

**2012
ANNUAL
REPORT**



UNITING THE TSC COMMUNITY

Local | National | Global



WE'LL GIVE EVERYTHING. BUT UP.



Uniting – present participle of *u-nite* (Verb)

1. Come or bring together for a purpose or action.

“The TS Alliance is uniting the community on a global basis to positively impact the future lives of anyone touched by tuberous sclerosis complex.”



Uniting the TSC Community

Throughout 2012, the Tuberous Sclerosis Alliance (TS Alliance) worked diligently to unite the TSC community on local, national and global platforms in a concerted effort to increase awareness of tuberous sclerosis complex (TSC); push research forward; update treatment, diagnosis and monitoring guidelines; and provide support and resources to help people impacted by the disease increase their quality of life.

- **Local:** From Regional TSC Conferences to volunteer-led support groups and social gatherings, the TS Alliance worked in partnership with our Community Alliances to ensure individuals and families connected as easily as possible to share information, offer each other support and learn about the latest in TSC treatment options and research efforts.
- **National:** The year kicked off with the TS Alliance's release of a white paper, entitled *Unlocking the Cure for Tuberous Sclerosis Complex: An Assessment of Scientific Progress and Research Needs*, to clearly identify key areas of TSC clinical care and research where significant progress has been made, areas where research is needed, barriers to progress in TSC research and the unmet clinical needs of people with TSC. Another milestone was the U.S. Food and Drug Administration's approval of Afinitor® as a treatment for renal angiomyolipoma associated with TSC. In addition, to highlight the creativity and unity of the TSC community across the country, the TS Alliance introduced two new major national initiatives – the very first Art for a Cure, which featured art created by people with TSC, and the inaugural Step Forward to Cure to TSC® National Walk on the Mall, attracting more than 400 participants to the nation's capital in Washington, DC.
- **Global:** The TS Alliance spearheaded two major global initiatives in 2012. On May 15, the very first TSC Global Awareness Day was held in partnership with the TSC International, the worldwide consortium of more than 30 TSC organizations. This marked the first concerted effort to increase TSC awareness around the world. The other significant advance was the TSC Clinical Consensus Conference, which attracted the world's top TSC experts who worked to develop the new international gold standards in TSC diagnosis, treatment and monitoring.



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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.

Moreover, TSC is the leading genetic cause of both autism spectrum disorder and epilepsy. Up to 50 percent of people with TSC develop autism, while 80 to 90 percent experience seizures at some point during their lives.

While there is currently no cure, there is hope and 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.

The TS Alliance

The TS Alliance is the only national organization dedicated to finding a cure for TSC while improving the lives of those affected.

In 1974, four mothers from Southern California with a dream formed the TS Alliance to provide fellowship, generate awareness, pursue knowledge and provide hope to those who shared the common bond of TSC. Today, with these same goals in the 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.



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 \$16.5 million in research on TSC.

The TS Alliance hosted the 2012 TSC Clinical Consensus Conference to update consensus recommendations for the diagnosis, surveillance, and management of TSC. The prior guidelines were based on a 1998 consensus conference, and the TSC field has made tremendous advancements in the meantime. Approximately 80 experts from 14 countries participated in this effort to update recommendations around all aspects of TSC: brain tumors, dermatology and dental, epilepsy, genetics, neuropsychiatry, pulmonary, renal, and a collection of additional manifestations including cardiac, endocrine, gastrointestinal, and retinal. Indeed, consensus was reached during the intense day-and-a-half meeting based on evaluation of data in the scientific literature and expert opinion. The TS Alliance will financially support open-access publication of peer-reviewed articles in medical journals to describe these guidelines so they are freely available to anyone around the world.

As of December 2012, 1,175 people were enrolled in the **TSC Natural History Database** project from among 15 U.S.-based sites and one international site. The database collects and stores medical information over the participants' lifetimes. 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 2012, the TS Alliance invested \$179,725 in the TSC Natural History Database. The TS Alliance received the second half of a two-year \$200,000 grant award from the Pediatric Epilepsy Research Foundation in fall 2012, which will underwrite a portion of the operational expenses of the database through 2013. Additionally, a major contract with Novartis was executed in November 2012 to provide the TS Alliance with funding to enhance and grow the database through 2015.

A total of 18 **research awards** were funded in 2012 for \$839,958, including the TS Alliance Rothberg Courage Award in Research, which was established by members of the Rothberg family to serve as a catalyst for innovative research to find treatments and a cure for TSC. The Rothberg Courage



Award in Research recognizes outstanding scientific merit applied directly to TSC and provides important funding to increase the TS Alliance's capacity to accelerate research. The TS Alliance Rothberg Courage Award for Research continued supporting five ongoing projects:

- the development of Seizure Tracker as an epilepsy clinical trial tool;
- the TSC neurocognitive trial, a clinical study of everolimus effects on neurocognition at Children's Hospital Boston and Cincinnati Children's Hospital Medical Center;
- work by Dr. Hope Northrup (University of Texas at Houston) to identify additional TSC genes;
- work by Dr. John Bissler (Cincinnati Children's Hospital and Medical Center) to develop MRI-guided high-intensity focused ultrasound to treat kidney or lung lesions; and
- 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 11 research grants awarded in previous years. Additionally, a new postdoctoral research grant was approved to support a young scientist working on TSC research. Dr. Jeannie Li (Harvard University) was awarded a post-doctoral fellowship in late 2012 that involves drug screening. Her goal is 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 TSC Drug Screening Program continued sponsoring research in Dr. Aristotelis Astrinidis' laboratory (Drexel University) toward finding FDA-approved oncology drugs that will stop tumor cell growth in TSC. The program also continued funding the work of Dr. John Frangioni (Beth Israel Deaconess Hospital), who has developed a new system for imaging of tumors in live mice and has set up a high-throughput screen using cells in culture in order to pre-screen potential drugs and compounds prior to testing in mice. 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 TS Alliance invested \$112,500 to support a new TSC **Clinical Research Network**, including Boston Children's Hospital, Cincinnati Children's Hospital, University of Alabama Birmingham Tuberous Sclerosis Clinic, UCLA Pediatric Neurology TSC Clinic and the University of Texas Medical School at Houston. The five clinics comprising this consortium received NIH grants to conduct two clinical studies over the next five years. 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, and
- 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 will develop infrastructure and processes to form the basis of an ongoing and growing TSC Clinical Research Network. 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

The TS Alliance's professional education efforts focus on expanding programs to target researchers and healthcare providers caring for individuals with TSC, medical students, genetic counselors and educators to minimize the consequences of ignorance and misinformation. The TS Alliance participated in and presented at several professional meetings including: LAM Foundation Conference; 4th International Birt-Hogg-Dubé Symposium; World Orphan Drug Congress; Association of Clinical Research Professionals Conference; National Institute of Neurological Disorders and Strokes (NINDS) Autism and Epilepsy Workshop; Interagency Collaborative to Advance Research In Epilepsy (ICARE); Partnering to Advance Therapeutics for Neurological Disorders: The NINDS Nonprofit Forum; NORD/DIA Annual Conference on Rare Diseases and Orphan Products; Child Neurology Society Annual Meeting; and the International TSC Research Conference in Italy. 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 the TSC Special Interest Group scientific session.

The TS Alliance also manages an online portal for healthcare professionals called "VeoMed" to encourage information exchange. Currently, 75 professionals use this portal, which also serves as a resource for those not familiar with TSC seeking guidance from peers. A monthly online newsletter called *TSC Alert* is sent to nearly 1,000 medical professionals and scientists.

Further, the Director of Advocacy & Education 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. Providing children with appropriate education is critical to individuals developing a good quality of life.

Support Services

The TS Alliance offers a wealth of programs and services to provide individuals with TSC direct access to the information, resources and specialists experienced in the diagnosis, treatment and management of TSC. Through the network of 32 volunteer branches of the organization, called Community Alliances, local educational and support group meetings are held throughout the country.

The TS Alliance hosted 12 educational meetings and 20 gatherings held at Community Alliance locations during 2012. These meetings facilitated stronger connections with peers, researchers and clinicians in the community and educated constituents about clinical trials, research and treatment options for those living with TSC.

The Department of Advocacy & Education supports families and individuals from all over the United States by providing support and information including direct during one-on-one meetings. In addition, volunteer Clinic Ambassadors supported more than 153 individuals at TSC Clinics in Miami, FL; Cincinnati, OH; Columbus, OH; Atlanta, GA; Nashville, TN; Birmingham, AL; and Denver, CO.

The Director of Advocacy & Education attends Individual Education Program meetings in person, through SKYPE and via conference calls to support parents or caregivers in getting educational services for their children. Eighteen Educational Liaison volunteers worked in 18 states to connect families to free educational advocacy trainings in collaboration with the states' Parent Training and Information Centers. In 2012, more than 1,300 free parent trainings and webinars on educational advocacy were offered to families dealing with educational issues for their children. Four educational situation videos were produced to support parents in getting an appropriate education for their children. Also in 2012, 30 online chats were held for siblings ages 8-13, 14-18, and adults to support issues siblings face on a daily basis with having a brother or sister with TSC.

The Director of Education & Advocacy also facilitates the Adult Task Force, which offered nine monthly topic calls on identified issues of importance to better support adults living with TSC. The Adult Regional Coordinator Program was developed with 10 volunteers supporting other adults throughout the country. The Adult Task Force also helped produce several videos for the website specific to adult issues.

Finally, the TS Alliance online social network via Inspire.com helps to connect individuals and families dealing with TSC and get support from each other's experience. Presently the TSC population through Inspire includes 1,500-plus members from 69 countries as of December 31, 2012.

Public Education

The organization continuously works to increase awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families. During 2012, the TS Alliance produced three issues of its national magazine, *Perspective*, which is mailed to more than 13,000 constituents as well as posted on the website. The TS Alliance provides extensive education through its website via 799,000 to 1.2 million hits monthly from an average of more than 9,250 unique visitors. The site's online mail list form continues to capture 50 or more new constituents every month.

The TS Alliance also uses social media to educate constituents and the general public as well as promote new resources and events. Our Facebook TSC Discussion Group boasts more than 5,000 members, while the Twitter account has 600-plus followers. The TS Alliance also provided public education through a series of Regional TSC Conferences; four were held in 2012 including Washington, DC; Houston, TX; Los Angeles, CA; and Boston, MA.



To boost public awareness, the TS Alliance heavily promoted May 2012 as National TSC Awareness Month via its various social media and web properties, and it took the lead in promoting the very first TSC Global Awareness Day on May 15. This included a radio media tour and audio release on TSC Global Awareness Day with total outreach to 8 million listeners on 2,007 networks and 2,015 airings, plus a window display in New York City's Rockefeller Center throughout May. With the FDA-approval of the second TSC indication, the TS Alliance broadened public awareness through outreach to press and participation in a second radio media tour reaching a total listenership of 3.9 million with placement on 19 networks.

In 2012, the TS Alliance co-sponsored a report on epilepsy by the Institute of Medicine through our partnership with Vision 20/20, a coalition that focuses on epilepsy research, care, services, education and advocacy efforts. This landmark study provides the blueprint for improving the outcomes for those living with epilepsy.

Government Advocacy

The TS Alliance's government advocacy program works to educate members of Congress about TSC to further TSC research, awareness and clinical care. In 2012, the TS Alliance grassroots volunteers conducted a March on Capitol Hill resulting in 66 members of the House of Representatives signing a letter of support circulated by Representative Loretta Sanchez (D-CA) and 13 Senators signing a bipartisan letter of support circulated by Senator Ron Wyden (D-OR) for FY2013 Appropriations. The U.S. Congress appropriated \$6 million to TSC research for FY2013 through the Department of Defense Congressionally Directed Medical Research Program (CDMRP).

The TSC Research Program (TSCRP) 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."

A hallmark achievement is TSCRP-supported research that examined the role TSC genes play in cell growth and proliferation — specifically in controlling the mammalian Target of Rapamycin (mTOR) signaling pathway in cells. This research rapidly led to clinical trials, resulting in the first drug approved by the FDA specifically for treatment of individuals with TSC.

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 FY2102; starting a multi-site clinical trial to test the efficacy of an experimental topical rapamycin cream to treat the disfiguring facial tumors, called facial angiofibromas, caused by TSC funded in FY2010; and supporting the TSC Natural History Database to better understand the progression of the disease over a lifetime.

Because of FY2010-funded research on glutamate receptors (mGluR5), several companies are now looking into the link between cognitive impairments in TSC to autism, anxiety and other mental disorders. Other TSCRP-funded research focuses on the development of animal models of TSC that have seizures to gain a better understand the etiology of TSC, and a clinical trial is planned 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 advocacy efforts included a Congressional Briefing on Capitol Hill to commemorate the inaugural TSC Global Awareness Day on May 15, 2012, which was attended by Congressional staff and key members of the TSC research and grassroots community.



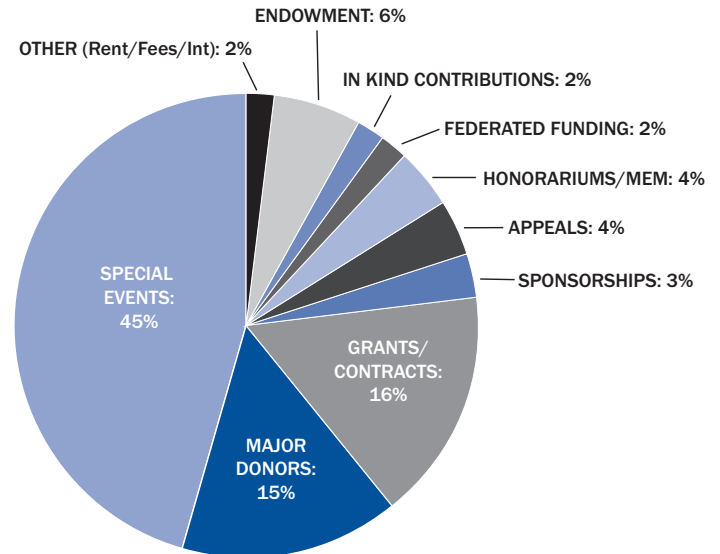
Congress appropriated \$6 million to TSC research...

Fund Development

The driving force of the TS Alliance has always been the TSC community – people from across the country coming together to raise much-needed funds to further research and to support community programs that provide information, hope and advocacy to individuals and families living with TSC. The local volunteer leadership of events, both large and small, makes a vital difference in the fight against TSC – whether it's Comedy for a Cure®, Step Forward to Cure TSC® walks, Art for a Cure or the many other community-based events such as Cookin' Up a Cure/Pampered Chef Charity Auction, Rock for Riley, golf tournaments and dinner parties, all of which also raise critical awareness of the disorder.

In 2012, special events netted nearly \$1.5 million, which represented 45% of the TS Alliance's overall revenue. A few highlights include:

- **Art for a Cure**, an inaugural event held in New York, raised \$159,110. Led by Presenting Sponsor Novartis, 100-plus guests enjoyed wine and cheese samplings from Bardi Catering, Atalanta Corporation, Cabot Cheese, Frederick Williams & Sons Wine, Josh Sellers Wines and Vino Divino School of Wine. The afternoon featured an exhibit of more than 45 art pieces created by people with TSC, which were critiqued by an esteemed judging panel of Lori Bookstein, Edina Kiss, Matt Mahurin and J. Courtney Sullivan. The event also honored Dr. Mark C. Fishman, President of Novartis Institutes for BioMedical Research, who directed the team of scientists who worked to change the practice of medicine focusing on therapeutics for diseases, no matter how rare, and developed the first TSC-specific treatment for fast-growing brain tumors associated with TSC.
- **Comedy for a Cure® Hollywood** celebrated its eleventh anniversary at the Hollywood Roosevelt Hotel. Comedy headliner Adam Corolla, comedian Jim Jeffries and featured comedic act, the Lampshades with Kate Flannery and Scot Robinson, provided the entertainment along with emcee Mo Collins. The TS Alliance also paid tribute to long-time supporter Beth Dean of Lundbeck Pharmaceuticals, who has been a partner with Comedy for a Cure and the TS Alliance for many years. The event raised more than \$198,000 with support from Platinum Sponsors Novartis, Lundbeck and *Variety* magazine.



- **The Step Forward to Cure TSC® National Walk on the Mall** took place at the base of the Washington Monument and attracted more than 400 individuals standing together to be heard and raise awareness of TSC. The walk raised \$125,000-plus, thanks to generous support from The Winifred M. Gordon Foundation, Novartis, Scitor, Cyberonics, Lundbeck, Questcor, Tetrad, BIO, Hollingworth LLP, Cavarocchi Ruscio Dennis Associates and many other donors across the country.
- **The largest TSC community fundraisers**, Step Forward to Cure TSC® walks, were held in 37 cities across the country and collectively raised more than \$1.21 million. Julianne Moore once again served as our National Honorary Chair, and additional support was provided by National Sponsors Novartis, LIDS, Lundbeck, Cyberonics and MetLife Center for Special Needs Planning. Since its inception, the Step Forward to Cure TSC walk program has raised an astonishing \$9.2 million.

2012 marked an extraordinary decade of progress in TSC research. To fund the next wave of scientific breakthroughs, the TS Alliance continued the **Unlock the Cure** capital 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 \$175,000 in 2012 to the Unlock the Cure campaign were matched. This funding has allowed the organization to 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 Grants Program.

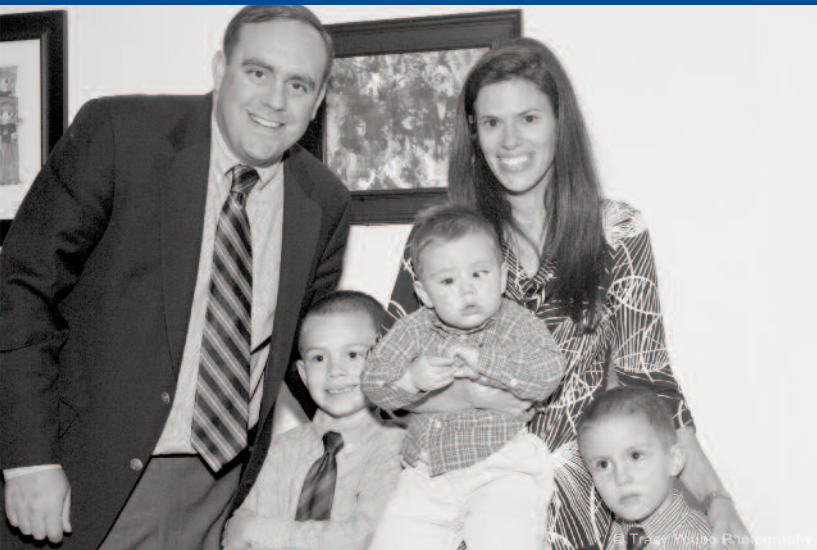
Events Raising More Than \$10,000

Step Forward to Cure TSC® Walkathons

- Alabama – Carole Pitard
- Arizona – Debora Moritz
- Atlanta/North Georgia – Reiko Donato
- Chicago (Elk Grove) – Event Planning Committee
- Connecticut – Jennifer Waldron
- Dallas – Scott and Mandy Striegel
- Florida (Miami) – Vanessa Vazquez
- Heartland – Ryan and Cindy Blackard
- Houston – Bill and Taska Fields
- Indiana – Faye Robison
- Kansas – Amy Dublinske
- Metro DC National Walk on the Mall – Reid and Lauren Novotny
- Michigan – Treasa Bolger and Matt Bolger
- Middle Tennessee – Brittany Schwaigert
- New England – Stacey Verrill
- New York (Long Island) – Rob and Denise Spear
- Northern California – Diane Burgis
- Pacific Northwest (Seattle) – Event Planning Committee
- Rocky Mountain – Dana Holinka
- Southern California – Barbara O'Neill, Cindy Chernow, Dawn Redfield and Tresha Bisang
- St. Louis – Gwen Montaigne and Donna Bullard
- Upper Midwest – Maria Gibbons
- Wisconsin – Kristin Champagne

Other Major Events

- Comedy for a Cure Hollywood – Event Planning Committee
- Art for a Cure New York – Event Planning Committee
- Cocktails for a Cure – Ben and Angie Windham
- Crashin' for the Cause – Joe and Abby Kopf
- Geneva Lakes Amazing Race – Rebecca Melka, Rob Keefe, Tim Schnake and Sharon Clark
- Rock for Riley – Melanie Vogel
- Wentworth Charities Golf Classic – Dennis Prue, Tom and Sharon Gwinn



Annual Fund – Major Donors

Fiscal Year 2012:
January 1 to December 31, 2012

President's Circle **(\$100,000–\$500,000)**

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

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Oil & Gas
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Sponsor **(\$20,000–\$49,999)**

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Whittingham Foundation

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National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Financial Position • 12-31-12

December 31,	2012	2011
Assets		
Current Assets		
Cash and cash equivalents	\$ 2,579,002	\$ 2,330,171
Short-term investments	507,831	865,450
Accounts receivable	86,517	319
Promises to give	336,000	379,000
Prepaid expenses and other assets	160,393	148,176
Total current assets	3,669,743	3,723,116
Long-term investments	4,290,430	4,174,493
Property and equipment	100,412	141,717
Total Assets	\$ 8,060,585	\$ 8,039,326
Liabilities and Net Assets		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	\$ 33,909	\$ 145,177
Accrued compensation	85,127	77,136
Gift annuity obligations, current portion	12,050	9,400
Total current liabilities	131,086	231,713
Gift annuity obligations, less current portion	85,344	55,248
Total liabilities	216,430	286,961
Commitments and contingencies	-	-
Net assets		
Unrestricted		
Undesignated	1,087,089	775,400
Designated	4,168,065	4,029,540
Total unrestricted	5,255,154	4,804,940
Temporarily restricted	1,709,557	2,067,981
Permanently restricted	879,444	879,444
Total net assets	7,844,155	7,752,365
Total liabilities and net assets	\$ 8,060,585	\$ 8,039,326

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 2012 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 at www.tsalliance.org. The 2012 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 of America. Supporting services reflected in the consolidated statement of activities include both the TS Alliance and the Endowment Fund. The consolidated financial statements show a Change in Net Assets with a surplus of \$91,790. To keep in line with the increasing priorities of the organization to fund groundbreaking research, the TS Alliance Operating Change in Net Assets was reduced by \$144,425, in large part by funding additional research in the amount of \$124,740 from net assets paid from the TS Alliance Rothberg Courage Award in Research, which was established by members of the Rothberg family to serve as a catalyst for innovative research to find treatments and a cure for TSC; the TS Alliance Endowment Fund Change in Net Assets had a surplus of \$236,215.

National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Activities

	Unrestricted	Temporarily Restricted	Permanently Restricted	2012 Total	2011 Total
Revenue and Support					
Special Events	\$ 1,594,096	\$ 89,152	\$ -	\$ 1,683,248	\$ 1,788,539
Cost of direct benefits to donors	(138,793)			(138,793)	(196,307)
Special events, net	1,455,303	89,152	-	1,544,455	1,592,232
Contributions	617,762	667,702		1,285,464	1,787,907
Memorials and honorariums	116,022	20,339		136,361	142,689
Interest and dividends	101,768	16,445		118,213	103,834
Conferences	116,286			116,286	212,084
Contracts	86,000			86,000	-
Federated funding	84,135			84,135	77,102
Other income	23,050			23,050	15,037
	2,600,326	793,638	-	3,393,964	3,930,885
Net assets from restrictions	1,203,459	(1,203,459)		-	-
Total revenue and support	3,803,785	(409,821)	-	3,393,964	3,930,885
Expenses					
Program services					
Research	1,672,220			1,672,220	1,970,929
Family services	563,287			563,287	380,633
Public health education	265,706			265,706	194,475
Government relations	141,410			141,410	163,120
Professional education	33,595			33,595	26,188
Total Program Services	2,676,218	-	-	2,676,218	2,735,345
Supporting Services					
Fund raising	575,589			575,589	567,685
Management and general	389,068			389,068	402,508
Total supporting services	964,657	-	-	964,657	970,193
Total expense	3,640,875	-	-	3,640,875	3,705,538
Change in net assets from operations	162,910	(409,821)	-	(246,911)	225,347
Net gain (loss) on investments	287,304	51,397		338,701	(116,271)
Loss on sublease					(19,000)
Changes in net assets	450,214	(358,424)	-	91,790	90,076
Net assets, beginning of year	4,804,940	2,067,981	879,444	7,752,365	7,662,289
Net assets, end of year	\$ 5,255,154	\$ 1,709,557	\$ 879,444	\$ 7,844,155	\$ 7,752,365



Tuberous Sclerosis Alliance

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WITH A CURE. WHERE OUR STORY MUST END.