UNLOCK
THE CURE

Tuberous Sclerosis Alliance

ANNUAL REPORT 2010.5

July 1, 2010 – December 31, 2010

Tuberous Sclerosis Alliance
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Unlock the Cure

Dear Friend,

As a strong supporter of our organization, we are pleased to send you the Tuberous Sclerosis Alliance's *2010.5 Annual Report*. No, this is not a typo. We have changed our annual year to a calendar year in order to provide the TS Alliance with more flexibility in allocating our resources to achieve our annual goals based on actual versus anticipated revenue. This report covers the six months from July 1, 2010 through December 31, 2010. Moving forward, we will be reporting our progress for the 12 months ending December 31, 2011.

The change in our fiscal year will enable us to better focus on our mission – finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected. Since our last report, we have made significant progress.

Through the tireless efforts of our researchers and staff, the FDA has approved the first drug for TSC indication. In the world of orphan diseases, this is "big news" and recognizes our progress serving the health and well being of our constituents. We're very optimistic this will be a preview of additional breakthroughs to come in research, science and treatments.

We believe this annual report will give you an update on the amazing progress being made on behalf of the thousands and thousands of individuals, adults and families touched by TSC in the United States. We continue to work diligently with our wide range of partners, including 2,000-plus committed volunteers, a cadre of dedicated researchers, compassionate physicians and other healthcare providers, and individuals and supporters like you who continue to make much-needed financial contributions.

Thank you for your steadfast belief in our cause. With a cure. Where our story must end.

Regards,

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Kari Luther Rosbeck
Kari Luther Rosbeck
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Research Program

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. The TS Alliance spent a total of $719,054 in research for the TSC Natural History Database and the research grant awards.

One major milestone in TSC treatment was reached in October 2010 when the U.S. Food and Drug Administration approved the first drug for an indication for TSC, which is used to treat individuals with subependymal giant cell astrocytomas (SEGAs) associated with TSC. Before this drug was approved, the only treatment option for SEGAs was surgery to remove them. Other clinical trials are currently ongoing to test the drug's efficacy to treat other TSC symptoms.

Developed in 2004 and implemented in 2006, the TSC Natural History Database identifies specific correlations between TSC gene mutations and the impact of the disease on a person's health over their lifetime. As of December 31, 2010, 15 US-based TSC clinics were entering data with 1,047 people with TSC enrolled in the project. Of those, 516 are male; 531 are female. Six hundred sixty four (63%) are less than 18 years old with the youngest 8 months old; the remaining 383 (37%) research participants are 18 or over with the oldest 77 years old. Medical information is entered in at least 13 areas affected by TSC (e.g. brain, eyes, heart, kidneys, skin). Epilepsy is entered as a condition affecting 83% of the research participants enrolled. 39% of those with epilepsy have a history of infantile spasms. Other conditions include: angiofibroma (52%), rhabdomyoma (37%), angiomyolipoma (41%) and subependymal giant cell tumor (22%). The TS Alliance provides funding to participating clinics to perform data entry, monitors the integrity of the database and utilizes the data to inform clinical trials and studies.

The first published article using information from the TSC Natural History Database Project appeared in *Mol Psychiatry*, advance online publication, November 16, 2010. The article – entitled "Gestational immune activation and Tsc2 haploinsufficiency cooperate to disrupt fetal survival and may perturb social behavior in adult mice" – reports findings from research using the Tsc2 mouse model, which suggests a possible explanation for the high incidence of autism spectrum disorders in TSC.

In the latter part of 2010, the organization grew its grant mechanisms, awarding $663,012 for 19 projects through continued and new funding. The TS Alliance also launched its new Drug Screening Program with two awards to Beth Israel Deaconess Medical Center and Drexel University. This new program will screen and test compounds in order to expand the potential new therapies for TSC. Grants of

$19,414 were awarded from net assets through the TS Alliance Rothberg Courage Award in continued support of the TSC Neurocognitive Clinical Trials taking place in Boston and Cincinnati.

Support Services

The TS Alliance 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. 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 18 town hall meetings held at Community Alliance locations from April to December 2010. 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 reaching constituents across the country with clinical care specialists and scientists from the convenience of their homes. In addition, the Department of Advocacy and Education supports 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 Miami, Cincinnati, Columbus and Atlanta during one on one meetings.

The Director of Advocacy and Education attends Individual Education Program (IEP) meetings in person, through SKYPE, and conference calls and also maintains an ongoing blog to encourage frequent and interactive conversation with constituents as they encounter challenges on a daily basis. The Director of Advocacy and Education also facilitates the Adult Task Force, which holds monthly topic calls in identified issues of importance to better support adults living with TSC. The TS Alliance also offers online interactive sibling chat groups held three times a month based on several age groups.

Finally, the TS Alliance created a new online social network in partnership with Inspire. This social network was developed to better fit the needs of our TSC population and included 553 members from 25 countries as of December 31, 2010.

Public Education

The TS Alliance works to heighten awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families. In Fall 2010, the TS Alliance used online banner outreach on epilepsy.com to increase awareness of the disorder and to drive visitors to our website for more information.

The TS Alliance website also instituted a new online form to capture visitor information, thus increasing the number of known constituents with TSC. The website provides extensive education via 950,000 to 1.1 million hits monthly from an average of 18,000 unique visitors.

The Fall 2010 issue of our national magazine, *Perspective,* was sent to 11,800 constituents. *Perspective* includes articles on research updates, constituent stories, educational initiatives, and community grassroots activities. The organization also updated its *Introduction to TSC* pamphlet to reflect the latest advances in treatments for various conditions caused by TSC.

The TS Alliance offers a prolific social media outreach program utilizing Facebook, YouTube, and Twitter, and its online discussion groups provide critical information to the newly diagnosed and others.

Government Relations

The TS Alliance government relations program focuses on educating members of Congress about TSC to further TSC research, awareness and clinical care. The U.S. Congress appropriated $6 million to TSC research through the Department of Defense Congressionally Directed Medical Research Program in 2010. 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 the research supported by the TSCRP that examined the role that 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.

Professional Education

The TS Alliance offers professional education to expand programs targeting health providers who provide care for individuals with TSC, medical students, genetic counselors and educators to minimize the consequences of ignorance and misinformation.

The TS Alliance participated and presented at several professional meetings including: the Gordon Conference on Mechanisms of Epilepsy; National Institute of Neurological Disorders and Strokes focus meetings on their new epilepsy Center Without Walls initiatives and Genetics of Epilepsy; Trans-National Institutes of Health Working Group Meeting for TSC; National Institute of Child Health and Human Development meeting on Epigenetics in Developmental Disabilities; and American Thoracic Society Leadership Summit. In addition, the TS Alliance held an educational reception at the American Epilepsy Society meeting as well as helped coordinate a Special Interest Group focusing on genetics of TSC and staffed an exhibit.

A new online portal was developed for healthcare professionals called “VeoMed” to encourage information exchange. There are currently 69 professionals using this portal, which also serves as a resource for professionals 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 and Education collaborated with national educational networks, such as the National Association of Middle Schools where she presented at their national conference, in outreach to 300 educators in the area of TSC and services needed for appropriate educational requirements. Providing children with appropriate education is the key to individuals having a good quality of life. A new publication, called *The Teachers Guide to TSC*, was produced specifically to help and meet that goal.

Fund Development

The TS Alliance has some of the most dedicated volunteers raising awareness and funds for us every season. Throughout the summer, fall and beginning of winter 2010, grassroots events were held all across the country. From powerhouse golf tournaments to a fun-filled demolition derby to a successful letter-writing campaign, a lot of hard work and fundraising were completed on behalf of the TS Alliance. Every dollar matters and can make a difference, so these efforts continue to help our organization as we work together to provide much-needed services and programs and drive progress toward finding better treatments and ultimately a cure. Special events of all shapes and sizes, including our walkathons, account for 50 percent of our overall revenue. This would not be possible without one of our most vital and significant resources—our volunteers!

Events Raising More Than $10,000

Step Forward to Cure TSC® Walkathons

Florida (Miami) – Vanessa Vazquez
Heartland – Cindy and Ryan Blackard
Metro D.C. – Nathalie Simoneau
Middle Tennessee – Amy and James Hobbs
New England – Tom and Sharon Gwinn
New York (Syracuse) – Stephanie Claxton Langstaff
New York (Long Island) – Denise and Rob Spear
Northern California – Suki Maharaj
Ohio (Cleveland) – Michelle Blood
South Carolina – Jeff and Christi Davis
Wisconsin – Pam Sztukowski

Tournaments for TSC Champions

Blazin' Buffalo Wild Wings Golf Tournament - Todd Kronebusch, Michael O'Connor, Nikki Butler and Rachelle Bellmore
National Golf Links of America - John Nicholson, MD
Wentworth Charities Golf Classic – Tom and Sharon Gwinn

Other Major Events

Comedy for a Cure® Boston – Jeffrey Hargreaves
Crashin' for the Cause - Joe and Abby Kopf
Stamp Out TSC – Cristina Fitzgerald

Annual Fund Major Donors

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Aspen Systems
Rockville, MD
Specialty: Genetic Counseling

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Specialty: Pediatric Neurology & Epilepsy

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Division of Surgery and Medical Genetics
Seattle, WA
Specialty: Surgery

Consolidated Statements of Financial Position: December 31, 2010

National Tuberous Sclerosis Association, Inc. (dba TS Alliance) and Affiliate (TS Alliance Endowment Fund)

Assets		
Current assets		
Cash - Note B	$	497,754
Short-term investments - Notes B & C		2,441,810
Accounts receivable		5,378
Promises to give, current portion - Note D		350,150
Inventory		15,410
Prepaid expenses		105,444
Total current assets		3,415,946
Long-term investments - Notes B & C		4,286,405
Promises to give, less current portion - Note D		25,000
Property and equipment - Note E		145,096
Total assets	$	7,872,447
Liabilities and Net Assets		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	$	78,297
Accrued compensation		56,440
Deferred revenue		11,171
Gift annuity obligations, current portion - Note F		9,400
Total current liabilities		155,308
Gift annuity obligations, less current portion - Note F		54,850
Total liabilities		210,158
Commitments and contingency - Note N		-
Net assets - Notes G & H		
Unrestricted		
Undesignated		510,876
Designated		4,526,320
Total unrestricted		5,037,196
Temporarily restricted		1,745,649
Permanently restricted		879,444
Total net assets		7,662,289
Total liabilities and net assets	$	7,872,447

The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year's auditors completed its audit (July 1-December 31, 2011) and submitted an unqualified opinion to the TS Alliance Board of Directors. The complete audited financial statements are on file at the TS Alliance. To obtain a copy, call 800.225.6872 or visit www.tsalliance.org. The summary was prepared from the audited consolidated statements of the TS Alliance and the TS Alliance Endowment Fund. The relationship of the organization requires consolidation per accounting principles generally accepted in the United States of America.

Consolidated Statements of Activities: December 31, 2010

National Tuberous Sclerosis Association, Inc. (dba TS Alliance) and Affiliate (TS Alliance Endowment Fund)

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Revenue and support				
Contributions	$ 440,551	$ 457,311	$ -	**$ 897,862**
Special events	395,116	86,517		**481,633**
Costs of direct benefits to donors	(30,071)			**(30,071)**
Special events, net	365,045	86,517	-	**451,562**
Interest and dividends - Note C	74,607	435		**75,042**
Memorials and honorariums	49,325	6,317		**55,642**
Federated funding	50,529			**50,529**
Other income	5,728			**5,728**
	985,785	550,580	-	**1,536,365**
Net assets released from restrictions - satisfaction of purpose restrictions - Note G	476,450	(451,450)	(25,000)	**-**
Total revenue and support	1,462,235	99,130	(25,000)	**1,536,365**
Expense				
Program services				
Research	919,009			**919,009**
Family services	230,124			**230,124**
Public health education	89,746			**89,746**
Government relations	74,182			**74,182**
Professional education	8,285			**8,285**
Total program services	1,321,346	-	-	**1,321,346**
Supporting services				
Management and general	239,566			**239,566**
Fund raising	230,243			**230,243**
Total supporting services	469,809	-	-	**469,809**
Total expense	1,791,155	-	-	**1,791,155**
Change in net assets before other item	(328,920)	99,130	(25,000)	**(254,790)**
Net gain on investments - Note C	513,658	3,262		**516,920**
Change in net assets	184,738	102,392	(25,000)	**262,130**
Net assets, July 1, 2010	4,852,458	1,643,257	904,444	**7,400,159**
Net assets, December 31, 2010	$ 5,037,196	$ 1,745,649	$ 879,444	**$ 7,662,289**