# Community THROUGH Consensus

2013 ANNUAL REPORT







## WE'LL GIVE EVERYTHING. BUT UP.

## IMPACTING COMMUNITY THROUGH CONSENSUS

In September 2013, the Tuberous Sclerosis Alliance (TS Alliance) formally announced newly updated clinical consensus guidelines for the diagnosis, surveillance and management of tuberous sclerosis complex (TSC). To communicate the recommendations to healthcare professionals, the October 2013 issue of Pediatric Neurology included two peer-reviewed papers detailing the new guidelines—one entitled "Tuberous Sclerosis Complex Diagnostic Criteria Update: Recommendations of the 2012 International Tuberous Sclerosis Complex Consensus Conference" and the other, "Tuberous Sclerosis Complex Surveillance and Management: Recommendations of the 2012 International Tuberous Sclerosis Complex Consensus Conference."

Prior guidelines were based on a 1998 TSC consensus conference, and since then, tremendous advances have been made in the field of TSC, particularly in the growth of new treatment options. We believe these new clinical consensus guidelines will improve the quality of life of everyone touched by this disorder. And as result, these newly updated "international gold standards" for TSC diagnosis, surveillance and management mean everyone in the TSC community worldwide is impacted.

Darcy A. Krueger, MD, PhD, of Cincinnati Children's Hospital Medical Center, and Hope Northrup, MD, of The University of Texas Medical School at Houston, wrote both papers in Pediatric Neurology. Drs. Krueger and Northrup served as co-chairs of the TS Alliance's 2012 International TSC Consensus Conference, which involved 79 TSC experts from 14 countries to develop the new guidelines.

Because TSC involves multiple systems in the body, specialists in genetics, neurology, epilepsy, cardiology, neurodevelopment and behavior, dermatology, dentistry, nephrology, pulmonology, ophthalmology, gastroenterology, endocrinology and others worked together toward the common goal of ensuring the best care for people with TSC. Since TSC's manifestations vary widely among individuals and can sometimes even be life threatening, accurate clinical consensus guidelines are critical to ensure optimal healthcare management. The new consensus guidelines are available at www.tsalliance.org/consensus.





In 1974, four mothers of children with tuberous sclerosis complex (TSC), having nowhere else to turn but each other, established the TS Alliance. Their goals were unmistakable: to provide fellowship, generate awareness, pursue knowledge and provide hope to those who share the common bond of facing the daily challenges of living with TSC.

The TS Alliance is committed to finding a cure for 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 tuberous sclerosis complex.

## What is Tuberous Sclerosis Complex?

Tuberous sclerosis complex, or TSC, is a genetic disorder that causes tumors to form in many different vital organs, including the brain, eyes, heart, liver, kidneys, skin and lungs. These tumors can lead to uncontrollable seizures, autism, heart disease, cognitive disabilities, facial disfigurement and kidney failure. In fact, TSC is a leading genetic cause of both autism spectrum disorder and epilepsy.

Currently, there is no cure.

Nearly 1 million people worldwide are known to have TSC, with approximately 50,000 in the United States. At least two children born each day in the United States will have TSC. While many cases go misdiagnosed and undiagnosed due to the obscurity of the disease and the mild form symptoms may take in some people, TSC is as common as ALS (Lou Gehrig's Disease) or cystic fibrosis.

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



#### **Expanding Research**

The TS Alliance 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. Since 1984, the TS Alliance has funded more than \$17.4 million in TSC research grants.

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 2013, 1,300 people with tuberous sclerosis complex were enrolled in the project from among 15 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 2013, the TS Alliance invested \$464,780 in this database, which represents a considerable increase over prior years for two reasons. First, the TS Alliance began development and testing of 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, more funding was provided to the 15 participating sites to increase enrollment and completeness of records prior to moving to the new platform. The TS Alliance received a one-year \$70,000 grant award from the Pediatric Epilepsy Research Foundation in Fall 2013, which will underwrite a portion of the operational expenses of the TSC Database through 2014. 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 TS Alliance hosted the 2013 International Research Conference on TSC and Related Disorders: Molecules to Medicines on June 20-23, 2013, at the Omni Shoreham Hotel in Washington, DC. Nearly 200 researchers, clinicians and other constituents attended this successful and productive conference. The conference's opening session revealed new data on multiple cellular mechanisms that impact mammalian Target of Rapamycin (mTOR) activity, which is elevated in TSC. Some of these mechanisms are associated with drugs being tested in animal models of TSC. The conference's keynote address by Dr. Mustafa Sahin of Boston Children's Hospital discussed how alterations in connections between neurons in the brain of individuals with TSC may be responsible for the neurologic and neuropsychiatric problems that so frequently occur. A session on clinical studies covered lessons learned from past clinical trials and ideas for future clinical trials in TSC. The session on genetics revealed that no third gene has yet been identified to cause TSC and that many individuals in whom mutations could not be identified are now being found to be mosaic for TSC1 or



TSC2 mutations, meaning only some of those persons' cells carry mutations. The final two sessions of the conference discussed both animal models and clinical data from which we are learning more about the TSC disease process and how we might identify new treatments or how we might more effectively deliver care using existing treatments. Working groups held during the conference enabled attendees from all different backgrounds to tackle specific questions or problems, including how to achieve the best comprehensive clinical care for individuals with TSC and how to utilize and develop a biobank of tissue and blood or urine samples from people with TSC.

The TS Alliance research grants program funds research focused on TSC that is proposed by researchers and aligned with the research priorities of the TS Alliance. Collaborations between basic and clinical researchers are encouraged.

A total of 16 research awards were funded during 2013 for \$906,474. The TS Alliance Rothberg Courage Award for Research continued supporting three ongoing projects: (1) the development of Seizure Tracker as an epilepsy clinical trial tool; (2) the TSC neurocognitive trial, a clinical study of everolimus effects on neurocognition at Children's Hospital Boston and Cincinnati Children's Hospital Medical Center; (3) a study by Dr. Elizabeth Henske (Brigham & Women's Hospital) to determine whether inhibition of autophagy might kill abnormally growing cells in TSC.

The TS Alliance continued to support nine research grants awarded in previous years. Additionally, five new research awards were announced this year; funding began in 2013 for three of these, and funding of the others will begin in 2014. The three newly funded awards beginning in 2013 were to (1) Dr. Carmen Priolo (Brigham and Women's Hospital) to study potential biomarkers in blood to assess progression of LAM, (2) Dr. Rebecca Ihrie (Vanderbilt University) to study the cellular origin of subependymal giant cell astrocytomas in TSC to determine new approaches to treatment, and (3) 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. Among the nine ongoing grants, the TSC Drug Screening Program continued sponsoring

#### Research (cont.)

research by 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.

The Drug Screening Program also continued to support projects testing drugs for their potential to influence neurologic manifestations of TSC. Dr. Mustafa Sahin (Children's Hospital Boston) is working to identify compounds that reverse changes induced by loss of TSC2 in cultured neurons and to understand their impact on learning and behavioral defects in mice deficient in TSC1 or TSC2. Dr. Seok-Hyung Kim (Vanderbilt University) is screening compounds to reverse abnormal neuronal phenotypes in TSC2 mutant zebrafish.

The final research award consisted of \$240,252 to help support the TSC Clinical Research Consortium and leverage NIH funding. The five clinics comprising this consortium (University of Alabama at Birmingham, Boston Children's Hospital, Cincinnati Children's Hospital Medical Center, Mattel Children's Hospital USA, University of Texas 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. The coordinated work to execute these studies will develop infrastructure and processes to form the basis of an ongoing and growing TSC Clinical Research Consortium. 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.

## **Educating Professionals**

TS Alliance professional educational 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 funded the open-access publication of two peer-reviewed articles in the *Journal of Pediatric Neurology* to make available to healthcare providers worldwide the latest recommendations on the diagnosis, surveillance, and management of TSC 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 available free to physicians to educate them on the published consensus recommendations. Additionally, the TS Alliance worked with other advocacy groups representing rare epilepsy syndromes to help implement some recommendations from an Institute of Medicine report on the epilepsies, including building the HERO website to enable individuals with epilepsy to locate relevant clinical studies.

The TS Alliance participated in and presented at several professional meetings including: LAM Foundation Conference; World Orphan Drug Congress; Association of Clinical Research Professionals Conference; Interagency Collaborative To Advance Research In Epilepsy; The NINDS Nonprofit Forum; NORD/DIA Annual Conference on Rare Diseases and Orphan Products; Partnering for Cures; Child Neurology Society Annual Meeting; and TSC Research Conferences in Germany and Norway. At the American Epilepsy Society 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.

## Supporting the TSC Community

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

Throughout 2013, the department provided support and resources to 2,272 individuals and families dealing with TSC. The Director of Advocacy and Education attended 26 Individual Education Program (IEP) meetings in person, through SKYPE, and via conference calls to support families in attaining educational services for their children throughout the country.

In 2013, 23 Educational Liaison volunteers, working in 23 states, connected families to free educational advocacy trainings in collaboration with the states' Parent Training and Information Centers. There were also more than 1,000 free parent trainings and webinars on educational advocacy offered to families dealing with educational issues for their children.

In addition, all educational advocacy publications were updated and a new educational advocacy publication, "What College Professors Need to Know about TSC," was written to help young adults self-advocate at the college level. A new



Educator Mentor Program (EMP) was developed for the support of school systems to help in the understanding the learning needs of children and young adults with TSC. The EMP is comprised of administrators, therapists, physiologists and teachers from pre-kindergarten to college level having experience with TSC. They provide one on one support to any professional in the school system needing education and support in understanding the educational complexities of TSC. This program supported 25 school systems in 2013.

To serve the adult population, nine adult calls were held on topics specific to independent and semi-independent adults with TSC. A pilot dependent adult topic call was also held for parents of dependent adults and a dependent adult task force developed to address the needs of this population. The Adult Regional Coordinator Program developed to support adults via a one-to-one basis supported 1,077 adults with TSC throughout the country.

The TS Alliance online social network through "Inspire" helps to connect individuals and families dealing with TSC and get support from each other's experience. The TSC community on Inspire includes 2,154 members from 79 countries as of December 31, 2013.

In addition, the TSC Clinic Ambassadors program supported 238 individuals and families one on one in eight TSC Clinics located in Miami, FL; Cincinnati, OH; Columbus, OH; Atlanta, GA; Nashville, TN; Birmingham, AL; Denver, CO, and Dallas, TX.

Through a network of 32 volunteer branches of the organization, called Community Alliances, local education and support group meetings are held throughout the country. The TS Alliance hosted 20 educational meetings and 33 gatherings and 4 regional conferences. These conferences were in Grand Rapid, MI; New York, NY; Birmingham, AL; and Kansas City, MO. These meetings, gatherings and regional conferences facilitated stronger connections and peers, researchers, and clinicians in the community and educated the TSC community about clinical trials, research and treatment options for those living with TSC. A Community Alliance Mentor program was also developed to support new Community Alliance Chairs in effort to develop leadership skills throughout the country.

#### Increasing 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 2013, the TS Alliance produced three issues of its national magazine, *Perspective*, which is mailed to more than 13,700 constituents as well as posted on the website.

The TS Alliance's website increases awareness and provides extensive resources via 950,000 to 1.2 million hits monthly from an average of more than 35,000 unique visitors each month. The site's online mail list form continues to capture 50 or more new constituents every month. The TS Alliance relies heavily on social media to educate constituents and promote new resources and events. Our Facebook TSC Discussion Group boasts more than 5,300 members, while its Twitter account has 800-plus followers.

To increase public awareness, the TS Alliance heavily promoted TSC Global Awareness Day on May 15. This year's event introduced a dedicated website – tscglobalday.org, to house a "Where in the World Is TSC?" social media/photo campaign which garnered 473 pictures from 34 countries as well as a huge Facebook/Twitter push. In addition, the TS Alliance President & CEO and Chief Scientific Officer participated in 10 radio interviews, which ultimately aired on 735 stations reaching more than 9.7 million listeners. Long-time TS Alliance supporter and famed actress Julianne Moore recorded a TSC Global Awareness Day PSA, which was played 1,326 times on 154 different stations, reaching 4.9 million listeners.

The TS Alliance also participated in a media tours in partner-ship with Novartis and the Special Olympics, sharing the story of two TSC Special Olympians. In May, TS Alliance President and CEO participated in 10 interviews with Kathy Groves who talked about her family, life with TSC, and her son Ryan and his participation in the Special Olympics. The Chief Scientific Officer participated in a radio media tour in November reaching a total listenership of 3,376,000 with placement on 17 networks. This media tour included Mandy and Scott Striegel, who addressed the family's experiences living with TSC, especially their son Steven's participation in the Special Olympics.

To help educate people with TSC, physicians and the general public, the TS Alliance also produced and released eight new educational videos in 2013. These may be viewed at www.youtube.com/tsalliance.



#### **Advocating for Federal Involvement**

The TS Alliance's government advocacy program focuses on educating members of Congress about TSC to further TSC research, awareness and clinical care. In 2013, TS Alliance grassroots volunteers participated in our annual March on Capitol Hill, resulting in 74 members of the House of Representatives signing a letter of support circulated by Representative Loretta Sanchez (D-CA) and 10 Senators signing a bipartisan letter of support circulated by Senator Ron Wyden (D-OR) for FY2014 Appropriations. As a result, Congress appropriated \$6 million for FY2014 to the Tuberous Sclerosis Complex Research Program (TSCRP) through the Department of Defense (DoD) Congressionally Directed Medical Research Program (CDMRP). This brings the cumulative total for TSC funding since 2002 to \$53 million. A total of 97 awards have been made through FY2012.

The TSCRP is administered from the appropriation is a competitive peer review grant program. According to the U.S. Army Medical Research and Material Command, CDMRP, Tuberous Sclerosis Complex Research Program Report "Today, the TSCRP is one of the leading sources of extramural TSC research funding in the United States. The TSCRP fills important gaps in TSC research not addressed by other funding agencies. The program's investment strategy is adapted yearly to facilitate rapid change and to better target funding to the most critical TSC research areas, thus ensuring that the program remains responsive to current needs and future opportunities."

Research performed through this program recently led to additional clinical trials including:

- testing a combination of two drugs to treat lymphangioleiomyomatosis (LAM), a life-threatening lung manifestation of TSC 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; and
- 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) linking cognitive impairments in TSC to autism, anxiety, and other mental disorders, several companies have drugs under development that may provide meaningful treatments in the future. 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, a clinical trial began to test mTOR inhibitors to treat epilepsy in individuals with TSC.

The TS Alliance also works closely with other Federal agencies including the National Institutes of Health (NIH), Center for Disease Control (CDC) and the Food and Drug Administration (FDA). Moreover, TSC language was included in the Senate FY2014 Labor-HHS-Education Appropriations Act regarding both the CDC and NIH:

- CDC NCBDDD language: Tuberous Sclerosis Complex [TSC]. Because TSC is a leading genetic cause of more prevalent neurological disorders such as autism and epilepsy, the Committee encourages CDC to incorporate information about TSC in CDC's surveillance systems for those conditions.
- NIH Office of the Director language: Tuberous Sclerosis Complex [TSC]. The Committee continues to encourage NIH to coordinate a multi-Institute approach to finding a cure for TSC. NINDS and NCATS should play leading roles, given the promising translational potential of new therapeutics for treating the neurological conditions of TSC, including autism and epilepsy. Other Institutes involved in this collaborative effort should include NCI, NIAMS, NHLBI, NIDDK, NINDS, NICHD, and NIBIB, as well as ORDR.

Government advocacy efforts also included a Congressional Briefing on Capitol Hill to commemorate TSC Global Awareness Day on May 15, 2013 attended by Congressional staff and key members of the TSC research and grassroots communities.



Visit with Senate Majority Leader Harry Reid.

## Raising Funds to Impact Community

The TSC community has always been the central strength of the TS Alliance, a community of people willing to channel all their effort, all their love and even all their anger into solutions. If not for themselves, they band together for someone else in the next generation. These supporters from all walks of life and all across this country help raise much-needed funds to support community programs that provide information, hope and advocacy to individuals and families living with TSC, as well as to help fund TSC research projects.

Special events make a true impact in the fight against TSC. Large-scale events like Comedy for a Cure, Step Forward to Cure TSC\* walks, and Art for a Cure along with many community events such as Cookin' Up a Cure/Pampered Chef Charity Auction, Rock for Riley, golf tournaments, and dinner parties also raise critically needed awareness.

In 2013, special events netted over \$1.3 million, which represented 32% of the TS Alliance's overall revenue. A few highlights include:

- Art for a Cure raised more than \$62,500. Led by our Gold Sponsors, Accurate Healthcare, Lundbeck and Novartis, 50-plus guests enjoyed wine and cheese samplings. The afternoon featured an art exhibit of over 50 fine works created by people with TSC critiqued by our esteemed judging panel of Jamie Beckwith, Chris Hawkey, Sara Hoey and Herb Williams. The event also honored James and Amy Hobbs for their unending passion and dedication toward supporting their local community as well as nationally helping drive the mission of the TS Alliance through their service and financial support.
- Comedy for a Cure® Hollywood celebrated its twelfth anniversary in 2013. Held at LURE nightclub, comedy headliner Mary Lynn Rajskub, The Lampshades featuring Kate Flannery and Scot Robinson as well as comedian Brad Wollock provided the entertainment along with our emcee and host Mo Collins. The TS Alliance paid tribute to long-term supporters and advocates, the Al and April Cooper Family, who have been leaders and influencers in the Southern California and national TS Alliance since their twin daughters, Abby and Amelia, were diagnosed with TSC. The event raised more than \$237,000 with support from Lundbeck, Novartis, Questcor and *Variety*.



- The Step Forward to Cure TSC® National Walk on the Mall took place at Constitution Gardens and hosted more 450 individuals standing together to be heard and raise awareness of TSC. The walk raised \$106,000-plus thanks for generous support from The Rothberg Institute for Childhood Diseases, Novartis, Scitor, Cyberonics, Lundbeck, Community Foundation for the National Capital Region, Questcor, Tetrad, Hollingsworth, The Dills Family, and Cavarocchi Ruscio Dennis Associates.
- The largest TSC community fundraisers, Step Forward to Cure TSC\* walks, took place in 30 cities across the United States and collectively raised more than \$1 million. 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, Buffalo Wild Wings, and Caribou Coffee.

2013 certainly marked an extraordinary continuation of progress in TSC research. To fund the next wave of scientific breakthroughs, the TS Alliance continued our Unlock the Cure fundraising campaign, a vital step toward implementing a next-generation research program needed to move potential treatments from the lab (pre-clinical) to the TSC community (trials).

With a three-year matching challenge grant from the Harold Simmons Foundation, contributions of up to \$150,000 in 2013 to the Unlock the Cure campaign were matched. This campaign raised \$518,490 in 2013 prior to this incredible match and has raised \$3,936,400 since its inception. This support allows the TS Alliance to support a Drug Screening Program, identify biomarkers, develop a Clinical Research Consortium, expand the TSC Natural History Database and increase support for the TS Alliance Grants Program.



#### Step Forward to Cure TSC® Walkathons

- Alabama Carole Pitard
- Arizona Debora Moritz
- Atlanta / North Georgia Planning Committee
- Chicago (Elk Grove) Lisa Smiley
- Connecticut Rebecca Therault
- Dallas Planning Committee
- Dayton, OH Lola Centeno
- Delta Region Temple Poche
- Houston Bill and Taska Fields
- Indiana Faye Robinson
- Kansas Denise Breen
- Metro DC National Walk on the Mall Planning Committee
- Michigan Treasa Bolger Dunlap and Matt Bolger
- Middle Tennessee Brittany Schwaigert
- New England Stacey Verrill
- New Jersey Tresha Bisang
- New York (Long Island) Rob and Denise Spear
- North Carolina Regional Amy Quintana
- Northern California Diane Burgis
- Pacific Northwest (Seattle) Susan Jorski
- Rocky Mountain Dana Holinka
- Southern California Barbara O'Neill and Dawn Redfield
- St. Louis Gwen Montaigne and Donna Bullard
- Upper Midwest Maria Gibbons

#### **Other Major Events**

- Art for a Cure Nashville Event Planning Committee
- Art for a Cure Sibling Showcase Planning Committee
- Comedy for a Cure Hollywood Planning Committee
- Crashin for the Cause Joe and Abby Kopf
- Geneva Lakes Amazing Race Rebecca Melka, Rob Keefe, Tim Schnake and Sharon Clark
- Singing for a Cure Allie Asensio
- Rock for Riley Melanie Vogel









#### Fiscal Year 2013: January 1 to December 31

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Specialty: Pediatric Neurology & Epilepsy

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#### National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Financial Position • 12-31-13

December 31,	2013	2012
Assets		
Current Assets		
Cash and cash equivalents	\$ 3,305,934	\$ 2,579,002
Short-term investments	268,244	507,831
Accounts receivable	326,326	86,517
Promises to give	162,675	336,000
Prepaid expenses and other assets	181,502	160,393
Total current assets	4,244,681	3,669,743
Long-term investments	4,807,500	4,290,430
Property and equipment	203,501	100,412
Total Assets	\$ \$9,255,682	\$ 8,060,585
Liabilities and Net Assets		
Liabilities		
Current liabilitie		
Accounts payable and accrued expenses	\$ 85,199	\$ 33,909
Accrued compensation	145,188	85,127
Deferred revenue	360,395	-
Deferred rent and lease incentive, current portion	14,263	-
Gift annuity obligations, current portion	12,050	12,050
Total current liabilities	617,095	131,086
Deferred rent and lease incentive, less current portion	119,825	_
Gift annuity obligations, less current portion	71,919	85,344
Total liabilities	808,839	216,430
Commitments and contingencies	-	-
Net assets		
Unrestricted		
Undesignated	1,594,761	1,087,089
Designated	4,358,358	4,168,065
Total unrestricted	5,953,119	5,255,154
Temporarily restricted	1,614,280	1,709,557
Permanently restricted	 879,444	 879,444
Total net assets	8,446,843	7,844,155
Total liabilities and net assets	\$ 9,255,682	\$ 8,060,585

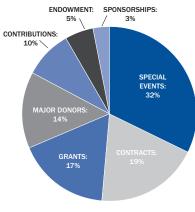
The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year's auditors completed their 2013 audit and submitted an unmodified opinion to the TS Alliance Board of Directors. The completed audited financials are on file at the TS Alliance. To obtain a copy, please call (800) 225-6872 or download them at www.tsalliance.org. The 2013 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 accounting principles generally accepted in the United States of America. Supporting services reflected in the consolidated statement of activities include both the TS Alliance and the Endowment Fund. The operating entity ended the year with a \$64,801 surplus.

#### **National Tuberous Sclerosis Association & Affiliate**

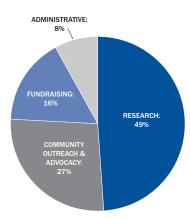
Consolidated Statements of Activities

	Ur	restricted	Temporarily Restricted	Permanently Restricted	2013 Total		2012 Total
Revenue and Support		<u> </u>			<u> </u>		
Special Events	\$ 1	,417,561	\$ 59,228	\$ -	\$ 1,476,7	89	\$ 1,683,248
Cost of direct benefits to donors	(	124,998)			(124,9	98)	(138,793)
Special events, net	1,	292,563	59,228	-	1,351,7	91	1,544,455
Contributions		606,306	920,189		1,526,4	95	1,285,464
Contracts		779,327			779,3	27	86,000
Interest and dividends		192,445	48,081		240,5	26	118,213
Conferences		203,800			203,8	00	116,286
Federated funding		77,105			77,1	05	84,135
Memorials and honorariums		62,420	11,090		73,5	10	136,361
Other income		5,984			5,9	84	23,050
	3,	219,950	1,038,588	-	4,258,5	38	3,393,964
Net assets from restrictions	1,	243,928	(1,243,928)			-	-
Total revenue and support	4,	463,878	(205,340)	-	4,258,5	38	3,393,964
Expenses							
Program services							
Research	2,	039,165			2,039,1	65	1,672,220
Family services		713,627			713,6	27	563,287
Public health education		196,462			196,4	62	265,706
Government relations		142,428			142,4	28	141,410
Professional education		22,109			22,1	09	33,595
Total Program Services	3	113,791	-	-	3,113,7	91	2,676,218
Supporting Services							
Fund raising		673,986			673,9	86	575,589
Management and general		388,637			388,6	37	389,068
Total supporting services	1,	062,623	-	-	1,062,6	23	964,657
Total expense	4	,176,414	-	-	4,176,4	14	3,640,875
Change in net assets from operations		287,464	(205,340)	-	82,1	24	(246,911
Net gain on investments		410,501	110,063		520,5	64	338,701
Change in net assets		697,965	(95,277)	-	602,6	88	91,790
Net assets, beginning of year	5,	255,154	1,709,557	879,444	7,844,1	55	7,752,365
Net assets, end of year	\$ 5	953,119	\$ 1,614,280	\$ 879,444	\$ 8,446,8	43	\$ 7,844,155

Operating Revenue Sources FY 2013



Operating Expense Types FY 2013



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WITH A CURE. WHERE OUR STORY MUST END.