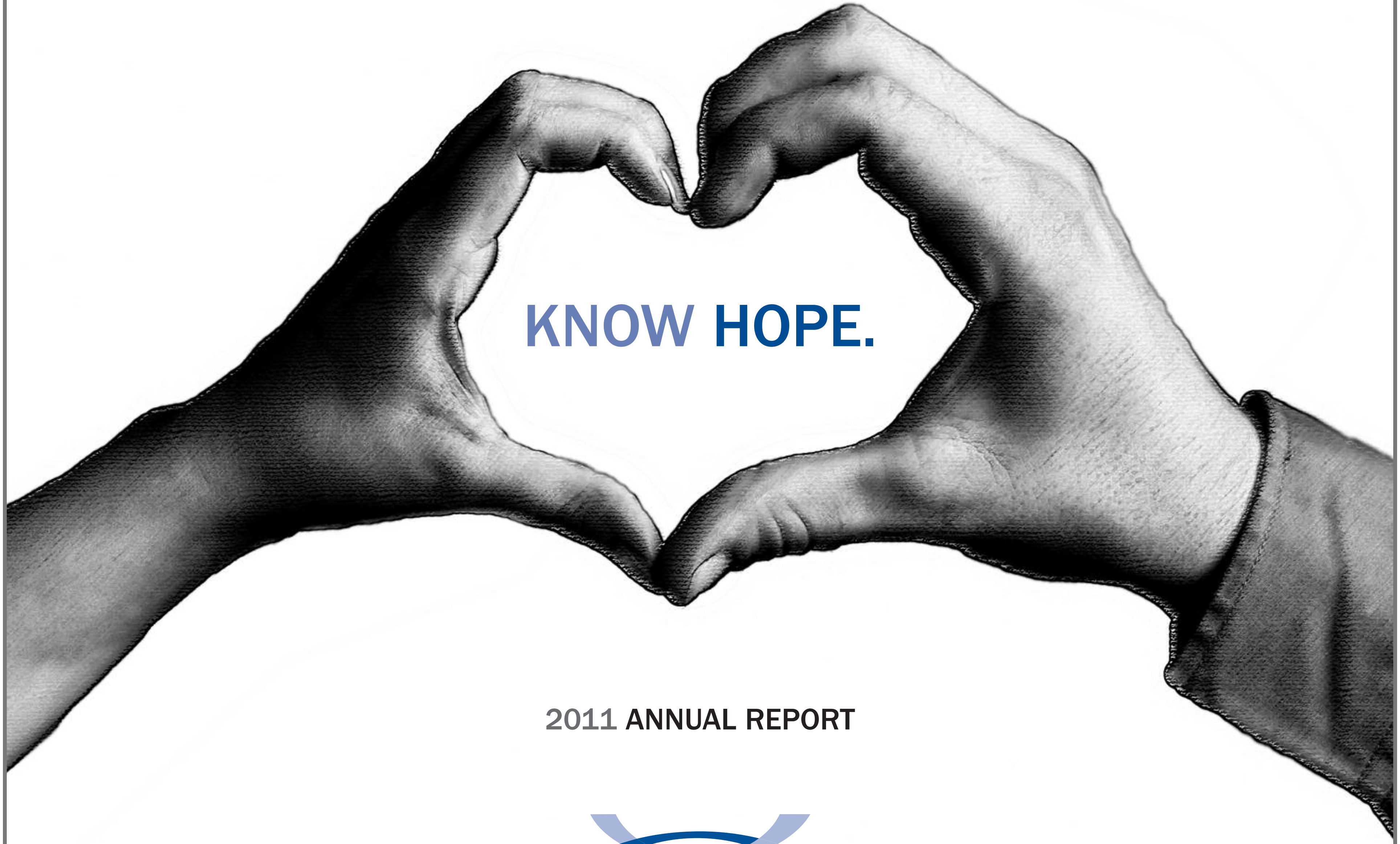


KNOW HOPE.

2011 ANNUAL REPORT

Tuberous Sclerosis Alliance

WE'LL GIVE EVERYTHING. BUT UP.

KNOW
HOPE

> “It is difficult to say what is impossible, for the dream of yesterday is the **hope of today** and the reality of tomorrow.”
>
> – Robert H. Goddard

Since the TS Alliance’s founding in 1974, hope has always driven the organization to further its mission to find a cure for tuberous sclerosis complex (TSC), while improving the lives of those affected. Hope that one day, everyone touched by this disease will never have to endure its devastating effects. Hope that more treatments will become available to help manage the disease’s varying manifestations. Hope that continued success in research efforts will lead to meaningful progress toward a cure.

2011 proved to be a pivotal year in offering tangible hope to those the TS Alliance serves: the thousands and thousands of families, individuals and others affected by TSC in the United States. This annual report details progress made on many fronts, including research, support services, public education, government relations, professional education and fund development.

ABOUT 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.

TSC is a linchpin disease. Because of TSC’s genetic pathway, every dollar spent finding cures and treatments for TSC may also bring about quantum leaps in the cures for autism, epilepsy and cancer.

RESEARCH

The TS Alliance 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. Since 1984, the TS Alliance has invested more than $15.3 million supporting TSC-focused research.

As of December 2011 more than 1,120 people with TSC were enrolled in the TSC Natural History Database from among 15 U.S.-based sites and one international site. 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. The TS Alliance received a two-year $200,000 grant award from the Pediatric Epilepsy Research Foundation, which will help underwrite nearly half of the cost of operating the TSC Database through 2013.

The TS Alliance hosted the 2011 International TSC Research Conference, “Summit on Drug Discovery in TSC and Related Disorders,” which provided the opportunity for research and healthcare communities to come together to discuss the latest progress in clinical, translational, and basic research. Exciting new clinical data presentations described the efficacy of everolimus and sirolimus at reducing growth of tumors in the brain and kidney, respectively. Additionally, a small clinical study demonstrated encouraging effects of sirolimus on reducing the severity of facial angiofibromas.

Scientists also described important progress on pre-clinical studies evaluating the effect of drugs that affect other parts of the mTOR pathway or other cellular mechanisms that impact cell growth. From basic research we are learning about new biological activities—such as neuron growth, protein degradation in the cell, and effects of glial cells on neuronal excitability—that could be important targets for new therapeutic approaches.

During the International TSC Research Conference, Dr. Howard Weiner was presented with the 2010 Manuel R. Gomez Award in recognition of the impact his advancements in neurological surgery have made on the lives of countless individuals. Also, the late Dr. Mark Mausner was presented with the 2011 Manuel R. Gomez Award in recognition of his life's devotion to the TSC community through his innovations in dermatological surgery.

(continued next page)

Manual R. Gomez Award winners
Dr. Howard Weiner (left) and Dr. Mark Mausner (center)
with TS Alliance President & CEO Kari Luther Rosbeck (right).

Since 1984, the TS Alliance has invested more than $15.3 million supporting TSC-focused research.

RESEARCH (cont.)

A total of 24 research awards were funded in 2011 for $1,174,277. The TS Alliance Rothberg Courage Award for Research continued supporting two ongoing projects:

- the development of Seizure Tracker as an epilepsy clinical trial tool and the TSC neurocognitive trial, and
- a clinical study of everolimus effects on neurocognition initiated in 2011 at Children's Hospital Boston and Cincinnati Children's Hospital Medical Center.

Three new Courage Awards were granted in 2011:

- to support the identification of additional TSC genes,
- for the development of MRI-guided high-intensity focused ultrasound to treat kidney or lung lesions, and
- to determine whether inhibition of autophagy might kill abnormally growing cells in TSC.

The Rothberg Courage Fund was established to serve as a catalyst for innovative research to find treatments and a cure for TSC. The fund provides support for the Rothberg Award for Courage in Research, recognizing outstanding scientific merit applied directly to TSC and provides important funding to increase the TS Alliance's capacity to accelerate research. We are grateful to Jonathan Rothberg, PhD; Bonnie Gould Rothberg, MD, PhD, MPH; and members of the Rothberg family for providing this support.

The TS Alliance continued to support 13 research grants awarded in previous years. Additionally, two new postdoctoral research grants were initiated this year to support young scientists working on TSC research. The TSC Drug Screening Program continued sponsoring research toward finding FDA-approved oncology drugs that will stop tumor cell growth in TSC and developing a high-throughput screen using cells in culture in order to pre-screen potential drugs. This year the TS Alliance awarded Drug Screening Program grants to support projects that will test drugs for their potential to influence neurologic manifestations of TSC using mouse and zebrafish models. The goal of these projects is to identify drugs that improve neuronal function and could be moved relatively rapidly into clinical testing.

As translational research in TSC produces additional ideas for clinical studies, the efficient initiation and conduct of future clinical trials will require infrastructure in place to enable investigators to quickly and affordably execute studies. To begin building such an infrastructure, clinicians from five TSC clinics came together to establish a TSC Clinical Research Consortium that can expand as needed to accommodate future clinical studies. The TS Alliance's Chief Scientific Officer is on the leadership team of the Consortium.

SUPPORT SERVICES

The TS Alliance develops support 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. 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 three town hall meetings held at Community Alliance locations during 2011 as well as 22 other educational meetings and support meetings. These meetings facilitated stronger connections with peers, researchers, and clinicians in the community and educated the TSC community about clinical trials. The TS Alliance also continued its series of free educational teleconferences aimed at connecting constituents across the country with clinical care specialists and scientists from the convenience of their homes. In addition, the Department of Advocacy and Education helps families and individuals from all over the United States by providing support and information including direct support two days per month at TSC Clinics in Atlanta, Cincinnati, Columbus or Miami during one-on-one meetings. In addition, volunteer Clinic Ambassadors provided individualized, one-on-one support at TSC Clinics in Atlanta, Birmingham, Cincinnati, Columbus and Miami.

The Director of Advocacy and Education attends Individual Education Program (IEP) meetings in person, through SKYPE, and conference calls. She answers questions over the phone and through e-mail to counsel constituents as they encounter challenges on a daily basis. Educational Advocate Liaison volunteers, currently working in 10 states, connect families to free educational advocacy trainings in collaboration with the states' Parent Training and Information Centers. In 2011, more than 309 free parent trainings and webinars on educational advocacy were offered to families dealing with educational issues for their children.

The TS Alliance sponsored 33 online chats for siblings ages 8-13, 14-18, and adults to support issues siblings face on a daily basis having a brother or sister with TSC. The Director of Advocacy and Education also facilitates the Adult Task Force, which holds monthly topic calls about identified issues of importance to better support adults living with TSC.

The Director of Advocacy and Education also facilitates quarterly conference calls to update the TSC Connect network on the latest medical information. TSC Connect is an organized partnership of more than 300 volunteers whose lives have been affected by TSC. This network offers support by sharing their experiences with others who are faced with the challenges of TSC.

Through its network of 32 volunteer-based Community Alliances, local educational and support group meetings are held throughout the country.

PUBLIC EDUCATION

The TS Alliance works diligently to heighten awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families. During 2011, the TS Alliance produced three issues of its national magazine, *Perspective*, which is mailed to more than 12,000 constituents as well as posted on the website.

The TS Alliance provides extensive education through its website via 850,000 to 1 million hits monthly from an average of more than 18,750 unique visitors. The site's online mail list form continues to capture 50 or more new constituents every month. The TS Alliance website was redesigned in summer 2011 to reflect simpler navigation, incorporate more video and allow for instant access to a wealth of information.

The TS Alliance also relies heavily on social media to educate constituents and promote new resources and events. In 2011, the TS Alliance Facebook Discussion Group boasted more than 4,700 members, while its Twitter account had almost 400 followers. The TS Alliance also provides public education through a series of free research teleconferences, featuring presentations from the nation's top researchers, clinicians and other healthcare providers, which are also recorded and made available on the website for all constituents.

GOVERNMENT RELATIONS

The TS Alliance government advocacy program focuses on educating members of Congress about TSC to further TSC research, awareness and clinical care. In 2011, TS Alliance grassroots volunteers conducted a March on Capitol Hill resulting in 40 members of the House of Representatives signing a letter of support circulated by Representative Loretta Sanchez (D-CA) and nine Senators signing a letter of support circulated by Senator Sherrod Brown (D-OH) for FY2012 appropriations.

The U.S. Congress appropriated $6.4 million for FY2011 in April 2011 and $5.1 million for FY2012 in December 2011 to TSC research via the Department of Defense Congressionally Directed Medical Research Program's TSC Research Program (TSCRP). The 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 of the research supported by the TSCRP examined the role TSC genes play in cell growth and proliferation – specifically in controlling the mammalian Target of Rapamycin (mTOR) signaling pathway in cells, which is important in normal cell growth and has been shown to be disrupted in many types of cancer. This research has rapidly led to the development of animal models of TSC and clinical trials, resulting in the first drug specifically to treat TSC being approved by the FDA in October 2010. None of this progress would have been possible without the critical support provided through the TSCRP.

FUND DEVELOPMENT

The heart and soul of the TS Alliance has always been the TSC community -- people from across the country locking arms in hope to raise much-needed funds to support community programs that provide information and advocacy to individuals and families living with TSC. Events large and small make a tremendous difference in the fight against TSC whether it's Comedy for a Cure, Step Forward to Cure TSC walks, DC Food and Wine, Cookin' Up a Cure/Pampered Chef Charity Auction or the many golf tournaments, garage sales and dinner parties that also raise critical awareness. In 2011, special events netted nearly $1.6 million which represented 40% of the TS Alliances overall revenue.
A few highlights include:

- **DC Food and Wine Tasting** celebrated its tenth year and raised $85,000. Led by our Presenting Sponsor, The Winifred M. Gordon Foundation, Inc., over 200 guests enjoyed chef samplings from Morton's, the Steakhouse and tasted wine donated by Chamard Vineyards and Cupcake Vineyards. The evening honored the late Dr. Mark and Karen Mausner and paid tribute to Dr. Vicky Whittemore for her 23 years of service to the TS Alliance.
- **Comedy for a Cure® Hollywood** also celebrated its tenth anniversary at the Hollywood Roosevelt Hotel. Comedy headliner Chelsea Handler and featured comedian Mark Schiff provided the entertainment along with our emcee and Honorary Chair Larry Miller. The TS Alliance paid tribute to long-term supporter Damon Casatico of Charity Auction Benefits, who has been a partner in Comedy for a Cure since its inception. One of the highlights of the evening was an impromptu performance by American Idol Season 9 winner Lee DeWyze. The event raised more than $220,000 with support from Platinum Sponsors C & C Market Research, Lundbeck, and Variety.
- **Comedy for a Cure® New York** was held at the Metropolitan Pavilion, raising more than $160,000 with support from our Premier Sponsors Larry and Diane O'Friel and Presenting Sponsors Novartis and Gotham Magazine. Actor and comedian Wayne Federman served emcee and auctioneer for the evening while comedian Pat Hazell and comedienne Arden Myrin provided the entertainment. Event attendees enjoyed the amazing delicacies from Bardi Catering.
- The largest TSC community fundraisers, **Step Forward to Cure TSC®** walks, took place in 37 cities across the country and collectively raised more than $1.25 million. Julianne Moore once again served as our National Honorary Chair and support was provided by national sponsors LIDS, Lundbeck, Cyberonics and MetLife Center for Special Needs Planning.

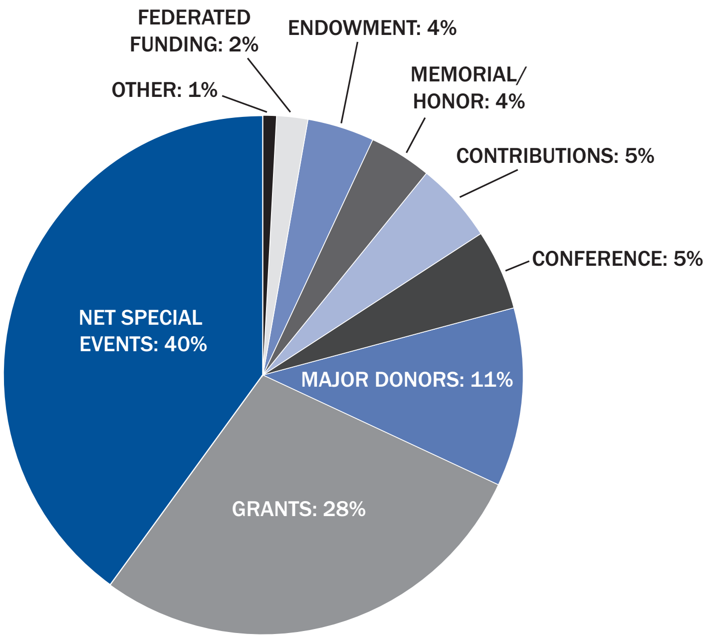
UNLOCK THE CURE

2011 marked an extraordinary decade of progress in TSC research. To fund the next wave of scientific breakthroughs, the TS Alliance launched 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 2011 to the Unlock the Cure campaign were matched. This campaign allows us 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.

(continued next page)

FUND DEVELOPMENT (cont.)

A major focus in 2011 was the expansion of the TS Alliance's outreach and diversification of funding support with emphasis on major donors and grants. As a result, the TS Alliance was able to increase its overall revenue by 16.8% and received 39% of our donations from major gifts and grants.



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) – Jenny Smiley
- Chicago (Galesburg) – Karen Johnson-Wenger
- Cleveland – Michelle Blood
- Connecticut – Jennifer Waldron
- Dallas – Scott and Mandy Striegel
- Florida (Miami) – Vanessa Vazquez
- Heartland – Ryan and Cindy Blackard
- Houston – Bill and Taska Fields
- Indiana – Susan Campbell
- Intermountain West – Ian and Stephanie Bobbermin
- Kansas – Amy Dublinske
- Metro DC – Nathalie Simoneau and Reid Novotny
- Michigan – Treasa Bolger and Matt Bolger
- Middle Tennessee – Brittany Schwaigert
- New England – Stacey Verrill
- New Jersey – Jeff and Wendy Sklarin
- New York (Long Island) – Rob and Denise Spear
- New York (Syracuse) – Stephanie Claxton-Langstaff
- North Carolina – Dee Triemer
- Northern California – Diane Burgis
- Pacific Northwest (Portland) – Nancy Wells
- Pacific Northwest (Seattle) – Kay Rawlings
- Rocky Mountain – Dana Holinka
- Southern California – Barbara O'Neill, Cindy Chernow, Dawn Redfield, Tresha Bisang
- St. Louis – Gwen Montaigne and Donna Bullard
- Upper Midwest – Maria Gibbons
- Wisconsin – Kristin Champagne

Other Major Events

- Chicago Food and Wine Tasting – Julie Scroggins
- Comedy for a Cure Hollywood – Event Planning Committee
- Comedy for a Cure New York – Event Planning Committee
- Crashin for the Cause – Joe and Abby Kopf
- DC Food and Wine – Julie Blum
- Geneva Lakes Amazing Race – Rebecca Melka, Rob Keefe, Tim Schnake and Sharon Clark
- Wentworth Charities Golf Classic – Dennis Prue, Tom and Sharon Gwinn

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January 1 to December 31, 2011

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The Pediatric Epilepsy Research Foundation
Tuberous Sclerosis Alliance Endowment Fund
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Step Forward to Cure TSC walkathon photos
by Sarah Moore Photography.

National Tuberous Sclerosis Association & Affiliate
Consolidated Statement of Financial Position
December 31, 2011

Assets		
Current Assets		
Cash and cash equivalents	$	2,330,171
Short-term investments		865,450
Promises to give, current portion		379,000
Inventory		8,002
Prepaid expenses and other assets		140,493
Total Current Assets		3,723,116
Long-term investments		4,174,493
Property and equipment		141,717
Total Assets	$	8,039,326
Liabilities and Net Assets		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	$	143,549
Accrued compensation		77,136
Deferred revenue		1,628
Gift annuity obligations, current portion		9,400
Total current liabilities		231,713
Gift annuity obligations, less current portion		55,248
Total liabilities		286,961
Commitments and contingencies		–
Net assets		
Unrestricted		
Undesignated		775,400
Designated		4,029,540
Total unrestricted		4,804,940
Temporarily restricted		2,067,981
Permanently restricted		879,444
Total net assets		7,752,365
Total liabilities and net assets	$	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 2011 audit and submitted an unqualified 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 2011 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 $331,176 surplus.

National Tuberous Sclerosis Association & Affiliate
Consolidated Statement of Activities
Year Ended December 31, 2011

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Revenue and Support				
Special Events	$ 1,656,334	$ 132,205	$ -	**$ 1,788,539**
Cost of direct benefits to donors	(196,307)			**(196,307)**
Special events, net	1,460,027	132,205	-	**1,592,232**
Contributions	574,991	1,212,916		**1,787,907**
Conference	212,084			**212,084**
Memorials and honorariums	120,278	22,411		**142,689**
Interest and dividends	103,834			**103,834**
Federated funding	77,102			**77,102**
Other income	15,037			**15,037**
	2,563,353	1,367,532	-	**3,930,885**
Net assets released from restrictions	1,045,200	(1,045,200)		**-**
Total revenue and support	3,608,553	322,332	-	**3,930,885**
Expense				
Program services				
Research	1,970,929			**1,970,929**
Family services	380,633			**380,633**
Public health education	194,475			**194,475**
Government relations	163,120			**163,120**
Professional education	26,188			**26,188**
Total Program Services	2,735,345	-	-	**2,735,345**
Supporting Services				
Fundraising	567,685			**567,685**
Management and general	402,508			**402,508**
Total supporting services	970,193	-	-	**970,193**
Total expense	3,705,538	-	-	**3,705,538**
Change in net assets before other items	(96,985)	322,332	-	**225,347**
Net loss on investments	(116,271)		-	**(116,271)**
Loss on sublease	(19,000)			**(19,000)**
Changes in net assets	(232,256)	322,332	-	**90,076**
Net assets, January 1, 2011	5,037,196	1,745,649	879,444	**7,662,289**
Net assets, December 31, 2011	$ 4,804,940	$ 2,067,981	$ 879,444	**$ 7,752,365**

Tuberous Sclerosis Alliance

801 Roeder Road
Suite 750
Silver Spring, MD 20910

800-225-6872
www.tsalliance.org