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.

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.

We’ll Give Everything. But Up.

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.

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

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.
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.

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.

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.
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 Wearingh
- 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 Dubinkse, 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
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Heart of the Valley Pediatric Cardiology
Joseph H. Helgott and Susan B. Whitman-Helgott
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
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Howard J. and Karen Lazerovich
Sung Woo Lee
William W. and Barbara Lee
Rodney and Caroline Lenz
Eric S. and Sheryl Lesser
Chester M. and Melissa Levey, Jr.
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Liberty Fruit Company
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Sylvia Lief
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Malloy Foundation
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David Martin
Kevin R. and Carrie Martin
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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
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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 Mobb
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Philip and Jane Molstre
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Muhlenberg Foundation
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James and Margot Mustich, Jr.
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National Association of Theatre Owners of California/
Nevada
National Oilwell Varco
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Jerold and Katie Nichols
Julian Norstand
Annual Fund – Major Donors (cont.)

North Coast Nautilus Inc.
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Ron and Kathie Oakes
Manuel P. and Isabelita Ocampo
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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
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Amaan Panjwani
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John D. Poutasse and Mara L. Flynn
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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
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Vic Reyes, Jr.
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Ridgeline Builders, Inc
Philip and Cheryl Rosen
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Steven Rosenblatt
Royal Arcanum
Fabrice and Liz Saadoun
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Thomas and Deborah Schaeffer
Molly Schaffer
Abe Schlabach
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James Sears
Joshua Segal
James Shaw
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Jeffery and Vickie Sprinkle
Robert B. and Nadine Sprinkle, Jr.
St. Patrick’s Altar & Rosary Society
Standard Tube Co
Stealthbits Technologies, Inc.
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Richard and Dee Dee Stephens
David Stewart
Joe Stockdale
Michael and Ruth Stoddard
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Dale J. and Kris Studer
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Robert and Lisa Szilagyi
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Trey and Lucy Tart
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Rhonda Taylor
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Tenaris
H.D. and Linda Tewis
Jeff Theis
Sean and Kelly Thomann
Keleigh Thomas
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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 Tolk
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Kevin and Ellen Traina
Richard and Susan Trester
Triad Pipe
Robert P. Trout and Ms. Janet Studley
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Gordon T. and Heather Ueland
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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 Wangness
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 Ziobor

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
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Julianne Moore
Morton’s Steakhouse
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Neil Lane
Nicaro
Patrone
Norman and Dadie Perlov
John Poutasse and Mara Flynn
Phyto
Piaget
Rachel 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 Emmony Shapses, ERS Charitable Foundation
Shore Club
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Terlato Wines International
Teleflora
The Doctors
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Tim Thompson, Smith Barney
Tosca
Truth and Salvage Company
US Cellular
Variety
Vicky Whittemore
Xante Liquor
Zaytinya

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
Margaret Cleveland
John and Janine Steenman
Kathy ‘Trapp
Alma A. Tutrone*

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

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Corcoran, MN

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Mary Jane Mudd
Houston, TX

Michael Thurston
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President & CEO

Gail Alexander
Senior Manager, Operations

Tyler Hoffman
Database Coordinator

Dena Hook
Director, Advocacy & Education

Jaye Isham
Senior Director, Marketing & Communications

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Controller

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Katie Smith
Science Coordinator

Dee Triemer
Manager, Community Outreach

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Vice President & Chief Scientific Officer

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Cindy Blackard, Chair

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Christy Hobart, Co-Chair
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Missy Anderson, Co-Chair

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Jennifer Weingarth, Chair

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Karen Sims, Co-Chair
Amy Quintana, Co-Chair
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Specialty: Pediatric Neurology

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Boston, MA
Specialty: Neurosurgery

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Department of Neurology
Detroit, MI
Specialty: Pharmacology

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Pediatric Neurology
Detroit, MI
Specialty: Pediatric Neurology

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Cambridge, UK
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Department of Neurology
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Dallas, TX
Specialty: Urological Surgery

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Department of Neurology
Cincinnati, OH
Specialty: Pediatric Neurology

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Saint Paul, MN
Specialty: Pediatric Neurology
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Department of Neurosurgery
Chicago, IL
Specialty: Neurosurgery

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

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Cleveland Clinic
Department of Neurology
Cleveland, OH
Specialty: Pediatric

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

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

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

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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 Kahrman, 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

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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

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Specialty: Pediatric Neurology

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

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University of Pennsylvania  
Philadelphia, PA

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Pediatric Neurosciences  
Tor Vergata University of Rome  
Rome, Italy

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Cambridge, UK

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Charlottesville, VA

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Lebanon, NH

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Children's Hospital/Harvard  
Boston, MA

Sergiusz Jozwiak, MD, PhD  
Department of Neurology  
Children's Memorial Health Institute  
Warsaw, Poland

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Renal Unit  
Brighton, UK

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Brigham & Women's Hospital  
Boston, MA

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Harvard School of Public Health  
Boston, MA

Hope Northrup, MD  
Department of Pediatrics, Division of Medical Genetics  
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Houston, TX

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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
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.

### Consolidated Statements of Financial Position  
**National Tuberous Sclerosis Association, Inc.  
(d.b.a. TS Alliance) and Affiliate  
(TS Alliance Endowment Fund)**  
**June 30, 2009 and 2008**

<table>
<thead>
<tr>
<th>Assets</th>
<th>2009</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash</td>
<td>$ 731,532</td>
<td>$ 558,270</td>
</tr>
<tr>
<td>Short-term investments</td>
<td>2,600,043</td>
<td>2,890,217</td>
</tr>
<tr>
<td>Accounts Receivable</td>
<td>21,815</td>
<td>74,736</td>
</tr>
<tr>
<td>Promises to Give, current portion</td>
<td>118,600</td>
<td>30,227</td>
</tr>
<tr>
<td>Inventory</td>
<td>23,841</td>
<td>13,720</td>
</tr>
<tr>
<td>Prepaid Expenses</td>
<td>47,609</td>
<td>65,534</td>
</tr>
<tr>
<td><strong>Total Current Assets</strong></td>
<td>3,543,440</td>
<td>3,632,704</td>
</tr>
<tr>
<td><strong>Long-Term Investments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promises to give, less current portion</td>
<td>100,000</td>
<td>--</td>
</tr>
<tr>
<td>Property and equipment</td>
<td>186,415</td>
<td>212,044</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td>$ 7,481,012</td>
<td>$ 8,725,621</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Liabilities and Net Assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Liabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current liabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$ 82,134</td>
<td>$ 198,277</td>
</tr>
<tr>
<td>Accrued compensation</td>
<td>46,768</td>
<td>73,936</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>3,900</td>
<td>--</td>
</tr>
<tr>
<td>Gift annuity obligations, current portion</td>
<td>9,400</td>
<td>9,400</td>
</tr>
<tr>
<td><strong>Total current liabilities</strong></td>
<td>142,202</td>
<td>281,613</td>
</tr>
<tr>
<td>Gift annuity obligations, less current portion</td>
<td>63,106</td>
<td>62,024</td>
</tr>
<tr>
<td><strong>Total liabilities</strong></td>
<td>205,308</td>
<td>343,637</td>
</tr>
<tr>
<td><strong>Commitments and contingencies</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Net Assets                     |             |             |
| Unrestricted                   | 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 |
## National Tuberous Sclerosis Association, Inc.
(d.b.a. TS Alliance) and Affiliate
(TS Alliance Endowment Fund)

### Consolidated Statements of Activities

<table>
<thead>
<tr>
<th>Revenue and Support</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>2009 Total</th>
<th>2008 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Events</td>
<td>$1,840,943</td>
<td>$74,432</td>
<td>-</td>
<td>$1,915,375</td>
<td>$2,109,619</td>
</tr>
<tr>
<td>Cost of direct benefits to donors</td>
<td>(272,432)</td>
<td>(272,432)</td>
<td>-</td>
<td>(276,172)</td>
<td>-</td>
</tr>
<tr>
<td>Special events, net</td>
<td>1,568,511</td>
<td>74,432</td>
<td>-</td>
<td>1,642,943</td>
<td>1,833,447</td>
</tr>
<tr>
<td>Contributions</td>
<td>730,418</td>
<td>547,211</td>
<td>-</td>
<td>1,277,629</td>
<td>1,095,531</td>
</tr>
<tr>
<td>Interest and dividends</td>
<td>125,390</td>
<td></td>
<td></td>
<td>125,390</td>
<td>321,042</td>
</tr>
<tr>
<td>Memorials and honorariums</td>
<td>96,492</td>
<td>7,690</td>
<td>-</td>
<td>104,182</td>
<td>171,698</td>
</tr>
<tr>
<td>Federated funding</td>
<td>78,586</td>
<td></td>
<td></td>
<td>78,586</td>
<td>60,323</td>
</tr>
<tr>
<td>Regional conferences</td>
<td>41,527</td>
<td></td>
<td>-</td>
<td>41,527</td>
<td>48,632</td>
</tr>
<tr>
<td>Other income</td>
<td>13,852</td>
<td></td>
<td></td>
<td>13,852</td>
<td>2,467</td>
</tr>
<tr>
<td>International research conference</td>
<td>-</td>
<td>-</td>
<td>130,465</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td><strong>Total revenue and support</strong></td>
<td>$3,179,109</td>
<td>$105,000</td>
<td>-</td>
<td>$3,284,109</td>
<td>$3,663,605</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Program services</th>
<th>2009 Total</th>
<th>2008 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>$1,311,445</td>
<td>$1,311,445</td>
<td>$1,744,493</td>
</tr>
<tr>
<td>Family services</td>
<td>558,814</td>
<td>558,814</td>
<td>727,106</td>
</tr>
<tr>
<td>Public health education</td>
<td>260,804</td>
<td>260,804</td>
<td>325,663</td>
</tr>
<tr>
<td>Government relations</td>
<td>142,286</td>
<td>142,286</td>
<td>163,066</td>
</tr>
<tr>
<td>Professional education</td>
<td>56,455</td>
<td>56,455</td>
<td>65,625</td>
</tr>
<tr>
<td><strong>Total Program Services</strong></td>
<td>$2,329,804</td>
<td>-</td>
<td>$2,329,804</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Supporting Services</th>
<th>2009 Total</th>
<th>2008 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management and general</td>
<td>651,886</td>
<td>651,886</td>
<td>792,165</td>
</tr>
<tr>
<td>Fund raising</td>
<td>487,227</td>
<td>487,227</td>
<td>736,074</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td>$1,139,113</td>
<td>-</td>
<td>$1,139,113</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Change in net assets before other item</th>
<th>2009 Total</th>
<th>2008 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in net assets before other item</td>
<td>(289,808)</td>
<td>105,000</td>
<td>-</td>
</tr>
<tr>
<td>Net loss on investments</td>
<td>(921,472)</td>
<td>-</td>
<td>(921,472)</td>
</tr>
<tr>
<td><strong>Changes in net assets</strong></td>
<td>(1,211,280)</td>
<td>105,000</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Net assets, beginning of year</th>
<th>2009 Total</th>
<th>2008 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net assets, beginning of year</td>
<td>6,108,591</td>
<td>1,368,949</td>
<td>904,444</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Net assets, end of year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net assets, end of year</td>
<td>$4,897,311</td>
</tr>
</tbody>
</table>