

WITH A CURE.
WHERE OUR STORY MUST END.







The Disease We're Up Against is Formidable. But So Are We.

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

During 2009, the TS Alliance marked 35 years of staying true to those original goals. But since 1974, our mission has expanded:

The TS Alliance is committed to finding a cure for TSC, while improving the lives of those affected by: 1.) developing programs, support services and resource information; 2.) stimulating and sponsoring research; and 3.) creating and implementing public and professional education programs designed to heighten awareness of the disease.

Today, the TS Alliance serves more than 20,000 constituents, sponsors more than 30 volunteer branches called Community Alliances nationwide, and receives an average of 1.2 million hits on our website each and every month.

About Tuberous Sclerosis Complex

Tuberous sclerosis complex is a genetic disorder that causes tumors to form in many different vital organs. 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 estimated 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.

We're Fighting for the Cure That Could Lead to More Cures

The brain, eyes, heart, kidneys, lungs and skin. Even the adrenal gland, liver, ovaries and pancreas. So many vital organs can be affected—and too often devastated—by TSC.

TSC is a lynchpin disease. Why? Because insights into TSC can provide insights into other diseases. And vice versa. Discoveries in TSC can bring about discoveries in other diseases. And vice versa. New treatments in TSC can bring about new treatments in other diseases. And vice versa.

What's the bottom line? Every minute and every dollar spent finding treatments and a cure for TSC could bring about quantum leaps forward in treatments and cures for autism, epilepsy and cancer.



We'll Give Everything. But Up.

Doctors and researchers. Moms and dads. Aunts and uncles. Sisters and brothers. Co-workers and friends. People who have tuberous sclerosis complex. People who don't.

The TS Alliance is just that—an alliance of different people committed to supporting each other, providing the best in care and searching not only for a cure, but also for better treatments. One step at a time.

Simply put, the TS Alliance is powered by people—people from all walks of life and from all parts of the United States, united together in a common cause.



PROGRAMS, SUPPORT SERVICES AND RESOURCE INFORMATION

Research Program

The TS Alliance's 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.

In 2009, the TS Alliance spent a total of \$1,311,445 for research that will achieve these goals, including the TSC Natural History Database and research grant awards. One of the interesting things about TSC is that it affects every single person differently. Until the TS Alliance developed the TSC Natural History Database five years ago, no way existed to document how TSC progresses over a lifetime in a large number of individuals. In previous studies, correlations between the specific TSC gene mutation and the clinical impact were identified only with small groups of people with TSC.

As of June 30, 2009, 15 TSC clinics were entering data with 810 individuals participating. The TS Alliance provides funding to participating clinics to enter the data and monitors the integrity of the database.

The TS Alliance also continued its commitment to funding research grants. In 2009, 24 research projects were funded for a total of \$686,027. In addition, the University of Cincinnati received continuing funding of \$100,000 from net assets through a TS Alliance Rothberg Courage Award to support the MILES Trial, a clinical trial for the study of rapamycin to treat lymphangioleiomyomatosis (LAM) associated with TSC and sporadic LAM.

**Nearly 1 million people worldwide are estimated to have TSC,
with approximately 50,000 in the United States.**

PROGRAMS, SUPPORT SERVICES AND RESOURCE INFORMATION (cont.)

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 more than 30 Community Alliances, multiple local educational and support meetings were held throughout the country.

In 2009, we added an educational advocacy program with 22 trainings held in collaboration with Community Alliances. 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 multiple educational advocacy training presentations, six new educational publications were produced including: *School Issues: Frequently Asked Questions*, *Parent's Rights: Understanding Individuals with Disabilities Education Act 2004*, *What is an IEP (Individualized Education Program)?*, *Transitioning from School to Community*, *Basic TSC Information for Teachers* and *Teacher's Guide: Educating a Child with TSC*.

The TS Alliance Director of Advocacy and Education also established a new online blog to encourage frequent and interactive conversations with constituents as they encounter challenges on a daily basis.

In February 2009, the TS Alliance sponsored and underwrote an annual leadership training program for our Community Alliance Chairs. These grassroots volunteer leaders are truly the heart and soul of our organization and their efforts not only account for half 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 them.

In April, the TS Alliance sponsored a Regional TSC Conference in Denver, Colorado. The purpose of the Regional TSC Conference, which was educational and constituent-focused, was to bring together individuals with TSC, parents, children, caregivers and health care providers to educate them about the most up-to-date treatments and therapies for those affected by TSC. There were 87 attendees from 7 states, 15 health care providers and expert speakers, 17 hours of one-on-one sessions, and a predominant number of attendees had never been to a TS Alliance conference previously.

To ensure proper services are being provided to adults with TSC, the TS Alliance initiated a series of topical conference calls to serve our adult population, particularly those who do not have access to computers. An Adult Task Force reviewed these needs and began to develop programs to support them. The Adult Task Force identified topic areas and speakers for conference calls, one of which was held in FY 2009.

In response to requests for support of siblings of children with TSC, the TS Alliance started an online, interactive sibling chat group in 2009. Siblings deal with unique issues and concerns that only other siblings understand. The TS Alliance facilitated 11 of these chats, with siblings participating from ages 9 to 56. The topics of these chats ranged from dealing with the holidays to finding resources within the community for those siblings who are caretakers.



Public Education

The TS Alliance heightens awareness of TSC throughout the general public to broaden the scope of support and understanding beyond the TSC individuals and their families. In 2009, the TS Alliance embarked on the development of a communications outreach initiative that included print advertisements in *Exceptional Parent* magazine and *M.D. News*. Moreover, the TS Alliance received significant publicity when a syndicated television show, "The Doctors," ran a full segment about TSC, the TS Alliance and epilepsy surgery in December 2008.

TSC, as well as the work of the TS Alliance, was also highlighted in dozens and 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. Two issues of our national magazine, *Perspective* were published in FY 2009 and sent to 12,000 constituents. *Perspective* includes articles on research updates, constituent stories, educational initiatives, and community grassroots activities. Finally, the TS Alliance increases awareness through our comprehensive website.

Grassroots volunteer leaders are truly the heart and soul of our organization, accounting for half of the revenue generated and much of the educational outreach conducted across the nation.

Government Relations

The TS Alliance and its volunteer advocates focus on obtaining federal resources for TSC research, clinical care and information dissemination. In 2009, the TS Alliance grassroots volunteers conducted a March of Capitol Hill resulting in 390 Congressional visits and the delivery of information to every Congressional office. These efforts resulted in 79 members of the House of Representatives signing a letter of support circulated by Representatives Loretta Sanchez (D-CA) and Gary Miller (R-CA) and 18 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 US Congress appropriated \$6 million to TSC research through the Department of Defense Congressional Directed Medical Research Program in February of 2009. The TS Alliance believes the investment into this program has a profound impact on moving new treatments and ultimately a cure forward. The research program administered from the appropriation is a competitive grant review program at Fort Dietrich and the TS Alliance currently receives no direct funding. It is, however, central to the mission of the organization.

Professional Education

The TS Alliance offers several programs targeting health care providers who treat individuals with TSC, medical students, genetic counselors and educators to minimize the consequences of misinformation or lack of education. In 2009, the TS Alliance presented and participated in professional conferences that assisted in educating these professionals, including the International Research Conference held in Brighton, UK, American Society of Nephrology, the American Epilepsy Society (AES), and American Association of Neurology.

In addition, an annual meeting of TSC Clinic Directors was held during the AES meeting for updates in research, clinical care, the TSC Natural History Database and new technology, such as www.seizuretracker.com. The TS Alliance also created a professional online discussion group in 2009 to connect professionals to provide access to the most updated information on treatment and education options.

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.

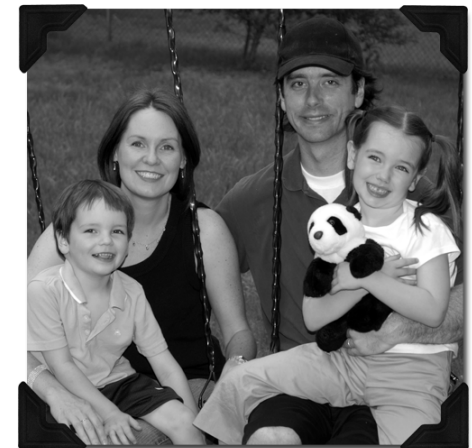
FUND DEVELOPMENT

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

For fiscal year 2009, special events raised \$1.9 million, which represented 55 percent of the TS Alliance's overall revenue. Some highlights include:

- Honorable Pete Sessions and the Honorable Chris Van Hollen generously loaned their support to the DC Food & Wine Tasting as Honorary Co-Chairs, which helped raise \$100,000.
- Across the country, champions of our cause participated in 28 Step Forward to Cure TSC® walkathons, raising \$933,889 in the hope of a cure and better treatments.

- On May 7, 2009, families, friends and other supporters celebrated the organization's 35 years of service at the TS Alliance's 35th Anniversary Gala in New York City, raising more than \$200,000. Honorary Chair Julianne Moore was joined by Rachael Ray, Curtis Sliwa, Amy Grant and Vince Gill, along with more than 300 others to mark the momentous milestone and honor Cartier, Tom and Peggy Lindsey, Dr. Peter Crino, Will Cooper and Wentworth Charities.
- Our signature event, Comedy for a Cure®, continued its successful run in Hollywood by honoring its co-founders: Chris Sheffield, Christy Hobart and Henry Shapiro. Melina Kanakaredes of the TV show *CSI:NY* served as Honorary Chair, while comedians Pat Hazell and Jeffrey Ross added star power to the evening. To date, Comedy for a Cure Hollywood has raised nearly \$1.5 million. Comedy for a Cure Boston enjoyed its third successful year with comedian and Honorary Chair Jimmy Dunn, while Comedy for a Cure Chicago held its second successful event with Honorary Chair Mark Giangreco (Primary Sports Anchor for ABC-7) and comedian Jim Short. The Chicago event honored Dr. Michael Kohrman, Director of TSC Clinic at the University of Chicago Children's Hospital, for his years of service at the clinic.



Step Forward to Cure TSC Walkathons

- Alabama – Carole Pitard
- Arizona – Debora Moritz
- Atlanta – Reiko Donato and Jennifer Weingarth
- Carolinas – Jeff and Christi Davis
- Connecticut – Jennifer Waldron
- Chicago – Jay and Lisa Smiley
- Dallas/Ft. Worth – Mandy and Scott Striegel
- Delaware/Lehigh Valley – Shelly and Cindy Richards
- Delta Region – Peggy Packard and Samantha Glass
- Heartland – Cindy and Ryan Blackard
- Houston – Bill and Taska Fields
- Indiana – Susan and Bob Campbell
- Kansas – Amy Dublinkse, Lisa Hart and Laura Kozisek
- Metro DC – Nathalie Simoneau
- Michigan – Treasa Bolger and Matt Bolger
- Milwaukee – Pam Sztukowski
- Middle Tennessee – Amy and Jim Hobbs
- New England – Tom and Sharon Gwinn
- Northern California – Dena Mitchell
- Ohio (Cleveland) – Frank and Elaine Gritti and Michelle Blood
- Seattle – Kay Rawlings
- St. Louis – Rene' Friedel and Jaime Schmitt
- Southern California – Cindy Chernow
- Upper Midwest – Maria Gibbons
- Western Pennsylvania – Lori Shoup

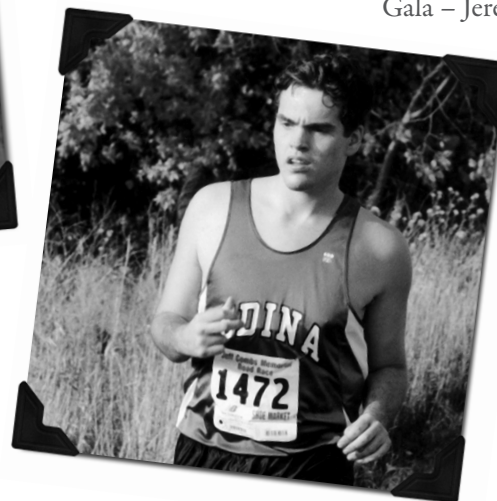
Tournaments for TSC Champions

- Buffalo Wild Wings Blazin' Golf Tournament – Todd Kronebusch
- Emmory Regan Shapses Golf Classic – Marc and Marla Shapses
- Heather Joy Memorial Golf Outing – Christy and Loren Buntrock
- Indiana – Mark Koers
- Kylie's Hope – Neil, Maria and Kelly Gibbons
- Wentworth Charities Golf Classic – Tom and Sharon Gwinn



Other Major Events

- Inaugural Taste of the Twin Cities – Missy Anderson, Janie Frost and Sarah Hoey
- Houston Bowling Tournament – Tony Lauer, Frank Reilly and Richard Schrag
- 3rd Annual Comedy for a Cure Chicago – Sandy Smiley
- Youman's Family BBQ – Bill Youman and Family
- Comedy for a Cure Boston – Jeffrey Hargreaves and Jane Ulwick
- Crashin' for the Cause Demolition Derby – Joe and Abby Kopf
- 8th Annual Comedy for a Cure Hollywood – Jennifer and Rick Glassman
- DC Food & Wine Tasting – Julie Blum and John Poutasse
- 23rd Annual Shrub Sale – Burt and Sue Goodrich 35th TS Alliance Anniversary Gala – Jeremy and Robin Krantz
- Geneva Lakes Amazing Race – Sharon Clark, Rob Keefe, Matt Mason and Tim Schnake



Annual Fund – Major Donors

Fiscal Year 2009: July 1, 2008-June 30, 2009

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

ICAP Services North America, LLC
Tuberous Sclerosis Alliance Endowment Fund
William E. and Kristina Watts
Wentworth Charities

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

Marc, Marla and Emmory Shapses, ERS Charitable Foundation
Lundbeck Inc.
Novartis
UCB Pharma, Inc.

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

Craig and Cindy Cunningham, C&C Market Research
East Fond du Lac County Chapter of Thrivent Financial
David and Cathy Krinsky
Pharmaceutical Research and Manufacturers of America
Scott and Susan Taylor, The Winifred M. Gordon Foundation Inc.
Tuberous Sclerosis Canada Sclerose Tubereuse
Wolf Popper LLP

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

America's Charities
Band From TV, LLC
Bank of America
Melvin and Roseanne Boldt
Buffalo Wild Wings
Cartier/Richemont of North America, Inc.
The Cowlin Foundation
The Gertrude and Philip Hoffman Philanthropic Fund of the United Jewish Federation of Greater Pittsburgh
James and Jessica Lawler, Glenn N. Howatt Foundation
James and Andrea Maginn
Lawrence and Diane O'Friel
James Medick, Precision Opinion, Inc.
Julianne Moore and Bart Freundlich

New York State Department of Health
The O.J. McDuffie Catch Foundation
Pediatrix
The Schnurmacher Foundations
Tepper Family Donor Fund Philanthropic Fund of the Jewish Community Foundation of MetroWest
Jack and Jeannie Whitaker
Karen White
C. Anthony Whittingham and Jean H. Whittingham

Defender (\$5,000-\$9,999)

George Ahn, Tiriga
The Arnold Foundation, Inc
AT&T
Comcast
Will & Kay Cooper, WNC & Associates, Inc.
Cyberonics, Inc.
Leonard and Amanda Davis
Richard and Lori Day
Brian and Lana DenHarder
Cornelius and Linda DenHarden
Chris and Joy Dinsdale, Pinnacle Bancorp, Inc.
Michael and Rita DiDomenico, DiDomenico Packaging Co., Inc
Moise and Carol Emquies, Emquies Family Fund of the Jewish Community Foundation Los Angeles
Mark and Judy Fox
Michael and Janie Frost
Genesco
Dennis Hanson
Inspiration Ministries
Intellisurvey
Francesca Judge
Kenvo Foundation
Ray Klein, Caddyshack Golf Tournament
Alan Marshall
Herbert and Sheila Marton
Abe and Celia Mastbaum
Robert Middleton

John and Carol Nicholson
Norman and Dadie Perlov
Thomas A. Plein Foundation LTD
Robert Rapaport
Leah Rial
Thomas and Kimberly Corbett, Shamrock Materials
James and Judy Shoulak
Ronald and Montie Smith
Jerrill and Heidi Sprinkle
Annie Szilagyi
Twentieth Century Fox Film Corporation
United Way of Lee County
Variety Magazine
Variety - The Children's Charity
Michael Webster
Lois Whitman
Hilda Wulach

Advocate (\$1,000-\$4,999)

600 GS Prop LP
A. Sturm & Sons Foundation Inc.
Earl Abramson
A&C Investments, Inc., LLC
ACE Transportation, Inc
Accurate Healthcare
The Active Network
Adobe Systems Incorporated
Aetna Foundation, Inc.
All American Technologies
Altria Group, Inc.
Alza Corporation
The Aric and Sandie Rosenbach Charitable Fund
Aronson Family Charitable Fund
Charles and Lucille Asensio
Athena Diagnostics Inc.
AT&T United Way Employee Giving Campaign
Baird Foundation, Inc.
Bank of North Georgia
Illa Barnes

Joanne M. Batey
 Be True & Mighty Productions, Inc.
 Kathleen B. Benning
 Best Buy
 Harendra Bhatia
 David and Linda Borg
 Andrew and Mary Bott, Merri-Makers Caterers
 Howard and Adrienne Brewer
 Briggs-Shaffner Company
 Broadpoint Capital, Inc.
 Brooks Sports, Inc.
 Gertrude Brown
 Pablo Burbridge
 Gerald and Suzanne Burt, Richmond Rebar LLC
 Evelyn Campbell
 Cantrio Concepts Inc.
 Trent and Susan Carmichael
 Mark and Kelly Carroll
 Charles Schwab Charitable Fund
 David and Linda Chen
 Chicago Title Insurance Company
 Children's Health Care
 Richard and Susan Clack
 Clothes Off Our Back Foundation
 Cobb Electric Membership Corporation
 Patricia W. Cochran
 Community Health Charities
 Linda G. Connors
 John S. Cooper
 James and Leslie Craige
 Eileen Creighton
 Peter Crino
 Robert and Elizabeth Cullins
 Currie Motors Frankfort
 CVS Caremark Charitable Trust
 Tommy Crudup
 John and Kathryn Cushing
 Desiree Dahms and Lori A. Gehret

Daniel and Mary Reeves Foundation
 Derenthal & Dannhauser LLP
 Tim and Kathi Dills
 Roland and Iris Dimattia
 Orrin Devinsky, NY Epilepsy and Neurology, PLLC
 Margaret Dolan
 Rich and Reiko Donato
 The Dove Family Foundation
 Downey Publishing Inc.
 Neil and Amy Dublinske
 E-Rewards, Inc.
 Edison International
 Pamela Edstrom
 Michael and Melissa Eichhorn
 Craig and Thistle Elias
 Terry and Nancy Elling
 Emerald Bowl
 Entertainment Publications
 Joseph Faber
 Paul and Laurie Feig
 Scott and Jill Feinstein
 Hilary Feshbach
 The Fiftieth Anniversary Foundation
 Robert and Cristina Fitzgerald
 Thomas and Susan Flanagan
 The Florence Mauboules Charitable Trust
 William and Vera Flynn
 William and Anita Ford
 David N. Franz
 Maureen Frear
 Freight Force, Inc.
 Friedman, James & Buchsbaum LLP
 Gerald and Irene Friedman
 Michael and Jacqueline Flaherty
 Garrard Construction Group, Inc.
 Fred and Mary Garrison
 Geo Knight & Co, Inc
 Holly Gilmour

Andrew Glassman
 Global Impact
 Robert and Shirley Goble
 Steven and Shari Goldstein
 Golf for Good, Inc.
 Goshgarian & Marshall
 William J. Grabb and Jean Leonard
 Thomas J. Grace
 Charles and Suzanne Graham
 Grainger Matching Gifts Program
 Donn Gray
 The Grunbeck Family Foundation
 Henry and Lucy Hahn
 Dean Hallett
 Roc and Cindy Hammerquist
 J.B. and Jan Hamilton
 Marc and Terry Hapstack
 Teri Hatcher
 Richard and Heather Hayden
 Heather Joy Memorial Fund
 Ron and Ann Heffron
 Elizabeth Petri Henske
 Higgins Mobile Homes, Inc.
 Jeffrey and Linda Hoffmann
 Honeywell, Inc.
 Ann Huber
 John and Alice Hulbert
 Shaun and Tracey Hutchinson
 Jonathan Hyman
 Mark and Sheryl Hyman
 Hyslop Shannon Foundation
 International Brotherhood of Electrical Workers 280
 IBM Employee Services Center
 Jacobs Trading Company
 Aziz Jamal
 JD Rush Corporation
 Joe Hand Promotions, Inc.
 Johnson & Johnson

Annual Fund – Major Donors (cont.)

Josefson Family Foundation
The Josephs Foundation
Jr. Woman's Club of Lexington
Jane Kaczmarek
KHPY Radio
John and Renee Kizer
Ken and Beth Kocher
Phyllis Koenig
Kohl's
Michael Kohrman
Jeremy and Robin Krantz
Todd and Debra Kronebusch
Kuipers' Family Farm
Anthony Kull
Ladies of Unico - Kearny, NJ Chapter
Anthony and Kara Lauer
Roger and Laura Lavan
James Leahy
Leonsis Family Office
Greg Linsin and Julie Blum
Lagacé Lise
Douglas and Linda Loftus
Los Angeles Times
Carl H. Loewenson, Jr. and Susan E. Brune
Alexander Macklin
M.A.D. World of Fitness, Inc.
William and Audrey Malesky
Mark and Karen Mausner
Mark Roberts Foundation
James and Michelle Manco
Paul Manton
Marsh Affinity
Stuart and Carina Marton
Ted and Peggy Mastroianni
John and Jill McBride, Camp Mac, Inc.
Chip McDermot
Terrance and Laura McLaughlin
James and Denise Meitz

Merck Partnership for Giving
Peter and Jean Meredith
Scott and Kasandra Merrill
Merrill Lynch
MetLife Center for Special Needs Planning
Michael and Carol Michael
Michael Bill Avner Memorial Fund of The Pittsburgh Foundation
Milan Women's Club
Mark and Heather Miller
MillerCoors
David and Jan Mintz
Mistler Family Foundation
James and Debora Moritz, Cake Arts, Inc.
Moss & Associate Attorneys PA
Greg and Laura Mlynarczyk
Joann Muchrcke
Mitchell and Nancy Muntner
Charles and Rosanne Myers
The National Foundation for Special Needs Integrity Inc.
Network for Good
New Bridge Baptist Church
Eric Nichol
Norgren Family Fund
North Coast Jaw Center LLC
Maureen OCallaghan
Sandra O'Connor
Orange County's United Way
Richard and Lauren Packard
James Paddock
Saddiq Panjwani
George and Joy Pantelis
Paper Products Company, Inc.
Michael and Nancy Parkes
PASCO
Muriel Pattis
Pfizer Foundation Matching Gifts Program
Alisa Pinnell

Andrew and Maureen Piotrowski
Thomas A. Pivec
Clark P. and Temple B. Poche
David and Margaret Poutasse
Premier Pipe
Prime Procurement Group, LLC
Prudential Foundation Matching Gifts
Jacie Pruitt
Pyramid Tubular Products, L.P.
Queen of the Valley Hospital
Marie Radigan and Adelphi University
John C. and Cheryl Raiss
Peter Rapaport
Heather Raymon
Ernest Reisinger
Richard Van Lunen Charitable Foundation
James and Laurie Richter
The Riley Foundation
Koni K. Robertson
Patrick and Maureen Roche
John C. and Debbie Roeser, III
Roncari Express Valet Parking
Rosetta W. Harris Charitable Lead Trust A
Domenic Ruscio and Betty Lou Taylor
William J. Rushton, III
Terry and Cindy Rust
Jeff Sacks
Sam's Club Foundation
Sanitary Maintenance Service, Inc.
David and Amy Schenkein
Vince and Cheryl Schillig
Ben and Beth Sehlhorst
Dave and Karen Senger
David and Rhonda Shaffer
Henry Shapiro and Christy Hobart
Stanley Shapiro
Kenneth and Fran Sheff-Mauer
Lori Shoup

Jeff and Wendy Sklarin
 SLC Enterprises, LLC
 Sim-Tex, L.P.
 Johnny and Vianne Smith
 Joseph and Kathleen Smith
 South Hampton Resources, Inc.
 Stephen Spady
 Gregory J Spanos
 Specialized Seal Design & Distribution
 Rocco and Camela Spinoso
 St. Vincent Hospital
 Carl and Rosemary Sterk
 Daniel and Carol Strickberger
 Warren and Jennifer Stringer
 Jeffrey and Candance Stone
 Ed and Sandra Swanson
 Switch
 Michael Tama
 Tackling T.S. Charity Inc.
 Third Rock Ventures
 Time Warner Inc. in honor of Lisa Moss for the Andrew
 Heiskell Community Service Award
 Tom and Lesley Todaro
 David and Charlene Torcia
 UGI Utilities, Inc.
 United Way of the Bay Area
 United Way of Central Maryland
 United Way of Greater Los Angeles
 United Way of The National Capital Area
 United Way of Tri-State
 US Bank
 U.S. Trust
 Adair Vasilovich
 Walter & Jean Voelkerding Charitable Trust
 Village of Rosemont
 Walmart Foundation
 Philip and Cindy Wales, Jr.
 Walgreens

William and Corinne Ward
 Linda Warren
 WellPoint Foundation
 John and Carol Weyandt
 Timothy Whitaker
 Michael Whitmore
 Clifford and Deborah White
 Joe White, White & Weddle, PC
 Stanley Worton
 Gene and Jane Wiggins
 Peter and Margaret Wilby
 Coe Wilson
 Robyn Winge
 Michael Wong and Cecilia Hsien-Tsing Yu
 Kirby and Jennie Woodard
 Cece Yorke
 Pierluigi Zappacosta and Enrica D'Ettorre
 Michael and Nancy Ziemba
 Mary Zilba
 Evan Zuckerman and Andy Bernstein

Champion (\$500-\$999)

17 John Rest Corp
 AAA Supply, Inc.
 James M. Achterhof and Arlene Bandstra
 Betty L. Adams
 Elizabeth N. Adams
 John C. Adams and Nancy A. Ory
 AIGdirect.com
 Roy and Joan Alexander
 Alexian Brother's Health System
 Farzana Ali
 Alisa Yaffa & Ken McElvain Family Philanthropic Fund
 The Allstate Foundation
 Allstate Giving Campaign
 Suzie Alsen
 American Endowment Foundation
 American Express Foundation
 Douglas E. and Marion Anderson

Apache Corporation
 Robert and Jeanette Apple
 Clara M. Armijo
 Peter and Deborah Aronson
 The Arthur & Patricia Price Foundation
 Arul Arulmoli
 Gina Ashley
 Michael and Milly Augustine
 Alicia Austin
 Auto Body & Glass
 Michael and Mary Aycox
 Bacco, Inc
 Charles K. and Francesca Bardes
 Broc Bengard
 Benoit Machine
 Kalpana Bhatia
 Niraj Bhatia
 Dennis H. Biery
 Andrew Bivens
 BJ Restaurant, Inc.
 Marc and Kelly Blasser
 William S. and Michelle Blood, Jr.
 Jon S. and Shelly Bloomquist
 Daniel Bloomstein
 BlueSky Technology Partners, Inc.
 Mark H. and Julie Bodenstab
 James B. Bolger
 BP Fabric of America Fund
 George and Laura Braunstein
 Nathan and Shannon Brown
 Eugene Bruns
 Joe T. and Donna Bryant
 Andrew and Elizabeth Buchsbaum
 Anthony Busillo, II
 Business Knowledge Services, Inc.
 Robert A. and Sarah Butler
 Stephen Butler
 Capital Services Inc.

Annual Fund – Major Donors (cont.)

Car Wash Enterprises, Inc.
John R. and Cathy Carlson
Bob and Susan Campbell
Frank M. and Barbara Capone
Kari Luther Carlson and Christopher Rosbeck
Joe and Mattie Carrillo
Catholic Family Life Insurance
Jon W. Caulfield
Cauthorn Nohr & O'Dell
Champions Pipe & Supply
Esther Chang
Marie Chargoy
The Charles I. Rosen Family Foundation
Children's Hospital Boston Neurology Foundation, Inc.
Cinco Pipe and Supply, LP
Jeffrey and Rachel Cohen
Colonial Properties Services, Inc.
Community Health Charities
Continental Alloys & Services
Continental Mills
David Cook
Alfred and April Cooper
Wilfred N. and Jennifer Cooper, Jr.
David Cowlin
William Cowlin
Council 278 Union St Jean Baptiste
Gretchen Cox
Morgan Cox
Kevin F. and Maureen Crahan
D. Scott and Sally Crowe
Richard Culpepper
Susan Cunard
Dalio Family Foundation Inc
Jason and Jenny Davis
Thomas Davis
Richard and Lori Day
De La Chapelle Charitable Foundation Trust
Tim and Joanna Connelly

Robert J. and Elizabeth Dennis
Blase and Debra DeOrsa
Stephen and Julie Des Jardins
John Dexter
Diane and Howard Wohl Family Foundation
Gerald Diaz
Debra DiFrancesco
Thatcher Dilley
Tim and Kathy Dills
Bailey Dixon
Diana Dobin Kauppinen
Harry and Chantal Dussouchaud-Dolman
Dottie Dorris
Rashmi Dubey
Seth and Vanessa Ebel
Allyson Edwards
Todd and Teresa Embury
EnerSys
Dixie Esseltine
Everett P. Euler
ExxonMobil Foundation
Susan Fahey
Justin Fallon
Jessica Fane
Farallon Consulting
T. Roper Fields
Brian T. and Patricia Finn
Foothills Community Foundation
Foss Maritime Co.
Jane Foster
Steve and Cindy Fowler
Mike and Leslie Fox
Wayne E. and Judith Fox
Franks International
Richard D. and Ellen Freeman
Barb Fryberger and Carole Fryberger
GB Tubulars Inc
Gap Foundation Gap Giving

Alfred and Johanna Garzino, Jr.
Greg Geiger and Gorety Ho
Jason Geiger
John R. and Pamela Gendreau
Genetech Inc.
Genentech Employee Giving Program
Georgia Asphalt Pavement Assoc, Inc.
Andrew and Gail Gershon
Tricia Gerum
Richard L. and Joan Gibbs
Eugene C. Gilder
Todd and Nathalie Gilder
Give With Liberty
Greg Goldstein
Josh Gordon
Bonnie E. Gould Rothberg and Jonathan M. Rothberg
Greater Kansas City Community Foundation & Affiliated Trust
Miriam S. Green
Sally E. Gresham
Johnny and Lynda Gresham, Gresham Real Estate Advisors Inc.
Randy Groover
Robert W. and Kathryn A. Groves
Gus Wetzel Family Foundation
Hamilton Metals, Inc.
Jeffrey and Lisa Hargreaves
K. Carter and Susan Harris
Harris and Smith Public Affairs
Owen Hatcher
Beth Headley
Heart of the Valley Pediatric Cardiology
Joseph H. Helfgot and Susan B. Whitman-Helfgot
Karleen J. Heller
Rick Heltzel
Craig and Allison Henning
Susan Henry
Mark and Karen Hermelin

Hill & Wilkinson
 HK Bass Insurance & Financial Services
 C. Dana Hobart
 G. Dana and Vicky Hobart
 Jeffrey S. Hoersch
 Bruce and Dana Holinka
 Holy Spirit Council, No 8334 (Knights of Columbus)
 Chris Holubowicz and Pam Sztukowski
 Byron L. Hooper
 Matthew R. and Marie Hopkins
 Michael Hopkins
 Tommy and Elizabeth Hord
 Walter Huybregts
 John Ikard
 Barry Jeffcote
 John Calvitti Company
 Daina Johnson
 Ken and Shonnie Johnson
 Jay Johnson
 Johnson County Sheriff
 Matt and Susan Jorski
 Jay and Deborah Julow
 Kimberly Kaleas
 Katlin Family Foundation
 Morton Katz
 John Kavanagh
 Bill T. and Kay Keck
 Thomas A. and Pamela Keiser
 Alison Kirby
 Kiss Designs
 Kiwanis Club of Marietta Lost Mountain Golden K
 Barbara L. Klein
 Knights of Columbus Council 8887
 KO Supply
 Dennis and Sandra Kollmann
 Michael B. and Joyce Komson
 Robert O. and Cynthia Kupper
 Marc J. and Mary Kurzman

Lawrence Livermore National Laboratories
 Gordon L. and Debra Lang
 Howard J. and Karen Lazerowich
 Sung Woo Lee
 William W. and Barbara Lee
 Rodney and Caroline Lenz
 Eric S. and Sheryl Lesser
 Chester M. and Melissa Levey, Jr.
 Lexis Nexis
 George Liapis
 Liberty Fruit Company
 Peter Liechty
 Sylvia Lief
 David C. and Jill Light
 Lincoln Financial Foundation, Inc.
 Leroy and Patricia Lind
 Lindquist Enterprises, Inc.
 Bennie Loro
 Paul Louiselle
 MacAllister Machinery Company, Inc.
 Audrey Malesky
 Malloy Foundation
 Barbara Martin
 David Martin
 Kevin R. and Carrie Martin
 Marubeni-Itochu Tubulars America Inc.
 Karen Marvin
 Andrew Maternowski
 G. Mather
 John P. Matthew
 Allen McBride
 Charles A. and Denise McCain-Tharnstrom
 Charles and Tina McCraw
 Janet McCutcheon
 Charles and Theresa McFadden
 Kurt McHenry
 Raymond A. and Alice McKeighan
 McMahon Steel Supply Inc.

Greg Meier
 Robert B. and Mary Melcher
 Memorial Hermann Hospital System
 Elvia Menendez
 Julio F. and Elizabeth Mercado
 Eric and Dawn Mesecke
 Andrew Maternowski
 Glenn A. Meyer
 Paul and Kate Meyer
 William A. Meyer
 David and Nancy Michaels
 Michael W. Mihelich
 Chris Mikosh
 Dennis C. and Janet Miller
 Ed Mills Jr.
 Velma Misner
 Laila Mobh
 David W. and Deborah Modjeski
 Modular Devices, Inc.
 Philip and Jane Molstre
 Melinda L. Monroe
 MPT Operating Partnership, LP
 Muhlenberg Foundation
 Timothy Mullen
 Michael J. Mungo Foundation
 John J. and Maureen Murphy
 Kevin J. and Stefanie Murray, Jr.
 Robert and Lisa Murray
 Gianluigi Mussinelli
 James and Margot Mustich, Jr.
 Jon F. Myers
 Myers Company, Inc.
 National Association of Theatre Owners of California/
 Nevada
 National Oilwell Varco
 Richard H. and Sharon Nicely
 Jerold and Katie Nichols
 Julian Norstand

Annual Fund – Major Donors (cont.)

North Coast Nautilus Inc.
Melissa Oakes
Ron and Kathie Oakes
Manuel P. and Isabelita Ocampo
Sheila O'Connor
David and Anna Oei
Patricia Ogden
Susan Olis
James W. Oliver
Randal J. and Jodell Olson
Alejandra Olvera
William R. Orr
Nancy Ory
Joseph W. Ostrow
Todd Owens
Ali and Shamsuddin Panjwani
Amaan Panjwani
Paragraphics, Inc.
David and Penney Parkes
Patricia Patterson
Robert Peiffer
Stephen Perlman and Jo Anne Nakagawa
Dennis M. and Kimmerly Pidherny
Stephen W. Pierson
Pine State Trading Co
Shelley Pirkey
Barbara J. Pitney
Leon K. Poche
Jozsef and Anna Postma
Andy Poteete
Steven and Lori Potolsky
John D. Poutasse and Mara L. Flynn
Fay Powell
Allan and Carla Price
The Premseelaar Foundation
Jason Pritchett
Progressive Medical Concepts, LLC
Quality Manufacturing Incorporated

R & R Electric
Remedy Interactive
The Roberts Foundation
Ralph Lawrence Smith Foundation
Michael S. Rapaport
Realty Service Group
Red Man Distributors, LLC
Regional Women's Health Group, LLC
Frank J. and Anne Reilly
Vic Reyes, Jr.
Douglas and Catherine Richardson
Ridgeline Builders, Inc
Philip and Cheryl Rosen
Nancy P. Rosenbach
Steven Rosenblatt
Royal Arcanum
Fabrice and Liz Saadoun
Raman and Oonagh Burke Sankar
JB Sarver
Thomas and Deborah Schaeffer
Molly Schaffer
Abe Schlabach
Robert T. and Mary Ellen Scott
James Sears
Joshua Segal
James Shaw
Michael Shinovich
Jeffrey D. Siemsen and Karan E. Guyon
Travis J. Simons
Gary J. and Debby Simpson
The Standard
Ukrit Siriprusanan
Doug Smith
Maurice and Lucille Solomon
Sonomarin, Inc.
Richard Spain
Steven P. and Maria Sparagana
Jeffery and Vickie Sprinkle

Robert B. and Nadine Sprinkle, Jr.
St. Patrick's Altar & Rosary Society
Standard Tube Co
Stealthbits Technologies, Inc.
John and Janine Steenman
Laurence and Ellen Steiner
Richard and Dee Dee Stephens
David Stewart
Joe Stockdale
Michael and Ruth Stoddard
Edward D. and Jane Stone
Pablo C. Straka
Dale J. and Kris Studer
Summit Credit Services, Inc.
Robert and Lisa Szilagy
Takeda
Trey and Lucy Tart
Stephen M. and Winifred Tart
Jimmy J. and Linda Tavis
James R. and Carol Taylor
Rhonda Taylor
Team Health Inc.
Tenaris
H.D. and Linda Tewis
Jeff Theis
Sean and Kelly Thomann
Keleigh Thomas
Paul Thomas
Wallace R. Thomas
J Wayne and Lisa Thompson
Mark and Nadine Thorn
Michael P. Thornton
Thrivent Financial for Lutherans
Rob and Loni Thurston
Todd Family Foundation
Bradley J. and Margaret Tolkin
Elizabeth M. Tomak and Kathy Cook
Kevin and Ellen Traina

Richard and Susan Trester
 Triad Pipe
 Robert P. Trout and Ms. Janet Studley
 Tyler's Gift Foundation, Inc.
 Thomas A. Tylman
 Gordon T. and Heather Ueland
 United Airlines
 United States Joint Forces Command J89
 United Way of Northeast Louisiana
 United Way of Pierce County
 United Way of San Diego
 US Steel
 V&M Tubes
 Vam USA
 Vanguard Charitable Endowment Program
 Vertical Screen, Inc.
 Patrick Walsh
 Dave and Lisa Wangsness
 Danny and Jenny Ward
 Washington Arbitration & Mediation Service
 Robert and Catherine Webster
 Katherine Wegner
 Lori Weingarten
 Andrew and Jennifer Weingarth
 Allan R. White, III
 Dale S. Wilson
 Otto and Angela Wilson
 Daniel Wolf
 Maggie Wong
 Thomas W. and Eleanor Woods
 Kevin and Sarah Wright
 John and Laurel Wrynn
 Joyce Wu
 Harold and Beverly Xavier
 XL Global Services
 Elaine Zabala
 Kathleen Zacharias
 Edward J. Zapp

Michael and Angela Zarrilli
 John Zaso
 Barbara F. Zimmerman
 Howard Zimmerman
 Connie Ziober

Major Gifts in Kind

Access Hollywood
 American Airlines
 American Idol
 animal Restaurant
 Baume & Mercier
 Best Buy
 Boulevard3
 Buffalo Wild Wings
 Billy Bush
 Brasserie Monte Carlo
 Byers Entertainment Solutions
 Damon Casatico, Charity Benefit Auctions
 Cartier
 Chamard Vineyards
 Eric Charbonneau
 Charlie Palmer Steakhouse
 Chickasaw Distributors
 Clay Enos
 Clothes Off Our Back Foundation
 Conrad-Pyle Company
 D'Acqua
 Diageo
 Chad Dillerud
 Edina Kiss
 Farrah Olivia
 Four Seasons Punta Mita
 Gap Inc.
 Mark Giangreco
 Andrew Glassman
 Godiva
 Gotham Magazine
 Hank's Oyster Bar

Teri Hatcher
 Chris Hawkey
 Pat Hazell
 Hat World/Lids
 Elizabeth Henske
 Hilton Chicago Indian Lakes Resort
 Improv Comedy Club
 Indique
 Ingram Design Studio
 ITS: Psychological and Learning and Support Service
 Kahlen Studios
 Melina Kanakaredes
 Keurig, Inc.
 KFAN-AM 1130
 Lundy & Flynn LLP
 Maker's Mark Bourbon
 Julianne Moore
 Morton's Steakhouse
 National Golf Links
 Neil Lane
 Nicaro
 Patrone
 Norman and Dadie Perlov
 John Poutasse and Mara Flynn
 Phyto
 Piaget
 Rachael Ray
 Mariam Razavi
 Retna
 Ron Abuelo Rum
 Santa Lucia Coffee
 Shaun Robinson
 Rocket Club
 Jeffrey Ross
 The Rothberg Institute for Childhood Diseases
 Marc, Marla and Emmory Shapses, ERS Charitable
 Foundation
 Shore Club

Annual Fund – Major Donors (cont.)

Jim Short
Souled Out
Switch Beverly Hills
Terlato Wines International
Teleflora
The Doctors
Thomas Connelly
Tim Thompson, Smith Barney
Tosca
Truth and Salvage Company
US Cellular
Variety
Vicky Whittemore
Xante Liquor
Zaytinya

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.

Endowment Fund

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.

Fiscal Year 2009: July 1, 2008 – June 30, 2009

Enrichment Society (\$5,000-\$9,999)

Will and Kay Cooper

Investment Society (\$500-\$4,999)

Clara M. Armijo
Robert W. and Kathryn A. Groves
Mark H. Hyman and Sheryl Newman
William H. Helman
Magdalena Lutsky
John F. Meyers
Ed Mills
Joseph and Deborah Yohn

The Eternal Flame Society

“Keepers of the Flame” include members of the TS Alliance community who have designated a planned gift through their wills or estates to the TS Alliance Endowment Fund or TS Alliance. We are pleased to honor the following distinguished members of the Eternal Flame Society:

Anonymous
Michael and Millicent Augustine
Jeffery and Gloria* Benham
Matt Bolger
Tresa Bolger
Scott and Jan Burton
Marguerite Cleveland
John and Katherine Conrad
Will and Kay Cooper
Richard and Reiko Donato
Cindy Fowler
David and Laura Grimes
Robert W. and Kathryn A. Groves
Shannon Hackley
Jeffrey and Lisa Hargreaves
Clara Harwell
James and Amy Hobbs
Ken and Shonnie Johnson
Arnold and Carol Kamm
Steve and Laura Kozisek
David and Cathy Krinsky
Mark Leal

Phyllis Leist
Craig T. Lewis*
Doug and Linda Loftus
James Lynch
Donna McGaha
David and Jan Mintz
Maria Shanon Munoz-Chargoy
David and Penney Parkes
Jeffrey and Bonnie Rickert
Pat and Jennifer Rolfes
Dave and Nancy Scott
Robert and Mary Ellen Scott
Fred and Ilse Smith
John and Janine Steenman
Kathy Trapp
Alma A. Tutrone*
Jim and Nancy Weir
Philip and Marion Winsor
Barbara K. Witten and William R. Bradley
Frieda K. Zimmerman*
*deceased

Endowment Named Funds

For gifts of \$25,000 or more (with a pledge payable over five years), a donor has the opportunity to name a fund in honor of someone. We are deeply grateful for the following named funds:

Megan Augustine Fund
John A. Conrad Jr. Memorial Fund
Carrie Cooper Memorial Fund
Lauren E. Krinsky Fund
The Lawler Fund
Cade Scott Fund

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

LEADERSHIP

TS Alliance Board of Directors

Cathy Krinsky, Chair
Laguna Beach, CA

Celia Mastbaum, Vice Chair
Marlboro, NJ

Rob Thurston, Treasurer
Provo, UT

Janie Frost, R.N., Secretary
Woodbury, MN

Terry Elling, Immediate Past Chair
Fairfax, VA

Julie Blum
Potomac, MD

Matt Bolger
Lansing, MI

Mark Carroll
Saratoga, CA

Will Cooper, Sr.
Newport Beach, CA

Reiko Donato
Roswell, GA

William Ford
Arlington, VA

Cindy Fowler
Littleton, CO

David Franz, M.D.
Cincinnati, OH

Jennifer Glassman
Los Angeles, CA

Steven Goldstein
Westport, CT

Ron Heffron
Irvine, CA

Elizabeth Henske, M.D.
Philadelphia, PA

Linda Jackson
Miami Beach, FL

Tommy Lindsey
Staten Island, NY

Alan Marshall
Scottsdale, AZ

Kathy Mayrsohn
Key Biscayne, FL

John Nicholson, M.D., M.B.A.
Greenwich, CT

Hiroaki (Rocky) Onda, Ph.D.
Trenton, ME

David Parkes
Fairfield, CT

David Schenkein, M.D.
South San Francisco, CA

Henry Shapiro
Santa Monica, CA

Chris Sheffield
N. Hollywood, CA

Stephany Sherman
Atlanta, GA

Judith Shoulak
Corcoran, MN

Karen Shulist, Ex-Officio
Canada

TS Alliance Endowment Board of Directors

Rob Thurston, Chair
Provo, UT

Julie Blum, Secretary
Potomac, MD

Robert Groves, III, Treasurer
Brighton, MI

Mark Carroll
Saratoga, CA

William Ford
Arlington, VA

Mary Jane Mudd
Houston, TX

Michael Thurston
Provo, UT

TS Alliance Staff

Kari Luther Carlson
President & CEO

Gail Alexander
Senior Manager, Operations

Tyler Hoffman
Database Coordinator

Dena Hook
Director, Advocacy & Education

Jaye Isham
Senior Director, Marketing &
Communications

LEADERSHIP (cont.)

Jo Anne Nakagawa
Manager, Clinical Projects

Mary Jane Perraut
Controller

Jenny Smiley
Director, Community Outreach

Katie Smith
Science Coordinator

Dee Triemer
Manager, Community Outreach

Vicky Holets Whittemore, Ph.D.
Vice President & Chief Scientific
Officer

Community Alliances

TS Alliance of Arizona
Debora Moritz, Chair

**TS Alliance of Atlanta/
North Georgia**
Jennifer Weingarh, Chair

TS Alliance of the Carolinas
Christi Davis, Co-Chair
Karen Sims, Co-Chair
Amy Quintana, Co-Chair

TS Alliance of Connecticut
Jennifer Waldron, Chair

**TS Alliance of the Dallas/
Ft. Worth Area**
Maria Cole, Co-Chair
Tricia Bodnar, Co-Chair

**TS Alliance of the Delaware/
Lehigh Valley**
Cindy Richards, Co-Chair
Shelley Richards, Co-Chair
Liz Saadoun, Co-Chair

TS Alliance of Florida
Joy Graydon, Chair

TS Alliance of the Delta Region
Samantha Glass, Chair
Julie Comeaux, Vice Chair

TS Alliance of Greater Alabama
Carole Pitard, Co-Chair
Shirley McAfee, Co-Chair
Donna Ross, Vice Chair

TS Alliance of Greater Chicago
Jay and Lisa Smiley, Co-Chairs

TS Alliance of Greater Kansas City
Amy Dublinske, Chair
Lisa Hart, Vice Chair

TS Alliance of Hawaii
Tricia Gerum, Chair

TS Alliance of the Heartland
Cindy Blackard, Chair

TS Alliance of Houston
Lucy Martinez, Chair

TS Alliance of Indiana
Susan Campbell, Chair

TS Alliance of Intermountain West
Stephanie and Ian Bobberman,
Co-Chairs
Julie Fleming, Vice Chair

TS Alliance of Metro DC
Rob and Lisa Moss, Co-Chairs

TS Alliance of Middle Tennessee
Amy and Jim Hobbs, Co-Chairs

TS Alliance of Michigan
Tresa Bolger, Chair

TS Alliance of Nevada
Kathleen Kingston, Co-Chair
Mary Ann Weidner, Co-Chair

TS Alliance of New England
Karin Sullivan, Chair
Jeffrey Hargreaves, Vice Chair

**TS Alliance of the New York Metro
& New Jersey**
Peggy and Tommy Lindsey, Co-Chairs

TS Alliance of Northern California

TS Alliance of Ohio
Carl and Lola Centeno, Co-Chairs
Jim and Nancy Weir, Co- Vice Chairs

TS Online Community Alliance
Maureen Reyes, Chair

TS Alliance of the Pacific Northwest
Susan Jorski, Chair

**TS Alliance of the Rocky Mountain
Region**
Dana Holinka, Chair

TS Alliance of Southern California
April Cooper, Co-Chair
Christy Hobart, Co-Chair
Julia K. Cohen, Vice-Chair

TS Alliance of St. Louis
Rene Friedel, Chair

TS Alliance of the Upper Midwest
Jim Hable, Co-Chair
Missy Anderson, Co-Chair

TS Alliance of Virginia

Kathy Henkel, Co-Chair
Kristy Wetmore, Co-Chair
Adrienne Cohen, Vice Chair

TS Alliance of Western Pennsylvania

Mike Seman, Chair

TS Alliance of Wisconsin

Kristin Champagne, Chair

Professional Advisory Board**Peter Crino, MD, PhD, Chair**

University of Pennsylvania School of Medicine
Department of Neurology
PENN Epilepsy Center
Philadelphia, PA
Specialty: Adult Neurology

Peter J. Aronson, MD

Wayne State University
Department of Dermatology
Detroit, MI
Specialty: Dermatology

Stephen Ashwal, MD

Loma Linda School of Medicine
Department of Pediatrics
Loma Linda, CA
Specialty: Pediatric Neurology

E. Martina Bebin, MD

University of Alabama at Birmingham
Department of Neurology
Huntsville, AL
Specialty: Pediatric Neurology

John Bissler, MD

Children's Hospital Medical Center
Division of Nephrology and Hypertension
Cincinnati, OH
Specialty: Pediatric Nephrology

Peter Black, MD, PhD

Children's Hospital
Department of Neurosurgery
Boston, MA
Specialty: Neurosurgery

Candida Brown, MD

Children's Hospital Oakland
Division of Neurology
Oakland, CA
Specialty: Pediatric Neurology

Diane C. Chugani, PhD

Children's Hospital of Michigan
Department of Neurology
Detroit, MI
Specialty: Pharmacology

Harry T. Chugani, MD

Children's Hospital of Michigan
Pediatric Neurology
Detroit, MI
Specialty: Pediatric Neurology

Petrus de Vries, MD, PhD

Cambridge University
Department of Psychiatry
Cambridge, UK
Specialty: Psychiatry and Psychology

Orrin Devinsky, MD

NYU Epilepsy Center
New York, NY
Specialty: Neurology

Francis J. DiMario, Jr, MD

Connecticut Children's Medical Center
Division of Pediatric Neurology
Hartford, CT
Specialty: Pediatric Neurology

Michael S. Duchowny, MD

Miami Children's Hospital
Department of Neurology
Miami, FL
Specialty: Pediatric Neurology

David W. Dunn, MD

Riley Hospital for Children
Indiana University School of Medicine
Department of Neurology
Indianapolis, IN
Specialty: Pediatric Neurology & Psychiatry

Nancy J. Elling, BSN, RN

Children's National Medical Center
Department of Neurology
Fairfax, VA
Specialty: Nursing

Kevin C. Ess, MD, PhD

Vanderbilt University
Department of Neurology
Nashville, TN
Specialty: Pediatric Neurology

David H. Ewalt, MD

Urology Clinic of North Texas
Dallas, TX
Specialty: Urological Surgery

David Neal Franz, MD

Children's Hospital Medical Center
Department of Neurology
Cincinnati, OH
Specialty: Pediatric Neurology

Michael D. Frost, MD

The Minnesota Epilepsy Group, P.A.
Saint Paul, MN
Specialty: Pediatric Neurology

LEADERSHIP (cont.)

David Frim, MD, PhD

The University of Chicago Children's Hospital
Department of Neurosurgery
Chicago, IL
Specialty: Neurosurgery

Patricia A. Gibson, MSW

Wakeforest University School of Medicine
Baptist Medical Center
Department of Neurology
Comprehensive Epilepsy Information Service
Winston Salem, NC
Specialty: Social Work

Ajay Gupta, MD

Cleveland Clinic
Department of Neurology
Cleveland, OH
Specialty: Pediatric

Elizabeth P. Henske, MD

Fox Chase Cancer Center
Department of Medical Oncology
Philadelphia, PA
Specialty: Oncology

Deborah Holder, MD

University of Pittsburgh
Department of Neurology
Pittsburgh, PA
Specialty: Pediatric Neurology

John Hulbert, MD

Urologic Physicians, P.A.
Edina, MN
Specialty: Urological Surgery

Janine Lewis, MS, CGC

Genetics and Rare Disease Hotline (GARD)
Rockville, MD
Specialty: Genetic Counseling

Raymond S. Kandt, MD

Johnson Neurological Clinic
High Point, NC
Specialty: Pediatric Neurology

Bryan H. King, MD

Children's Hospital
Department of Psychiatry
Seattle, WA
Specialty: Child Psychiatry

Susan Koh, MD

University of California, Los Angeles
Division of Pediatric Neurology
Los Angeles, CA
Specialty: Pediatric Neurology

Michael Kohrman, MD

University of Chicago
Department of Pediatrics
Chicago, IL
Specialty: Pediatric Neurology

David J. Kwiatkowski, MD, PhD

Genetics Lab, Hematology Division
Brigham and Women's Hospital
Harvard Medical School
Boston, MA
Specialty: Genetic Research

Paul Levisohn, MD

University of Colorado
Department of Neurology
Denver, CO
Specialty: Pediatric Neurology

Mark Mausner, MD

Georgetown University
Washington, DC
Specialty: Plastic and Reconstructive Surgery

William McClintock, MD

Children's National Medical Center
Department of Neurology
Fairfax, VA
Specialty: Pediatric Neurology

Frank McCormack, MD

University of Cincinnati School of Medicine
Pulmonary Division
Cincinnati, OH
Specialty: Pulmonology

Greg Mlynarczyk, DDS

Santa Rosa, CA
Specialty: Dentistry

Hope Northrup, MD

The University of Texas Medical School at Houston
Department of Pediatrics, Division of Medical Genetics
Houston, TX
Specialty: Pediatrics & Genetics

E. Steve Roach, MD

Ohio State University
Department of Neurology
Specialty: Pediatric Neurology

Mustafa Sahin, MD, PhD

Children's Hospital
Department of Neurology
Boston, MA
Specialty: Pediatric Neurology

Steven P. Sparagana, MD

Texas Scottish Rite Hospital for Children
Department of Neurology
Dallas, TX
Specialty: Pediatric Neurology

Elizabeth A. Thiele, MD, PhD

Massachusetts General Hospital
Department of Neurology
Boston, MA
Specialty: Pediatric Neurology

William G. Ward, MD

Wake Forest University School of
Medicine

Baptist Medical Center
Department of Orthopedic Surgery
Winston Salem, NC
Specialty: Orthopedic Surgery

Howard Weiner, MD

New York University Medical Center
Division of Pediatric Neurosurgery
New York, NY
Specialty: Neurosurgery

Joyce Wu, MD

University of California, Los Angeles
Division of Pediatric Neurology
Los Angeles, CA
Specialty: Pediatric Neurology

Raymond Yeung, MD

University of Washington School of
Medicine
Division of Surgery and Medical
Genetics
Seattle, WA
Specialty: Surgery

**International Scientific
Advisory Board****Elizabeth Petri Henske, MD, Chair**

Director, Center for LAM Research
and Clinical Care
Brigham & Women's Hospital
Boston, MA

Peter Crino, MD, PhD

Department of Neurology
University of Pennsylvania
Philadelphia, PA

Paolo Curatolo, MD

Pediatric Neurosciences
Tor Vergata University of Rome
Rome, Italy

Petrus de Vries, MD, PhD

Department of Psychology
Cambridge University
Cambridge, UK

Howard Goodkin, MD, PhD

Department of Neurology
University of Virginia
Charlottesville, VA

Gregory Holmes, MD

Department of Neurology
Dartmouth University
Lebanon, NH

Frances Jensen, MD

Department of Neurology
Children's Hospital/Harvard
Boston, MA

Sergiusz Jozwiak, MD, PhD

Department of Neurology
Children's Memorial Health Institute
Warsaw, Poland

Chris Kingswood, MD

Brighton & Sussex University
Hospitals Trust
Renal Unit
Brighton, UK

David Kwiatkowski, MD, PhD

Department of Medicine
Brigham & Women's Hospital
Boston, MA

Brendan Manning, PhD

Department of Genetics and Complex
Diseases
Harvard School of Public Health
Boston, MA

Hope Northrup, MD

Department of Pediatrics, Division of
Medical Genetics
University of Texas Health Science
Center
Houston, TX

Bernardo Sabatini, MD, PhD

Department of Neurobiology
Harvard Medical School
Boston, MA

Julian Sampson, MB

Chair, Institute of Genetics
University of Wales College of
Medicine
Cardiff, UK

Andrew Tee, PhD

Institute of Genetics
University of Wales College of
Medicine
Cardiff, UK

Cheryl Walker, PhD

Center for Research on Environmental
Disease
The University of Texas
M.D. Anderson Cancer Center
Science Park-Research Division
Smithville, TX

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

Consolidated Statements of Financial Position • June 30, 2009 and 2008

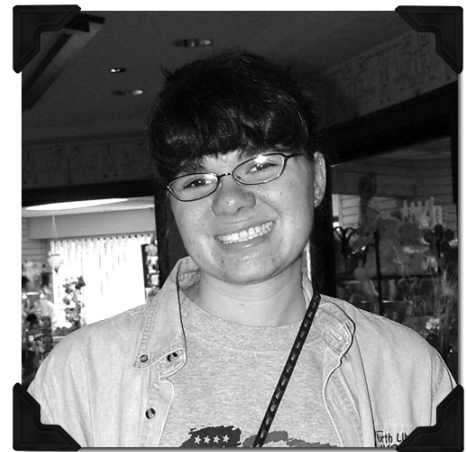
	2009	2008
Assets		
Current Assets		
Cash	\$ 731,532	\$ 558,270
Short-term investments	2,600,043	2,890,217
Accounts Receivable	21,815	74,736
Promises to Give, current portion	118,600	30,227
Inventory	23,841	13,720
Prepaid Expenses	47,609	65,534
Total Current Assets	3,543,440	3,632,704
Long-Term Investments	3,651,157	4,880,873
Promises to give, less current portion	100,000	–
Property and equipment	186,415	212,044
Total Assets	\$ 7,481,012	\$ 8,725,621
Liabilities and Net Assets		
Liabilities		
Current liabilities		
Accounts payable and accrued expenses	\$ 82,134	\$ 198,277
Accrued compensation	46,768	73,936
Deferred revenue	3,900	–
Gift annuity obligations, current portion	9,400	9,400
Total current liabilities	142,202	281,613
Gift annuity obligations, less current portion	63,106	62,024
Total liabilities	205,308	343,637
Commitments and contingencies		
Net Assets		
Unrestricted		
Undesignated	337,257	(334,721)
Designated	4,560,054	6,443,312
Total unrestricted	4,897,311	6,108,591
Temporarily restricted	1,473,949	1,368,949
Permanently restricted	904,444	904,444
Total net assets	7,275,704	8,381,984
Total liabilities and net assets	\$ 7,481,012	\$ 8,725,621

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 2009 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. The 2009 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 the Statement of Position (SOP) 94.3, Reporting of Related Entities by Not-for-Profit Organizations. Due to the downturn in the markets, the investments in the TS Alliance Endowment Fund showed a loss in 2009. The operating entity ended the year with a \$67 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	2009 Total	2008 Total
Revenue and Support					
Special Events	\$ 1,840,943	\$ 74,432	\$ -	\$ 1,915,375	\$ 2,109,619
Cost of direct benefits to donors	(272,432)			(272,432)	(276,172)
Special events, net	1,568,511	74,432	-	1,642,943	1,833,447
Contributions	730,418	547,211		1,277,629	1,095,531
Interest and dividends	125,390			125,390	321,042
Memorials and honorariums	96,492	7,690		104,182	171,698
Federated funding	78,586			78,586	60,323
Regional conferences	41,527			41,527	48,632
Other income	13,852			13,852	2,467
International research conference				-	130,465
	2,654,776	629,333	-	3,284,109	3,663,605
Net assets released from restrictions - satisfaction of program restrictions	524,333	(524,333)		-	-
Total revenue and support	3,179,109	105,000	-	3,284,109	3,663,605
Expenses					
Program services					
Research	1,311,445			1,311,445	1,744,493
Family services	558,814			558,814	727,106
Public health education	260,804			260,804	325,663
Government relations	142,286			142,286	163,066
Professional education	56,455			56,455	65,625
Total Program Services	2,329,804	-	-	2,329,804	3,025,953
Supporting Services					
Management and general	651,886			651,886	792,165
Fund raising	487,227			487,227	736,074
Total supporting services	1,139,113	-	-	1,139,113	1,528,239
Total expense	3,468,917	-	-	3,468,917	4,554,192
Change in net assets before other item	(289,808)	105,000	-	(184,808)	(890,587)
Net loss on investments	(921,472)			(921,472)	(410,066)
Changes in net assets	(1,211,280)	105,000	-	(1,106,280)	(1,300,653)
Net assets, beginning of year	6,108,591	1,368,949	904,444	8,381,984	9,682,637
Net assets, end of year	\$ 4,897,311	\$ 1,473,949	\$ 904,444	\$ 7,275,704	\$ 8,381,984







801 Roeder Road
Suite 750
Silver Spring, MD 20910

800-225-6872
www.tsalliance.org