cavarocchi, Ruscio, Dennis & Associates, LLC to represent the TS Alliance on Capitol Hill.
- 2004**
 - TS Alliance begins to formally address the needs of adults affected by TSC.
 - TS Alliance increases its number of volunteers to more than 1,000.

2005

- TS Alliance increases Community Alliances to 26 locations nation-wide.
- TS Alliance celebrates 30th Anniversary with a Gala in NYC, raising \$500,000.
- The TS Alliance amends its Articles of Incorporation to be inclusive of people with TSC across their lifespan and continues to expand services for adults with TSC.
- TS Alliance partners with the LAM Foundation to initiate the first clinical trial with an FDA-approved drug (Rapamycin).
- Nine institutes at the National Institutes of Health have funded approximately \$10 million in TSC research.
- TS Alliance sponsors its first-ever TSC Adult Summit.

2006

- National TSC Conference held outside Chicago with 1,000 participants.
- Developed partnerships with Polycystic Kidney Disease Foundation and American Epilepsy Society.
- Continued increased media coverage, both nationally and in local media markets, including Times Square billboard displaying Julianne Moore PSA; three episodes of "House" (FOX TV series) mention tuberous sclerosis complex.
- TS Alliance volunteers make more than 200 visits to Capitol Hill to advocate for increased research funding.
- TSC Natural History Database launched.
- Continued expansion of services for adults with TSC, including a new Adult Journal, Adult Town Hall Meeting, specific adult education tracks at national and regional conferences, and increased adult participation in Community Alliances.

2007

- TS Alliance and the PKD Foundation co-fund two research grant awards to study the link between TSC and polycystic kidney disease. The PKD Foundation also co-funds a grant award with the TS Association of the UK.

2008

- TS Alliance coordinates the International Research Conference on Tuberous Sclerosis Complex: From Genes to New Therapeutics in Annapolis, MD.
- Publication in the *New England Journal of Medicine* reports the results of the single site trial for the use of rapamycin (Sirolimus) to treat renal angiomyolipomas in individuals with TSC and/or LAM.
- TS Alliance launches nation-wide IEP training program.
- TS Alliance produces widely successful Infantile Spasms educational video.

2009

- TS Alliance and TSC epilepsy surgery featured on "The Doctors" syndicated TV program.
- During an FDA Advisory Panel Hearing, TS Alliance constituents advocate for approval of vigabatrin (Sabril®), which is eventually approved by the FDA to treat infantile spasms
- TS Alliance launches new outreach program via social networking sites, including Facebook and YouTube.
- Novartis Oncology launches multi-center, international clinical trials for subependymal giant cell tumors and renal angiomyolipomas in TSC.
- Group of investigators led by Mustafa Sahin, MD, PhD develops protocol for the study of the impact of an mTOR inhibitor on neurocognition and seizures in individuals with TSC, and gain approval for study from Novartis Oncology.

2010

- Fourth edition of *Tuberous Sclerosis Complex*, edited by Kwiatkowski, Whittemore, and Thiele, published by Wiley-Blackwell.
- FDA approves the first drug (called Afinitor®) designated to specifically treat SEGAs associated with TSC.
- Introduction of 18 nation-wide Town Hall Meetings to educate constituents on a local basis.
- TS Alliance establishes TSC Drug Screening Program.
- H.P. Acthar Gel approved by FDA to treat infantile spasms.
- TSC Natural History Database enrollment reaches more than 1,000 participants at 15 U.S.-based TSC Clinics.
- TS Alliances introduces new online support community in partnership with Inspire.com.

2011

- TS Alliance implements new Adult Initiative to ensure continued focus on the needs of adults with TSC and their specific issues.
- TS Alliance receives \$200,000 grant from the Pediatric Epilepsy Foundation to support the TSC Natural History Database.
- TS Alliance is awarded a \$500,000 challenge matching grant from the Harold Simmons Foundation and the Unlock the Cure Campaign is launched.
- TS Alliance recognizes the 10th anniversary of the TSC research program in the Department of Defense's Congressionally Directed Medical Research Program, which has funded \$35 million in research directly relevant to TSC since 2001.
- TS Alliance celebrates tenth anniversary of the Community Alliances.
- The TS Alliance sponsors an International TSC Research Conference - the 2011 Summit on Drug Discovery in TSC and Related Disorders - in Washington, DC, where its International Scientific Advisory Board meets face-to-face for the first time.
- TS Alliance hosts a TSC International (TSCi) Summit, which attracts representatives from 19 TSC organizations from around the world; meeting results in development of the first TSCi website.

2012

- TS Alliance earns 2012 GreatNonProfits Top-Rated Award.
- The U.S. Food and Drug Administration approves Afinitor® as a treatment for renal angiomyolipoma associated with TSC.
- TS Alliance sponsors the first TSC Clinical Consensus Conference since 1998 to update the recommendations for diagnosis, surveillance and management of TSC. The conference includes participants from 14 countries.
- The TSC Clinical Research Network is awarded grants to initiate two clinical studies at five TSC Clinics to find biomarkers or signals that identify which newly diagnosed infants with TSC are at highest risk of developing infantile spasms by age two or signs of autism by age three.
- TS Alliance leads and participates in first worldwide TSC Global Awareness Day, held May 15.
- A new Young Adult Transition Task Force forms to develop strategies and materials to support young adults with TSC.

2013

- International Research Conference on TSC and Related Disorders: Molecules to Medicine held in Washington, DC.
- Open-access publication of updated clinical consensus guidelines for diagnosis, management, and treatment of TSC.
- First global TSC Clinic is recognized in Israel by the TS Alliance.
- Partnered with PeerReview Institute to offer CME course to educate physicians about new TSC Clinical Consensus Guidelines.

2014

- TS Alliance holds first World TSC Conference from July 3-6 in Washington, DC.
- TS Alliance of Israel becomes first-ever Global Alliance.
- John Morogiello commissioned to script 40-year history into the play FOUR DECADES | ONE COMMUNITY performed as the cornerstone of the 40th Anniversary Celebration held at the Hudson Theatre, New York, NY, October 2014.
- TS Alliance earns 4 Star Rating from Charity Navigator, attains Gold Level rating from Guidestar, gains accreditation by the Better Business Bureau Wise Giving Program, and receives GreatNonProfits Top-Rated Award for third year in a row.



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2014 was a true milestone for the Tuberous Sclerosis Alliance (TS Alliance), as it marked our 40th anniversary. In 1974, four mothers had the foresight to come together to start an organization at a time when the future for people with tuberous sclerosis complex (TSC) was often bleak. With 40 years of progress celebrated throughout 2014, true hope exists due to ongoing research, new treatments, extensive support programs and a committed community.

Highlights of the year include the monumental success of the 2014 World TSC Conference; the 40th Anniversary Celebration held in New York City, featuring the world-premiere reading of the play *FOUR DECADES | ONE COMMUNITY* written by John Morogiello; the establishment of our first global alliance, the TS Alliance of Israel; new research initiatives; a Four Star Rating from Charity Navigator; and an updated Strategic Plan, to name a few.

Our four decades of progress would not have been possible without the TS Alliance's founding mothers – Debbie Castruita, Adrienne Cohen, Susan (Diaz) McBrine and Verna Morris. Forty years ago, these four visionary women formed the TS Alliance to provide fellowship, pursue knowledge and provide hope to anyone who shared the common bond of tuberous sclerosis complex.

These goals still remain the driving force of the Tuberous Sclerosis Alliance.

ABOUT THE TUBEROUS SCLEROSIS ALLIANCE

The Tuberosus Sclerosis Alliance is dedicated to finding a cure for tuberous sclerois 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.

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, there is certainly hope.

Ongoing research has shown TSC to be a linchpin disease. Why? Because TSC's genetic pathway is so similar to other major diseases, every dollar spent finding cures and treatments for TSC may also bring about quantum leaps in treatment, care and even cures for epilepsy, autism, diabetes and even some forms of cancer.



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.

The TS Alliance has funded almost \$18 million in research on TSC since 1984. Directed by Steven L. Roberds, PhD, Chief Scientific Officer, the TS Alliance grants program funds projects focused on TSC that are proposed by researchers and aligned with priorities of the TS Alliance. Collaborations between basic and clinical researchers are encouraged and fostered, for example, by biennial International TSC Research Conferences. Through the TS Alliance research grants program, applications can be submitted for postdoctoral fellowships, research grants, and Rothberg Courage Awards.

A total of 13 research awards were funded during 2014 for \$486,788. The TS Alliance continued to support six research grants awarded in previous years. Additionally, seven new research awards were funded beginning in 2014 to:

- The Van Andel Research Institute to initiate and operate a TSC Biosample Repository under the direction of the TS Alliance;
- Dr. Gabriella D'Arcangelo (Rutger's University) to develop human TSC neurons derived from induced pluripotent stem cells;
- Dr. Wei Shi (Children's Hospital, Los Angeles) to develop and test a novel mouse model of LAM;
- Dr. Gerta Hoxhaj (Harvard School of Public Health) to study the role of the protein TBC1D7 in cell migration in neurons and angiomyolipomas;
- Dr. Michael Higley (Yale University) to learn how loss of TSC1 disrupts brain signaling circuits in mice;
- Dr. Mustafa Sahin (Boston Children's Hospital) for supplemental support of imaging analysis in a new NIH-funded Rare Diseases Clinical Research Network (RDCRN); and
- Boston Children's Hospital to enable a face-to-face kick-off meeting for the RDCRN to facilitate a rapid start to open collaboration between researchers working on three related rare disorders: TSC, Phelan-McDermid Syndrome, and PTEN disorders.

Among the six ongoing grants, the TS Alliance continued supporting:

- Dr. Jeannie Li (Harvard University) to identify new ways of treating TSC by blocking the ability of cells with TSC1/TSC2 loss to use special nutrient sources and, therefore, selectively kill these cells without killing normal cells;
- Dr. Carmen Priolo (Brigham and Women's Hospital) to study potential biomarkers in blood to assess progression of LAM;
- Dr. Rebecca Ihrie (Vanderbilt University) to study the cellular origin of subependymal giant cell astrocytomas in TSC to determine new approaches to treatment;
- Dr. David Kwiatkowski (Brigham and Women's Hospital) to collect and analyze biosamples from a new European clinical trial to treat or prevent infantile spasms in TSC;
- Dr. Gina Lee (Cornell University) to test for compounds that affecting cellular metabolism that could be used to better treat tumors associated with TSC; and
- Dr. Sue Povey (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 a lifetime. As of December 2014, 1,500 people with tuberous sclerosis complex were enrolled in the project from among 17 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 2014, the TS Alliance invested \$487,708 in the TSC Database. This spending is similar to 2013 but represents a considerable increase over pre-2013 years for two reasons. First, the TS Alliance moved existing records to a new database platform that is better suited for research queries, can accept patient-reported data on quality of life, and will be more cost effective to use. Second, two database sites were added and more funding was provided to the 17 participating sites to increase enrollment and completeness of records moved to the new platform. A contract with Novartis was executed in November 2012 to provide TS Alliance with funding to enhance and grow the TSC Database through 2015.

The TSC Biosample Repository is a new 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 only 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. Sample collection begins in early 2015.

The TSC Biosample Repository is a new TS Alliance-directed project initiated in 2014 that will impact research over the next ten years or more.

The organization also 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 received NIH grants to conduct two clinical studies initiated in 2013. These two clinical studies will determine what early signs or tests can identify infants with TSC at highest risk of developing autism by age three, as well as 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 studies will have a major impact on our ability to intervene very early to prevent some of the most devastating manifestations of TSC. 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 consortium received a new five-year, multi-million dollar award from NIH to be part of the RDCRN described previously. The consortium is also running a sub-study of a larger industry-sponsored Phase 3 trial. As 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.

PROFESSIONAL EDUCATION

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

The TS Alliance funded the open-access publication of two additional peer-reviewed articles to make available to healthcare providers worldwide the latest recommendations on the surveillance and management of cardiac and neuropsychiatric aspects of TSC arising from the 2012 TSC Clinical Consensus Conference. The TS Alliance also co-sponsored a continuing medical education program with PeerView Institute and the University of Florida that reached 3,084 healthcare providers to educate them on the published consensus recommendations.

The TS Alliance worked with other advocacy groups representing rare epilepsy syndromes to further implement recommendations from an Institute of Medicine (IOM) report on the epilepsies, including helping build an online portal where epilepsy researchers can in real-time search for funding opportunities available from non-profit organizations. The TS Alliance also joined forces with other non-profit organizations committed to epilepsy research to create the Epilepsy Leadership Council, an alliance that will continue to keep the focus on patient-centered research and educational initiatives recommended by the IOM report.

The TS Alliance participated in and presented at several professional meetings including: LAM Foundation's LAMposium; a LAM Biomarker Summit; the International Research Conference on TSC and LAM in Beijing, China; Congressional Showcase with the Coalition for Imaging and Bioengineering Research (CIBR); iPharma Conference; Association of Clinical Research Professionals Conference; Interagency Collaborative To Advance Research In Epilepsy (ICARE); Rare Disease Day at NIH; The NINDS Nonprofit Forum; NORD/DIA Annual Conference on Rare Diseases and Orphan Products; Partners Against Mortality in Epilepsy (PAME) conference; and Partnering for Cures. In addition, at the American Epilepsy Society (AES) annual meeting the TS Alliance hosted a TSC reception for more than 50 researchers and 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. She also collaborates with Parent Training Information Centers throughout the country, since providing children with appropriate education is one key to individuals having a good quality of life.

OUTREACH AND SUPPORT

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

The TS Alliance's 2014 World TSC Conference, held July 3-6 in Washington, DC was a huge success, attracting 690 participants from 44 states and 20 countries during the three-day event. Attendees included families and individuals with TSC; caregivers; healthcare professionals; researchers; a wide array of exhibitors; and others interested in TSC. Thirty-four of the 48 educational sessions were videotaped and uploaded to the TS Alliance YouTube channel for anyone to view after the conference; these recordings garnered 3,035 views by the end of 2014. In addition to the educational sessions offered throughout the conference, many social activities took place, including those specifically for adults with TSC.

The need for a conference of this magnitude was evident in the eight-year hiatus from the TS Alliance's last National TSC Conference held in 2006. Since then, tremendous changes have occurred in clinical care and approved treatments, including two approved indications to shrink tumors associated with TSC in the brain and kidneys, and in 2012, updating the TSC consensus guidelines for diagnosis, testing and treatment created new gold standards in care. To acknowledge this need, the TS Alliance began planning another national conference in 2012. This plan quickly morphed into addressing the ever-expanding global TSC network and became the 2014 World TSC Conference.

In addition to the World TSC Conference, the Outreach Department provided support and resources to 2,519 individuals and families dealing with TSC. The Vice President of Outreach attended 34 Individual Education Program meetings in person, through SKYPE, and via conference calls to support families in getting educational services for their children throughout the country.

In 2014, 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. Throughout the year, 1,766 free parent trainings and webinars on educational advocacy were offered to families dealing with educational issues for their children.

There were four new publications developed for the young adult webpage, including "Choosing Health Insurance for Young Adults with TSC," "Healthy Eating Tips," "Healthy Grocery Shopping for Young Adults with TSC," and "Finance for Young Adults with TSC Wanting to Live Independently."

The TS Alliance offered nine adult topic calls on topics specific to independent and semi-independent adults with TSC. A pilot Dependent Adult Transition Resource Coordinator Program was developed for Louisiana to support caregivers of dependent adults. Three Dependent Adult Topic Calls supported caregivers of dependent adults. The Adult Regional Coordinator Program provided one-on-one support to 1,508 adults with TSC across the country. In addition, the TSC Clinic Ambassadors program supported 503 individuals and families at TSC Clinics located in Miami, FL; Cincinnati, OH; Columbus, OH; Atlanta, GA; Nashville, TN; Birmingham, AL; Denver, CO; Dallas, TX; Austin TX; and Salt Lake City UT.

Through the network of 34 volunteer branches of the organization, called Community Alliances, local education and support group meetings are held throughout the country. The TS Alliance hosted 18 educational meetings and 41 gatherings held at Community Alliance locations during the fiscal year 2014.

Officially launched in 2014 with the TS Alliance of Israel, the TS Alliance Global Alliance Program was created as a way to address unmet needs within the global TSC community at the country level. This program provides the opportunity for the TS Alliance to share experiences and assist in the start-up or support of TSC-related organizations in other countries and fosters stronger links between the TS Alliance, communities and individuals around the world.

PUBLIC AWARENESS

The TS Alliance strives to heighten awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families. During 2014, the TS Alliance produced three issues of its national magazine, *Perspective*, which is mailed to almost 15,000 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 37,500 unique visitors. 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 6,398 members, while our Twitter account has 1,100-plus followers.

To increase public awareness, the TS Alliance heavily promoted TSC Global Awareness Day on May 15. This year's event included a dedicated website, tsglobalday.org, to house a "World of Thanks" social media/photo campaign, which garnered 160 pictures from 24 countries as well as a huge Facebook/Twitter push. In addition, the TS Alliance President & CEO,

Chief Scientific Officer and Dr. Kevin Ess participated in nine radio interviews, which ultimately aired on 1,764 times reaching more than 10.4 million listeners.

To help educate physicians, the TS Alliance updated its "Diagnosis, Surveillance and Management of Individuals with TSC" publication to reflect current standards. The organization also produced an educational video focused on government advocacy.

GOVERNMENT ADVOCACY

The TS Alliance'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 2014. More than 80 members of the TSC community participated, asking their senators and representatives to sign onto Dear Colleague letters in support of TSC research.

In the House, 25% or 110 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 was sponsored by Senators Chris Murphy (D-CT) and Johnny Isakson (R-GA) and included 17 signatures. In FY2015, the TSC Research Program at the CDMRP received a \$6 million appropriation, bringing the cumulative funding to \$59 million since 2002 as a result of our successful grassroots efforts.

Research done through the TSCRP 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 lymphangiomyomatosis (LAM), a life-threatening lung manifestation of TSC, funded in FY2013 (the most recent year for which awards have been announced);
- 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 leading to a clinical trial funded in FY2012.

The TSCRP has also funded research to develop animal models of TSC that have seizures, enabling a better understanding of the causes 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 advocacy efforts included a Congressional Briefing on Capitol Hill to commemorate TSC Global Awareness Day on May 15, 2014. Congressional staff and key members of the TSC research and grassroots communities attended the event.

FUND DEVELOPMENT

It is inspiring to see what the TSC community is able to accomplish when faced with the shared goals of both raising awareness and generating funds to support community programs and to further valuable research projects. Year after year, people from across the United States support the TS Alliance through a wide a range of events, such as garage sales, bake sales, golf tournaments, walkathons and comedy nights. These events are successful because of the dedication and creativity of the TSC community.

In 2014, special events netted \$1,470,814, representing 33 percent of the organization's overall revenue. Highlights included:

The **40th Anniversary Celebration** held on Broadway in New York City raised \$267,673. The evening was a smashing success to fuel the fight against TSC, while also revering the past and inspiring hope for the future. We were honored to highlight the significant contributions of Abe and Celia Mastbaum and Drs. Jonathon and Bonnie Rothberg of The Rothberg Institute for Childhood Diseases for their unending passion and dedication to the TS Alliance and TSC research. Our wonderful and talented celebrity friends brought our play, **FOUR DECADES | ONE COMMUNITY**, to life as the showcase of the event. It was a beautiful living history of the triumphs and challenges so many have endured. This unique performance validated our organization's journey while paying tribute to the sacrifices of individuals and families to ensure a brighter future for the next generation.

Fund Development (cont.)

Comedy for a Cure® celebrated its thirteenth anniversary in 2014 at LURE in Hollywood, CA, raising \$206,410 for the TS Alliance. Over the last 13 years, Comedy for a Cure has garnered nearly \$4 million cumulatively. This year's event honored the Lauren Krinsky Family and TS Alliance President & CEO Kari Luther Rosbeck for their tireless commitment and dedication to support families living with TSC. Mo Collins headlined the evening's show, supported by hilarious performances by Kate Flannery, as well as comic Jerrod Carmichael. The funny, warm and talented Jim O'Heir served as emcee. Auctioneer Damon Casatico once again led the live auction, where attendees bid on items ranging from custom-made jewelry by Edina Kiss to a trip to Scotland.

The **Step Forward to Cure TSC®** walks took place in 33 cities across the United States and collectively raised \$1,046,964. Julianne Moore once again served as our National Honorary Chair with support provided by national sponsors Novartis, Lids, Lundbeck, Cyberonics, and MetLife Center for Special Needs Planning.

The **Step Forward to Cure TSC® National Walk on the Mall** was held at Henry Bacon Park, raising more than \$150,000 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, Questcor, Hollingsworth, LIDS, Buffalo Wild Wings, The Law Office of Joseph P. Smith, III, Cavarocchi Ruscio Dennis Associates and Caribou Coffee.

The year also saw the end of the first phase of the hugely successful **Unlock the Cure** fundraising campaign, which raised \$751,171 and a total of \$4,687,571 over three years including the \$500,000 challenge grant from the Harold Simmons Foundation. The Unlock the Cure campaign helped the TS Alliance implement a Drug Screening Program, identify biomarkers, develop a Clinical Research Consortium, expand the TSC Natural History Database, and increase support for the TS Alliance research grants program.

Events Raising More Than \$10,000

Step Forward to Cure TSC® Walkathons

- Alabama - Carole Pitard and Margaret Cox
- Arizona - Debora Moritz
- Atlanta/North Georgia - Planning Committee
- Chicago (Galesburg) - Karen Johnson-Wenger
- Chicago (Westmont) - Geri Greenberg and Lisa Smiley
- Connecticut - Rebecca Thereault
- Dallas - Planning Committee
- DC Metro National Walk on the Mall - Planning Committee



- Delta Region - Temple Poche
- Heartland (Iowa) - Ryan and Cindy Blackard
- Houston - Bill and Taska Fields
- Indiana - Pat Schmutte
- Memphis - Brittany Schwaigert
- Michigan - Treasa Bolger-Dunlap
- New England - Stacie Verrill
- New York (Long Island) - Rob and Denise Spear
- Northern California - Diane Burgis
- Pacific Northwest (Seattle) - Susan Jorski
- Rocky Mountain - Caroline Clough
- Southern California - Barbara O'Neill and Dawn Redfield
- St. Louis - Gwen Montaigne
- Upper Midwest - Judy Prudhomme and Maria Gibbons

Major Events

- Comedy for a Cure - Event Planning Committee
- Crashin' for the Cause - Joe and Abby Kopf
- Geneva Lakes Amazing Race - Rebecca Melka, Rob Keefe, Tim Schnake and Sharon Clark
- The 8th Annual Heather Joy Memorial TS Alliance/LAM Foundation Golf Outing
- Ironman Chattanooga Marathon - Reiko Donato
- Rock for Riley - Melanie Vogel
- San Luis Obispo, CA Marathon - Kim Sabreda
- Strikeout TSC Softball Tournament - Laura Laramie
- Will's Quest - Will Cooper, Jr.

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January 1 to December 31**

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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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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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National Tuberos Sclerosis Association & Affiliate

Consolidated Statements of Financial Position • 12-31-14

December 31,	2014	2013
Assets		
Current Assets		
Cash and cash equivalents	\$ 2,149,653	\$ 3,305,934
Short-term investments	838,562	268,244
Accounts receivable	274,463	326,326
Promises to give	417,226	162,675
Prepaid expenses and other assets	75,260	181,502
Total current assets	3,755,164	4,244,681
Long-term investments	5,082,040	4,807,500
Property and equipment	185,887	203,501
Total Assets	\$ 9,023,091	\$ 9,255,682
Liabilities and Net Assets		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	\$ 30,557	\$ 85,199
Accrued compensation	163,779	145,188
Deferred revenue	-	360,395
Deferred rent and lease incentive, current portion	16,781	14,263
Gift annuity obligations, current portion	12,530	12,050
Total current liabilities	223,647	617,095
Deferred rent and lease incentive, less current portion	101,986	119,825
Gift annuity obligations, less current portion	76,912	71,919
Total liabilities	402,545	808,839
Net assets		
Unrestricted		
Undesignated	1,220,131	1,594,761
Designated	4,864,263	4,358,358
Total unrestricted	6,084,394	5,953,119
Temporarily restricted	1,656,708	1,614,280
Permanently restricted	879,444	879,444
Total net assets	8,620,546	8,446,843
Total liabilities and net assets	\$ 9,023,091	\$ 9,255,682

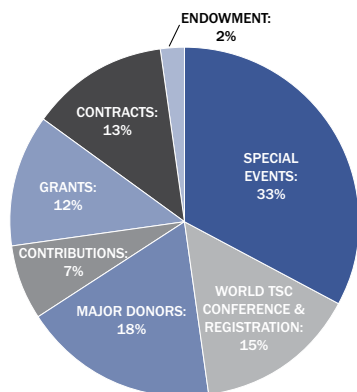
The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year's auditors completed their 2014 audit and submitted an unmodified opinion to the TS Alliance Board of Directors. The complete audited financials are on file with the TS Alliance. To obtain a copy, please call (800) 225-6872 or download at www.tsalliance.org. The 2014 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 operating entity ended the year with a \$109,987 surplus.

National Tuberosus Sclerosis Association & Affiliate

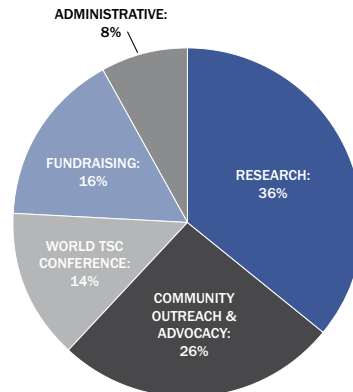
Consolidated Statements of Activities

	Unrestricted	Temporarily Restricted	Permanently Restricted	2014 Total	2013 Total
Revenue and Support					
Special Events	\$ 1,597,336	\$ 73,855	\$ -	\$ 1,671,191	\$ 1,476,789
Cost of direct benefits to donors	(206,047)			(206,047)	(124,998)
Special events, net	1,391,289	73,855	-	1,465,144	1,351,791
Contributions	532,821	977,192		1,510,013	1,526,495
Conferences	657,556			657,556	203,800
Contracts	550,887			550,887	779,327
Interest and dividends	302,952	81,318		384,270	240,526
Federated funding	79,771			79,771	77,105
Memorials and honorariums	67,180	5,230		72,410	73,510
Other income	9,351			9,351	5,984
	3,591,807	1,137,595	-	4,729,402	4,258,538
Net assets from restrictions	1,053,224	(1,053,224)		-	-
Total revenue and support	4,645,031	84,371	-	4,729,402	4,258,538
Expenses					
Program services					
Research	1,508,138			1,508,138	2,039,165
World TSC Conference	651,254			651,254	-
Family services	629,770			629,770	713,627
Public health education	284,172			284,172	196,462
Government relations	178,975			178,975	142,428
Professional education	39,012			39,012	22,109
Total Program Services	3,291,321	-	-	3,291,321	3,113,791
Supporting Services					
Fundraising	705,401			705,401	673,986
Management and general	364,898			364,898	388,637
Total supporting services	1,070,299	-	-	1,070,299	1,062,623
Total expense	4,361,620	-	-	4,361,620	4,176,414
Change in net assets from operations	283,411	84,371	-	367,782	82,124
Net (loss) gain on investments	(152,136)	(41,943)		(194,079)	520,564
Change in net assets	131,275	42,428	-	173,703	602,688
Net assets, beginning of year	5,953,119	1,614,280	879,444	8,446,843	7,844,155
Net assets, end of year	\$ 6,084,394	\$ 1,656,708	\$ 879,444	\$ 8,620,546	\$ 8,446,843

Operating Revenue Sources FY 2014



Operating Expense Types FY 2014





The 2014 Annual Report is dedicated to Dee Triemer – a TSC mom and advocate as well as a long-time TS Alliance volunteer and staff member.

Dee passed away May 19, 2015, but her legacy, tireless efforts and achievements live on and inspire the entire TSC community.

Dee truly demonstrated that one person can make an impactful difference as she literally touched thousands of lives.



WITH A CURE. WHERE OUR STORY MUST END.