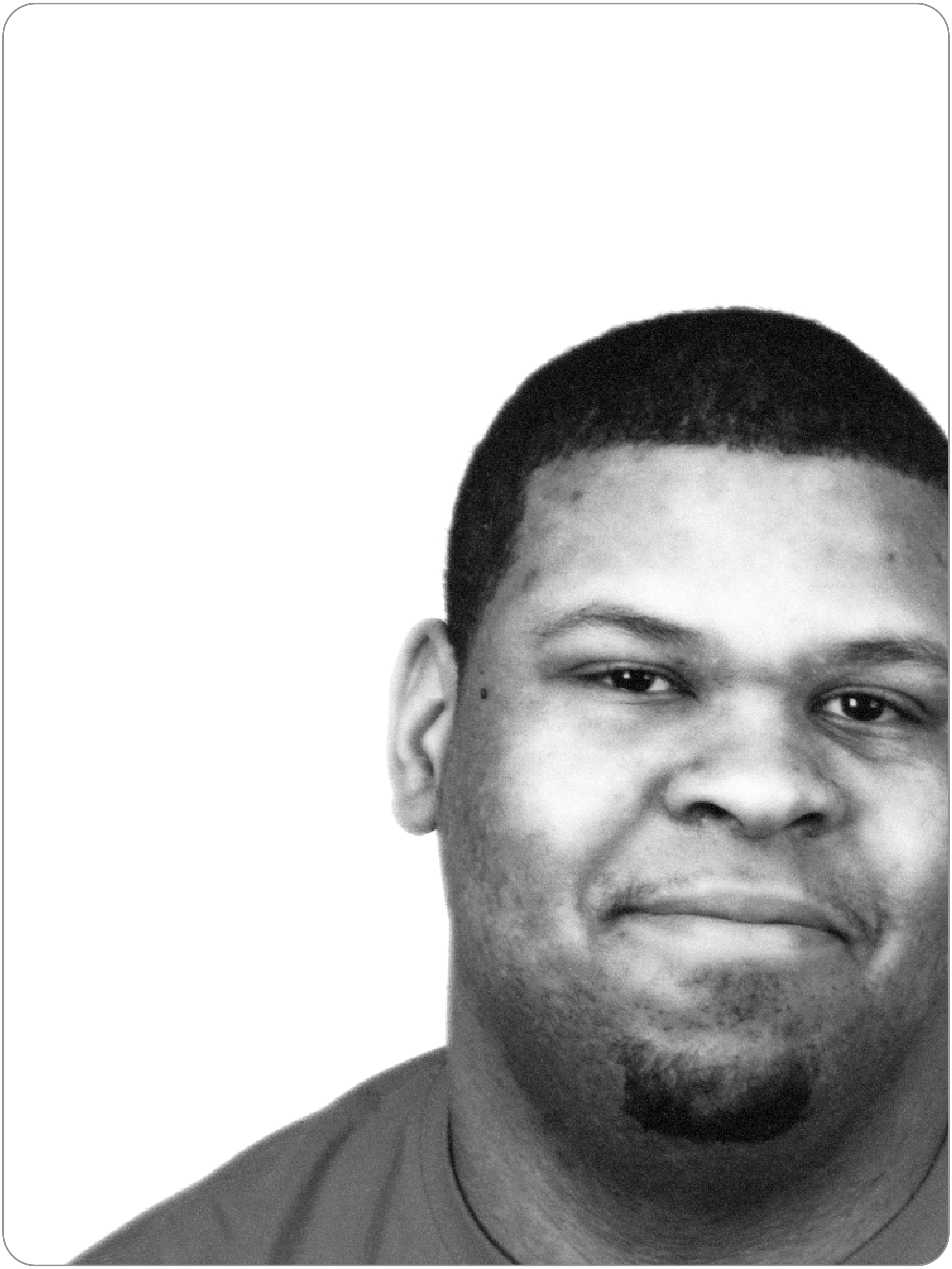
Tuberous Sclerosis Alliance

ANNUAL REPORT 2010

MISSION MOMENTUM

Accelerate. Empower. Mobilize.



Mission Momentum
Accelerate. Empower. Mobilize.

Throughout the TS Alliance's Fiscal Year 2010 (July 1, 2009 to June 30, 2010), the organization remained dedicated to our vision to bring about the day when no one has to endure the devastating effects of tuberous sclerosis complex (TSC).

As a result, the TS Alliance's 2010 focus was to strengthen the organization and raise funds to:

- Accelerate basic, clinical and translational research;
- Empower our constituents with information and improved treatments; and
- Mobilize public and government support.

This annual report provides information on our success reaching these goals, while serving as a reminder that every minute and every dollar spent finding treatments and a cure for TSC could bring about quantum leaps forward in treatments and cures for other diseases too – like autism, epilepsy and even cancer.

Our Mission

The Tuberous Sclerosis Alliance is committed to finding a cure for tuberous sclerosis complex (TSC), while improving the lives of those affected by:

- Developing programs, support services and resource information;
- Stimulating and sponsoring research; and
- Creating and implementing public and professional education programs designed to heighten awareness of the disease.

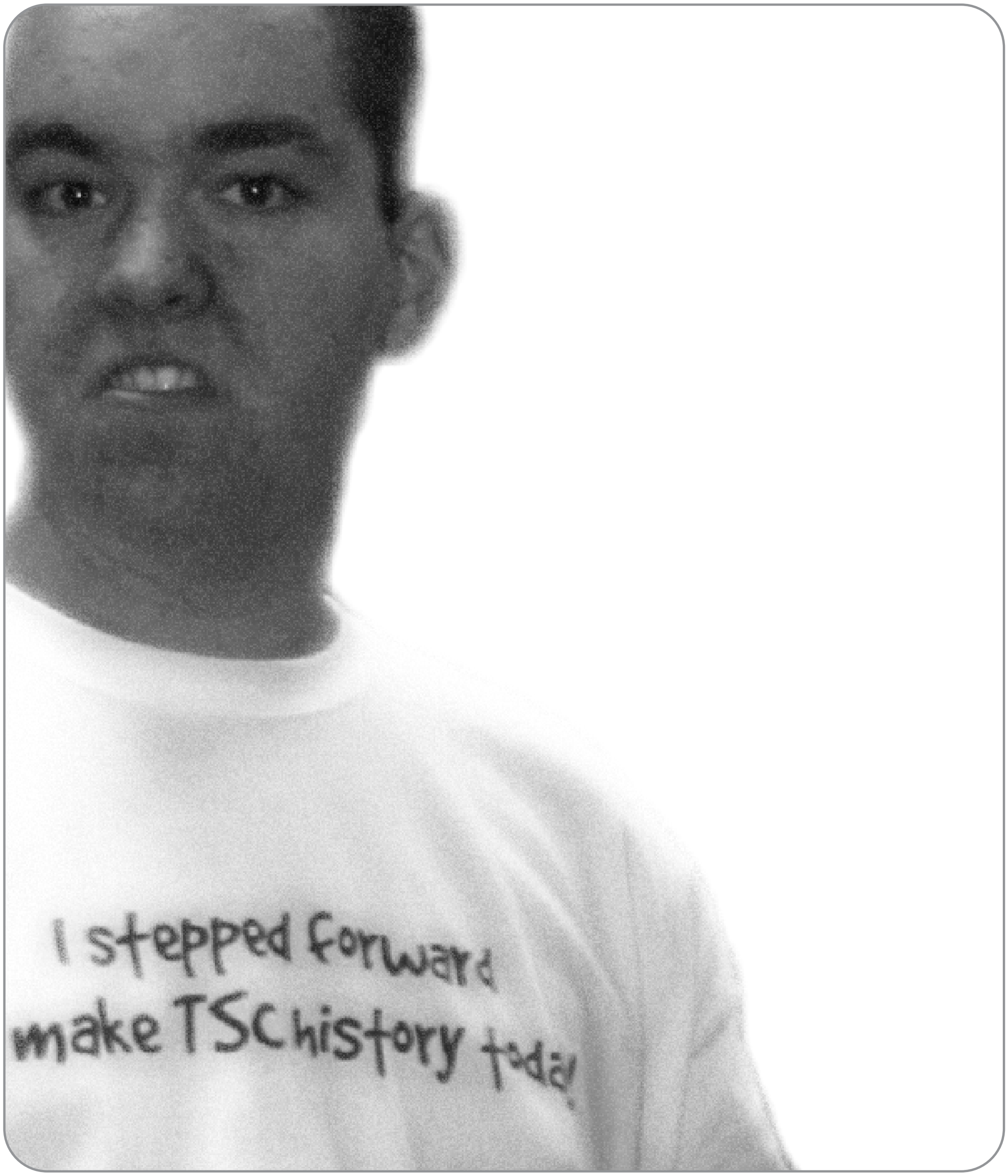
About Tuberous Sclerosis Complex

Tuberous sclerosis complex is a genetic disorder that causes tumors to form in many different vital organs, including the brain, eyes, heart, livery, kidneys, skin and lungs. Epilepsy, autism spectrum disorders, and other intellectual disabilities are also often found in individuals affected by TSC. 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.

The TS Alliance is committed to finding a cure for tuberous sclerosis complex while improving the lives of those affected.


I stepped forward
make TSC history toda!

Programs, Support Services and Resource Information

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 find a cure for TSC. In 2010, the TS Alliance spent a total of $1,425,738 for TSC research.

One of the interesting things about TSC is it affects every person differently. The TS Alliance developed the TSC Natural History Database six years ago to identify if specific correlations exist between TSC gene mutations and the impact of the disease on a person's health over a lifetime. As of June 30, 2010, 15 U.S.-based TSC clinics were entering data with 1,014 people with TSC enrolled in the project. Of those, 498 are male; 516 are female. Six hundred sixty four (66%) are less than 18 years old with the youngest 3 months old; the remaining 350 (34%) research participants are 18 or over with the oldest 76 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 81% of the research participants enrolled, and 39% of those with epilepsy have a history of infantile spasms. Other conditions include: angiofibroma (48%), rhabdomyoma (36%), angiomyolipoma (36%) and subependymal giant cell tumor (19%).

A poster of the first research findings from the TSC Natural History Database was presented at the American Epilepsy Society in December 2009. 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 TS Alliance also continued its commitment to funding research grants. In 2010, ongoing funding of $844,094 supported 15 research projects awarded in previous fiscal years. In addition, a grant of $75,000 was awarded from net assets through the TS Alliance Rothberg Courage Fund in support of a new TSC Neurocognitive Clinical Trial that will recruit study participants in Boston and Cincinnati.

In September 2009, the TS Alliance sponsored the International TSC Research Conference: From DNA to Human Therapies. The goal of the conference was to bring together researchers and health care professionals to discuss our current knowledge of the underlying mechanisms that cause the various manifestations of TSC and what research is needed in the future. The conference was attended by 150 people from 14 countries, including Australia, Canada, China, England, Germany, Italy, Japan, Macedonia, The Netherlands, Northern Ireland, Norway, Scotland, Sweden and the United States. Participants included physicians, genetic counselors, nurses, basic researchers, clinical researchers, parents of individuals with TSC and industry representatives.

Support Services

TS Alliance Support Services include programs and services that provide individuals with TSC and their caregivers with direct access to information, resources and specialists experienced in the diagnosis, treatment and management of TSC.

Through the network of 33 volunteer branches of the organization, called Community Alliances, local educational and support group meetings are held throughout the country.

In February 2010, the TS Alliance sponsored and underwrote its annual leadership training for our Community Alliance Chairs in Washington, D.C. These grassroots volunteer leaders are truly the heart and soul of our organization and their efforts not only account for 50 percent of the revenue generated by the organization, but also much of the educational outreach conducted across the nation. The TS Alliance believes strongly in investing in the advocacy program and leadership training to provide skills for our community leaders to effectively build networks across the country, to make TSC more visible in their communities, to strengthen their special events and to empower volunteers.

In April 2010, the TS Alliance instituted the first of 18 town hall meetings held at Community Alliance locations from April to December 2010. These meetings facilitate stronger connections with peers, researchers, and clinicians in the community and educate the TSC community about clinical trials. The TS Alliance also continued a series of teleconferences aimed at reaching constituents across the country with clinical care specialists and scientists from the convenience of their homes. Eight teleconferences took place on subjects including Understanding Neurocognition and Brain Manifestations in TSC, Genetics and TSC, Kidney Involvement in TSC, Autism Spectrum Disorder and TSC, TS Alliance Research Update, and TSC Clinical Trials Updates.

The Department of Advocacy and Education supports families and individuals from all over the United States by attending Individual Education Program (IEP) meetings in person, through SKYPE and via conference calls during the IEP season of April to June 2010. There were 16 trainings held in collaboration with Community Alliances through conference call training in special education. The TS Alliance also co-sponsored an Educational Rights Training Program with the Ohio State Department of Education's State Support Team Region 7, with more 190 participants attending. Educational advocacy is an important service to TSC individuals and families as they navigate the school system and as those affected transition from school into the community as adults. In addition to the training programs, the following new educational publications were published by the TS Alliance: *Teacher's Guide: Educating Children with TSC*, *Behavioral Issues and TSC* and *What is Section 504?*

The TS Alliance Director of Advocacy and Education also maintained an ongoing blog to encourage frequent and interactive conversations with constituents as they encountered challenges on a daily basis and facilitated the Adult Task Force. A survey was sent out to adults to identify areas of needs for adults with TSC. The Adult Task Force implemented topic calls in these identified need areas to support our adult population. There were five Adult Topic Conference calls held in 2010 to address the needs of adults dealing with TSC. The topics were: "Anxiety in the Work Place and School, Part 1 and Part 2," "Working with Your Doctor," and two open forums.

In response to requests for support of siblings of children with TSC, the TS Alliance continued to offer online, interactive chat groups held three times a month based on several age groups. There were more than 30 Sibling Chats held in 2010. The TS Alliance also hosted four online discussion groups to offer education and support, based on peer types: Adults with TSC, Parents/Caregivers, Teens, and TSC Professionals.

Finally, TS Alliance launched an online constituency study to gauge the organization's performance and determine constituents' unmet needs. The specific objectives of the 2010 TS Alliance Constituency Study were as follows:

- To gauge the performance of the TS Alliance in meeting constituents' needs and living up to its mission;
- To determine awareness, usage and opinion of various TS Alliance resources, programs and events;
- To gain a better understanding of the challenges faced by individuals and families living with TSC and identify unmet needs; and
- To prioritize the organization's strategic goals.

The survey was conducted between February 11, 2010 and April 6, 2010 with 759 total respondents. The results will assist the TS Alliance in evaluating future goals and strategies of the organization and the needs of future programs and services.

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 2010, the TS Alliance used online banner outreach on *epilepsy.com* and *USnews.com* to increase awareness of the disorder and to drive visitors to our website for more information.

TSC, as well as the work of the TS Alliance, was also highlighted in dozens of local stories generated by our grassroots volunteers, ranging from reports on events such as Step Forward to Cure TSC to human interest and health reports about families and individuals dealing with the daily struggles of TSC.

Three issues of our national magazine, *Perspective*, were published in 2010 and sent to 11,800 constituents. *Perspective* includes articles on research updates, constituent stories, educational initiatives, and community grassroots activities.

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

The TS Alliance also increases awareness and provides extensive education though its website via 950,000 to 1.1 million hits monthly from an average of 18,500 unique visitors. The TS Alliance also has a prolific social media outreach program utilizing Facebook, MySpace, YouTube, and Twitter, and our online discussion groups provide critical information to the newly diagnosed and others.

Government Relations

Our Government Advocacy Program focuses on educating members of Congress about TSC to obtain federal resources to further TSC research and clinical care. In 2010, the TS Alliance grassroots volunteers conducted a March on Capitol Hill resulting in more than 390 personal Congressional visits and the delivery of information to every Congressional office. These efforts lead to 90 members of the House of Representatives signing a letter of support circulated by Representatives Loretta Sanchez (D-CA) and Gary Miller (R-CA) and 22 Senators signing a bipartisan letter of support circulated by Senators Sherrod Brown (D-OH) and Mike Crapo (R-ID).

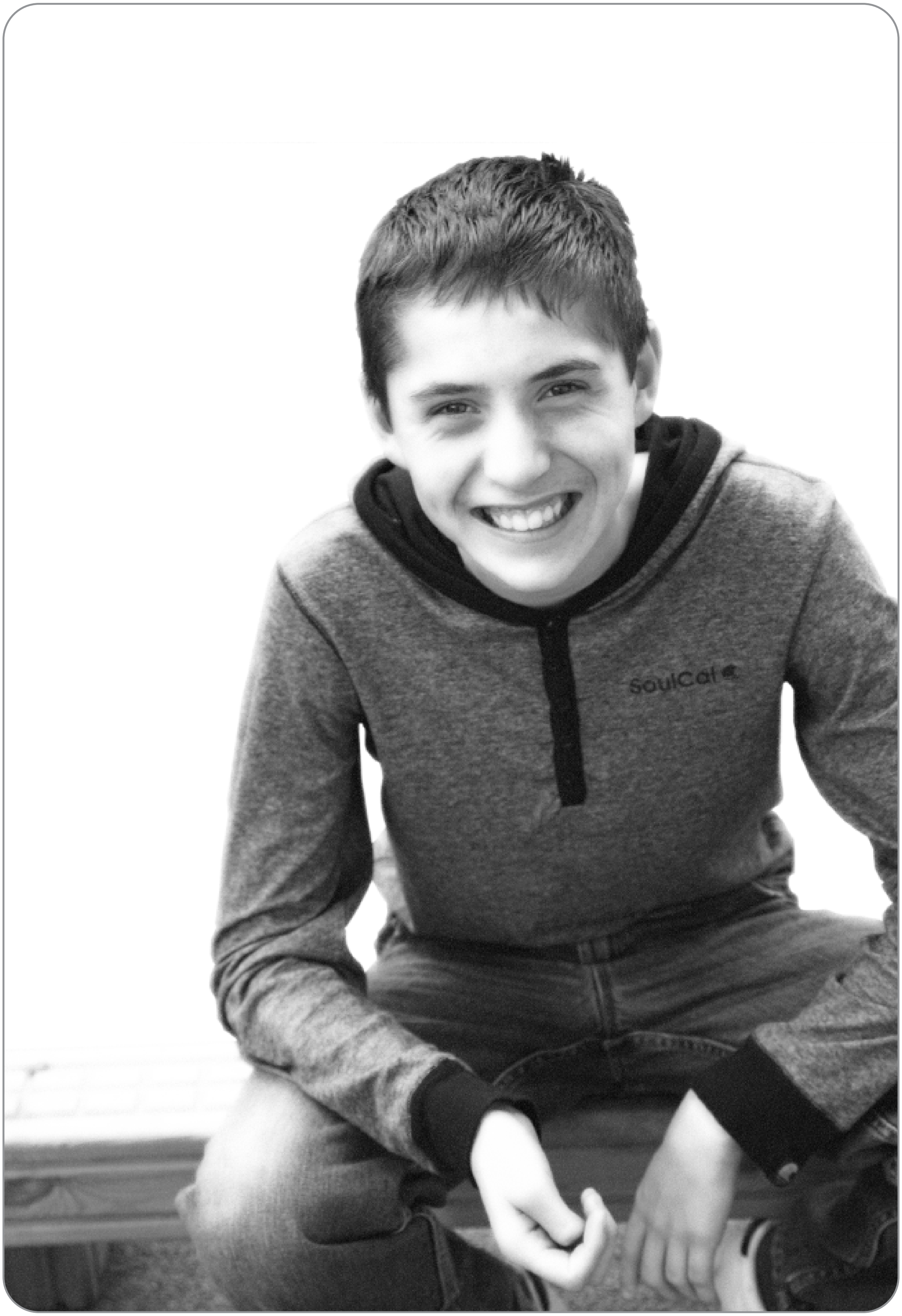
From similar efforts of these volunteers the prior year, the U.S. Congress appropriated $6 million to TSC research through the Department of Defense Congressionally Directed Medical Research Program in 2010. The TS Alliance believes the investment in this program has a profound impact on moving new treatments, and ultimately a cure for TSC, forward. The research program administered from the appropriation is a competitive grant review program. While the TS Alliance receives no direct funding, these Federal research dollars are central to our mission.

Professional Education

Professional Education expands programs targeting health care providers who offer care for individuals with TSC, medical students, genetic counselors and educators to minimize the consequences of ignorance and misinformation. In 2010, the TS Alliance presented and participated in professional conferences that assisted in educating these professionals, including the Child Neurology Society, the American Epilepsy Society, and the American Thoracic Society. In addition, an annual meeting of TSC Clinic Directors was held during the International Research Conference for updates in research, clinical care, and the TSC Natural History Database.

The TS Alliance continued to monitor a listserv/online discussion group in 2010 that connects professionals in the field of TSC care, research and science. There are currently 50 professionals on this list, which also serves as a resource for professionals not familiar with TSC seeking guidance from peers.

In addition, a monthly online newsletter called *TSC Alert* was 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, in outreach to educators in the area of TSC and services needed for appropriate educational requirements. The Director presented at five professional conferences in Ohio, Pennsylvania and Texas. These professional presentations provided outreach to more than 389 teachers and administers in the educational needs of children with TSC. Providing children with appropriate educations is the key to individuals having a good quality of life.



Photograph by Rick Guidotti for Positive Exposure

Fund Development

Each year, people from across the United States help the TS Alliance raise much-needed funds by organizing events ranging from garage sales and bake sales or golf tournaments to walkathons or food and wine events to star-studded comedy nights. Others raise money on their own through events like Cookin' Up a Cure/Pampered Chef Charity Auction, Charity Shrub Sale, The Geneva Lakes Amazing Race and Crashin' for the Cause Demolition Derby. No matter the amount, these efforts continue to help our organization provide crucial services, programs and fund research for all those affected by TSC while increasing awareness in their communities.

For fiscal year 2010, special events raised nearly $1.6 million, which represented 50 percent of the TS Alliance's overall revenue. Highlights include:

- Representatives Gary Miller (R CA), Loretta Sanchez (D CA), Pete Sessions (R TX) and Chris Van Hollen (D MD) generously loaned their support to the DC Food & Wine Tasting as Honorary Co-Chairs where we also paid tribute to Billy Tauzin, President and CEO of Pharmaceutical Research and Manufacturers of America (PhRMA).

- Champions of our cause participated in 35 Step Forward to Cure TSC® walkathons across the country, raising more than $1 million! This year's National Sponsors included LIDS and Lundbeck, and we had our first National Honorary Chair – Julianne Moore.

- After 15 years our signature event Comedy for a Cure® was brought back to New York City where it originated. More than 300 families, friends and other supporters celebrated in this night of laughter and hope, while raising $200,000-plus. Honorary Chair Julianne Moore, special guest Rachael Ray and comedians Richie Byrne, Seth Herzog, Joey Kola and RC Smith helped honor ICAP and Jeff and Wendy Sklarin.

- Comedy for a Cure® Hollywood ran its ninth year by honoring Co-Founders of C&C Market Research, Craig & Cindy Cunningham. Long time supporter Patricia Heaton served as our host, while comedians Ray Romano, Larry Miller, Jeff Allen, and Mike Polk added comic relief to the evening, which helped raise $250,000.

- Comedy for a Cure® grew across the country this year. For the first time we received a national sponsorship for all five Comedy events from Lundbeck. Boston held their fourth annual event where comedians Tony V., Bob Seibel and Johnny Pizzi and honorary chairs Dr. Elizabeth Thiele and Dr. Mustafa Sahin joined us in honoring Sharon and Tom Gwinn. Chicago held their third successful event, where comedian Mark Curry packed the house to help honor CEO Sean Nolan and Vice President of Epilepsy Beth Dean from Lundbeck. New for 2010 was Atlanta, where comedian Jamie Bendall kicked things off while honoring Dr. Robert Flamini, Director of the new TSC Clinic in Atlanta.

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Events Raising More Than $10,000

Step Forward to Cure TSC® Walkathons

- Alabama – Carole Pitard
- Arizona – Debora Moritz
- Atlanta – Reiko Donato
- Connecticut – Jennifer Waldron
- Chicago (Galesburg) – Karen Johnson-Wenger
- Chicago (Elk Grove) – Jenny Smiley
- Dallas/Ft. Worth – Scott and Mandy Striegel
- Delaware/Lehigh Valley – Shelly Richards
- Delta Region – Peggy Packard
- Heartland – Cindy and Ryan Blackard
- Houston – Bill and Taska Fields
- Indiana – Susan Campbell
- Intermountain West (Utah) – Stephanie and Ian Bobbermin
- Metro DC – Nathalie Simoneau
- Michigan – Treasa Bolger and Matt Bolger
- Middle Tennessee – Amy and James Hobbs
- New England – Tom and Sharon Gwinn
- New York (Syracuse) – Stephanie Claxton Langstaff
- Ohio (Cleveland) – Michelle Blood
- Pacific Northwest (Seattle) – Susan Jorski
- Pacific Northwest (Portland) – Nancy Wells
- Rocky Mountain – Dana Holinka
- St. Louis – Rene' Friedel
- Southern California – Cindy Chernow, Barb O'Neill, Dawn Redfield and Tresha Bisang
- Upper Midwest – Maria Gibbons
- Western Pennsylvania – Lori Shoup
- Wisconsin – Pam Sztukowski

Tournaments for TSC Champions

- Blazin' Buffalo Wild Wings Golf Tournament – Todd Kronebusch, Justin Banks, Michael O'Connor, Nikki Butler and Rachelle Bellmore
- Emmory Regan Shapses Golf Classic – Marc and Marla Shapses
- Kylie's Hope Golf Tournament – Maria, Neil and Kelly Gibbons
- Tournament for TSC Champions in Indiana – Mark and Dawn Koers
- Wentworth Charities Golf Classic – Tom and Sharon Gwinn

Other Major Events

- 35 Dinners Across America (Out on the Town) – Alexandria Asensio
- 35 Dinners Across America (Food & Wine Tasting) – Julie Scroggin
- 35 Dinners Across America (Youmans Family BBQ) – Bill and Nancy Youmans
- Comedy for a Cure® Atlanta – Dee Triemer
- Comedy for a Cure® Chicago – Jenny and Sandy Smiley
- Comedy for a Cure® Hollywood – Rick and Jennifer Glassman
- Comedy for a Cure® New York – Tommy and Peggy Lindsey
- Crashin for the Cause – Joe and Abby Kopf
- DC Food & Wine Tasting – Julie Blum and John Poutasse
- Geneva Lakes Amazing Race – Rebecca Melka, Rob Keefe, Tim Schnake and Sharon Clark
- Shrub Sale – Burt and Sue Goodrich
- Stamp Out TSC – Cristina Fitzgerald
- Taste of the Twin Cities Food & Wine Tasting – Missy Anderson

Annual Fund – Major Donors

Fiscal Year 2010:
July 1, 2009 – June 30, 2010

President's Circle ($100,000-$499,999)

Cowlin Family Fund
Lundbeck Pharmaceuticals, Inc
Tuberous Sclerosis Alliance Endowment Fund
Wentworth Charities Organization

Benefactor ($50,000-$99,999)

Novartis Pharmaceuticals Corporation
Robertson Foundation

Sponsor ($20,000-$49,999)

America's Charities
Buffalo Wild Wings
Craig and Cindy Cunningham, C&C Market Research
East Fond du Lac County Chapter of Thrivent Financial
David and Cathy Krinsky
James T. Medick, Precision Opinion
National Institute of Neurological Disorders and Stroke (NINDS), National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS), the Office Of the Director, National Institutes Of Health (OD), the Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Cancer Institute (NCI)
Lawrence and Diane O'Friel
Harold Simmons Foundation
Marc, Marla, and Emmory Shapses, ERS Charitable Foundation
Tuberous Sclerosis Canada Sclerose Tubereuse
Bill and Kristina Watts, Watts Charitable Fund

Protector ($10,000-$19,999)

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Michael and Janie Frost
Genesco
James and Jessica Lawler, Glenn N. Howatt Foundation
ICAP Services North America, LLC
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Variety
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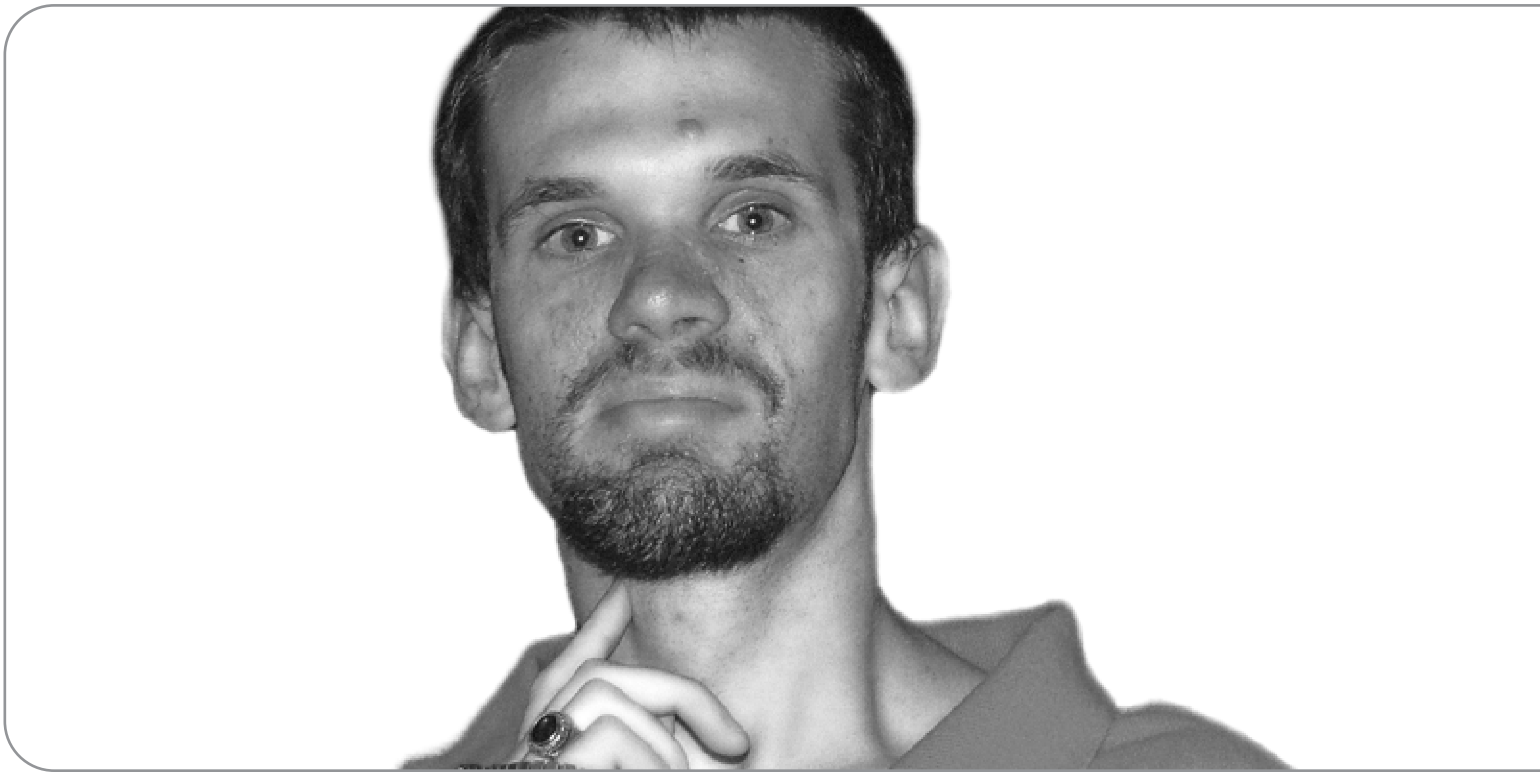
The TS Alliance strives to correctly recognize all donors. We apologize in advance for any errors, omissions or misspellings in this annual report. Please call our office at (800) 225-6872 with any corrections.



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The Tuberous Sclerosis Alliance Endowment Fund is a separate fiduciary organization specifically chartered to receive gifts that will be invested to generate an income stream that will help fulfill the mission of the TS Alliance. The endowment fund will ensure the TS Alliance has an ongoing source of funding to better serve those touched by tuberous sclerosis complex through research, support services and education.

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Please remember the Tuberous Sclerosis Alliance Endowment Fund when planning for the future by designating a gift to the organization.

Photograph by Rick Guidotti for Positive Exposure

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National Tuberous Sclerosis Association, Inc.
(d.b.a. TS Alliance) and Affiliate
(TS Alliance Endowment Fund)

Consolidated Statements of Financial Position • June 30, 2010 and 2009

	2010	2009
Assets		
Current Assets		
Cash	$ 552,417	$ 731,532
Short-term investments	2,732,673	2,600,043
Accounts receivable	15,130	21,815
Promises to give, current portion	82,900	118,600
Inventory	17,793	23,841
Prepaid expenses	86,797	47,609
Total current assets	3,487,710	3,543,440
Long-term investments	3,882,272	3,651,157
Promises to give, less current portion	50,000	100,000
Property and equipment	158,842	186,415
Total Assets	$ 7,578,824	$ 7,481,012
Liabilities and Net Assets		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	$ 53,655	$ 82,134
Accrued compensation	57,359	46,768
Deferred revenue	-	3,900
Gift annuity obligations, current portion	9,400	9,400
Total current liabilities	120,414	142,202
Gift annuity obligations, less current portion	58,251	63,106
Total liabilities	178,665	205,308
Commitments and contingency	-	-
Net assets		
Unrestricted		
Undesignated	566,132	337,257
Designated	4,286,326	4,560,054
Total unrestricted	4,852,458	4,897,311
Temporarily restricted	1,643,257	1,473,949
Permanently restricted	904,444	904,444
Total net assets	7,400,159	7,275,704
Total liabilities and net assets	$ 7,578,824	$ 7,481,012

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 2010 audit 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, please call 800.225.6872 or visit our website at tsalliance.org. The 2010 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. The operating entity ended the year with a $8,883 surplus.

National Tuberous Sclerosis Association, Inc.
(d.b.a. TS Alliance) and Affiliate
(TS Alliance Endowment Fund)

Consolidated Statements of Activities

	Unrestricted	Temporarily Restricted	Permanently Restricted	2010 Total	2009 Total
Revenue and Support					
Special Events	$ 1,728,207	$ 91,779	$ -	**$ 1,819,986**	$ 1,915,375
Cost of direct benefits to donors	(234,166)			**(234,166)**	(272,432)
Special events, net	1,494,041	91,779	-	**1,585,820**	1,642,943
Contributions	571,138	596,568		**1,167,706**	1,277,629
Interest and dividends	108,185	695		**108,880**	125,390
Memorials and honorariums	89,762	14,209		**103,971**	104,182
Federated funding	91,347			**91,347**	78,586
Conferences	56,970			**56,970**	41,527
Other income	3,967			**3,967**	13,852
	2,415,410	703,251	-	**3,118,661**	3,284,109
Net assets released from restrictions - satisfaction of program restrictions	535,104	(535,104)		**-**	-
Total revenue and support	2,950,514	168,147	-	**3,118,661**	3,284,109
Expenses					
Program services					
Research	1,425,738			**1,425,738**	1,311,445
Family services	384,849			**384,849**	558,814
Public health education	189,302			**189,302**	260,804
Government relations	152,958			**152,958**	142,286
Professional education	11,778			**11,778**	56,455
Total Program Services	2,164,625	-	-	**2,164,625**	2,329,804
Supporting Services					
Fund raising	517,486			**517,486**	487,227
Management and general	520,765			**520,765**	651,886
Total supporting services	1,038,251	-	-	**1,038,251**	1,139,113
Total expense	3,202,876	-	-	**3,202,876**	3,468,917
Change in net assets before other item	(252,362)	168,147	-	**(84,215)**	(184,808)
Net gain (loss) on investments	207,509	1,161		**208,670**	(921,472)
Changes in net assets	(44,853)	169,308	-	**124,455**	(1,106,280)
Net assets, beginning of year	4,897,311	1,473,949	904,444	**7,275,704**	8,381,984
Net assets, end of year	$ 4,852,458	$ 1,643,257	$ 904,444	**$ 7,400,159**	$ 7,275,704

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