inspiration
HOPE
innovation
On multiple fronts, 2019 will be remembered as a banner year for the Tuberous Sclerosis Alliance (TS Alliance). The year began by marking the organization’s 45th anniversary and ended with bold tuberous sclerosis complex (TSC) research plans, enhanced community support and education programs, expanded awareness efforts and record-breaking fundraising.

Our 45th anniversary’s theme, “45 Years of Changing the Future: Inspiration, Innovation and Hope,” could not have been more appropriate! The TSC community and their needs remain the TS Alliance’s inspiration on a daily basis. Our organization thrives on innovation in everything we do as we work to ensure a future full of hope for anyone and everyone touched by tuberous sclerosis complex.

In 1974, four mothers from Southern California met for the first time to lay the groundwork for what would eventually become the Tuberous Sclerosis Alliance. In those days, a TSC diagnosis was quite daunting. But today, more than 45 years later, the TSC journey is vastly different for the newly diagnosed. Of course, many challenges remain for people with the disorder, their caregivers and their loved ones. But the TS Alliance’s progress along with the multiple discoveries and advancements throughout our history mean we are able to inform, educate and advocate in ways many never thought possible.

Today, people with TSC are certainly in a better place because of the dedication and efforts of the original moms and countless others throughout the years.

Highlights from 2019 include:

• The 45th Anniversary Gala, held in New York City, shattered the organization’s previous fundraising record, raising a staggering $1 million in one evening.
• The TS Alliance introduced a new Research Business Plan, laying the groundwork to accelerate TSC research through collaborative and aggressive programs.
• The organization debuted several new digital initiatives, including a bimonthly e-newsletter and a monthly podcast series.
• Our government advocacy efforts continued on both Federal and State levels, securing another $6 million appropriation for the TSC Research Program in the Congressionally Directed Medical Research Program and $750,000 in state funding for TSC Centers in Maryland and Missouri.
• The organization launched the TSC-Associated Neuropsychiatric Disorders (TAND) Initiative to begin addressing one of the most challenging manifestations of TSC for individuals, parents and caregivers.

• To educate professionals about TSC, the TS Alliance participated in and presented at 40 professional meetings, and we co-hosted a reception with the University of Maryland during the annual American Epilepsy Society meeting, where more than 120 attended including the Honorable Larry Hogan, Governor of Maryland.
• In 2019 the TS Alliance’s TSC Connect Program facilitated 32,932 peer-to-peer supports by our amazing volunteer corps of Adult Regional Coordinators, Clinic Ambassadors, Dependent Adult Transition Resource Coordinators, Education Parent Mentors, Community Alliance Leaders and Junior Leaders.

In the following pages of this annual report, you’ll be able to read more about 2019 and our continued focus to bring about the day when no one has to endure the devastating effects of tuberous sclerosis complex.

What is Tuberous Sclerosis Complex?

Affecting 50,000 in the United States and 1 million worldwide, tuberous sclerosis complex (TSC) is a genetic disorder that causes tumors to form in vital organs, including the brain, eyes, heart, kidneys, lungs and skin. TSC is also the leading genetic cause of both epilepsy and autism.

About the Tuberous Sclerosis Alliance

The Tuberous Sclerosis Alliance is an internationally recognized nonprofit organization dedicated to finding a cure for tuberous sclerosis complex while improving the lives of those affected. We accomplish this through:

• developing programs, support services and resource information;
• stimulating and sponsoring research; and
• creating and implementing public and professional education programs designed to heighten awareness of the disease.
Driving TSC Research

In a nutshell, the TS Alliance’s Research Department works to alter the course of the disease to not only create a more hopeful future for generations to come but to also improve the quality of life for those currently impacted by TSC. Our organization is uniquely positioned to help focus research to quickly move new drugs or treatments from laboratories to actual use by people with TSC. To ensure future TSC research efforts target their most pressing unmet medical needs, a comprehensive seven-year Research Business Plan was released in 2019. This plan leverages partnerships with industry, private funders and governmental agencies, with the expertise and guidance of the TS Alliance.

Basic, translational and clinical research are crucial to identify, develop and implement new therapies and treatments for the TSC community. Our research efforts focus on building and fostering collaborations between basic and clinical researchers, promoting preclinical and clinic research program partnerships and hosting International TSC Research Conferences.

The TS Alliance’s research program includes five major pillars – our Research Grants Program, Preclinical Consortium, Clinical Research Consortium, Natural History Database and Biosample Repository.

Since 1984, the TS Alliance has funded more than $21.2 million in research grants. Through the Research Grants Program, applications can be submitted then reviewed for postdoctoral fellowships and research grants. We believe it’s crucial to financially support early-stage exploratory science to build the next generation of TSC researchers. In 2019, the TS Alliance awarded the following:

Postdoctoral Fellowship Awards

Ilaria Barone, PhD
Children’s Hospital, Boston
Harnessing the circadian clock to modulate TSC-related neuronal phenotypes

Elodie Villa, PhD
Northwestern University
Defining the molecular epigenetic signature downstream of mTORC1 signaling

Research Grant Award

Mustafa Sahin, MD, PhD
Children’s Hospital, Boston
Non-cell autonomous mechanisms of epilepsy in TSC2

Launched in 2015, the TSC Preclinical Consortium enables prioritization of candidate treatments based on comparing head-to-head data using consistent animal models and rigorous testing procedures. The TS Alliance has licenses to use specific TSC mouse models for experiments carried out by the Preclinical Consortium, and all mouse license agreements include the rights for the TS Alliance to perform experiments under contract for commercial entities. 2019 accomplishments include:

- Two new pharmaceutical companies joined the Preclinical Consortium, bringing the cumulative total to 11 industry partners.
- 16 studies ran to test 12 compounds.
- Two of these studies focused on TSC-Associated Neuropsychiatric Disorders (TAND) model development, a key priority for the TSC community.

Formed by five TSC Clinics in 2012, the TSC Clinical Research Consortium initiates and implements clinical studies as quickly and efficiently as possible. The TS Alliance’s Chief Scientific Officer serves on the leadership team and our early funding helped establish its data coordinating center. In 2019, the Clinical Research Consortium:

- Continued to make history with the PREVeNT trial – Preventing epilepsy using vigabatrin in infants with tuberous sclerosis complex, the first preventative trial for any form of epilepsy in the US, which has expanded the consortium to 13 sites.
- Received more than $35 million cumulatively in competitive grant funding from the National Institutes of Health.
- Awarded two new Clinical Research Consortium Grants:
  - Darcy A. Krueger, MD, PhD
    Cincinnati Children’s Hospital Medical Center
    Stopping TSC Onset and Progression 2 (STOP-2): Epilepsy prevention in TSC infants
  - Mustafa Sahin, MD, PhD
    Children’s Hospital, Boston
    Rare Diseases Clinical Research Consortium

The TS Alliance believes collecting detailed clinical data and biosamples – such as blood, DNA and tissue – from people with the disorder is crucial to truly understand why TSC affects individual so differently – even identical twins. Our Natural History Database and Biosample Repository work hand in hand to document the impact of the disease on a person’s health over his or her lifetime. By the end of 2019:

- 2,227 people enrolled in the Natural History Database.
- 967 biosamples were obtained from database participants, the Rare Disease Clinical Research Network's Developmental Synaptopathies Consortium and the PREVeNT clinical trial.
• Individuals with TSC of any age can now donate blood for the Biosample Repository from the convenience of their homes as part of the Waxlax Biosample Repository Collection and with generous gifts from Lorne and Heidi Waxlax.

• Two Biosample Repository Seed Grants were awarded:
  • Carmen Priolo, MD, PhD
    Brigham and Women’s Hospital, Inc.
    Identification of immunogenic structures of the TSC glycome through glycan microarrays
  • Paul Dutchak, PhD
    Université Laval
    Novel approaches to treat TSC

Co-sponsored with Tuberous Sclerosis Canada Sclérose Tubéreuse (TSCST) and the TS Alliance of Mexico, the 2019 International TSC Research Conference: Changing the Course of TSC was held June 20-22, 2019, in Toronto, Canada, attracting 251 people from 28 countries. The conference featured 34 oral presentations and 62 posters. Additionally, three working groups of clinical and basic science researchers discussed induced pluripotent stem cell applications for TSC, genetic heterogeneity and modifiers and clinical trial design for neurological aspects of TSC. TSCST sponsored a Canadian clinicians’ meeting the evening of June 19. The conference’s closing session featured a joint session including individuals and families affected by TSC together with researchers in a discussion of ideas for important and timely clinical studies in TSC.

The TAND Initiative

TSC is associated with a wide range of cognitive, behavioral and psychiatric manifestations, which together are known as TSC-Associated Neuropsychiatric Disorders (TAND). TAND describes the interrelated functional and clinical manifestations of brain dysfunction in TSC, including aggressive behaviors, autism spectrum disorder, intellectual disabilities, psychiatric disorders, neuropsychological deficits, as well as school and occupational difficulties.

Because these issues are some of the most challenging aspects of TSC for individuals, parents and caregivers, the TS Alliance launched the TAND Initiative in 2019. The initiative focuses on advancing therapies for TAND at both the preclinical and clinical levels, while offering interventions and resources to help those affected manage cognitive, behavioral and psychiatric aspects of the disease now. The project includes educational webinars, continuing medical education courses for medical professionals and targeted research efforts. In addition, the TS Alliance also began working with partners around the world on the TANDem Project, which is developing a mobile app to help people with TSC and caregivers.

In 2019, the TS Alliance served as the Lead Advocacy Partner of Child Neurology Foundation’s CME: Harmful and Disruptive Behaviors. More than 200 child neurologists attended this groundbreaking symposium conducted during the Child Neurology Society annual meeting, which featured the caregiver perspective beautifully delivered by Leslie Russell, mom to Anna. In preparation for the symposium, surveys were conducted among the caregiver community with a response of 1,910, including 469 from the TSC community. The TS Alliance also hosted four community-based webinars and one podcast on TAND to provide meaningful information and resources.
Advocating for Federal and State TSC Appropriations

While the TS Alliance provides some research funding, our extensive and TSC community-driven Government Advocacy program focuses on increasing federal and state appropriations for TSC research, raising awareness and collaborating with government partners to drive TSC research forward and improve clinical care and treatment options for individuals with TSC. In 2019, the TS Alliance and volunteers worked together to:

- Successfully obtain $750,000 in state appropriations, including $250,000 for existing TSC Center in Missouri and $500,000 to launch the new TSC Treatment Center of Maryland.
- Participated in another March on Capitol Hill in Washington, DC to advocate for continued funding for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense's Congressionally Directed Medical Research Program, which resulted in a $6 million appropriation bringing the cumulative TSCRP funding to $89 million since 2002.
- Held a record-breaking year with 485 Congressional meetings being held; 235 House signers on a Dear Colleague Letter sponsored by Dave Loebsack (D-IA) and Markwayne Mullen (R-OK); and 35 Senate signers on a Dear Colleague Letter sponsored by Johnny Isakson (R-GA) and Chris Murphy (D-CT).

Supporting Individuals and Families

Our constituents rely on our organization to provide support and resources any hour or day of the week, expertise in navigating school issues and referrals to medical professionals experienced in diagnosing, treating and managing the disorder. To meet these needs, the TS Alliance’s Support Services department develops and offers services and programs for anyone affected by TSC, including their caregivers and loved ones.

Because the TSC-related issues of parents, young children, teens, siblings and adults all differ, our highly regarded TSC Connect program is implemented by a diverse and dedicated group of volunteers, including Adult Regional Coordinators, TSC Clinic Ambassadors, Dependent Adult Transition Resource Coordinators, Education Parent Mentors and Junior Leaders.

Providing Accurate Information and Increasing Awareness

The TS Alliance’s Communications Department creates and manages a wide range of tools to keep individuals with TSC and their loved ones informed. These tools include our website, publications, digital initiatives and robust social media outreach. In 2019:

- The TS Alliance website averaged 36,450 unique visitors each month.
- Our Facebook TSC Discussion Group had more than 9,800 members.
- 2,240 people followed our Twitter account.
- 1,800-plus followed our Instagram account.
- Eight episodes of our new podcast series, TSC Now, were downloaded 1,400 times.
A bi-monthly e-newsletter, TSC Matters, debuted with five issues reaching 5,800 each.

Our communications team also works to increase awareness of TSC among the general public as well as the undiagnosed. In 2019, these efforts included:

- Participating in the annual TSC Global Awareness Day on May 15 and TSC Awareness Month throughout May, with our news release about TSC Global Awareness Day garnering 15.8 million impressions.
- Leading communication efforts for Infantile Spasms Awareness Week (December 1 to 7), including targeted social media outreach, a satellite media tour that gained 235,812 broadcast impressions and a new release reaching 313 million.

**Educating Researchers and Healthcare Professionals**

Although diagnosing and treating TSC is well understood by experts in the field, the TS Alliance offers Professional Education programs to target researchers, healthcare providers caring for individuals with TSC perhaps for the first time, medical students, genetic counselors and educators. These opportunities are critically important to ensure these professionals gain the most up-to-date information about the disorder so they can properly care and support people with TSC. In 2019, TS Alliance staff:

- Participated in or served as presenters at 40 professional meetings, ranging from federal agency events to medical society conferences to other rare disease forums.

**Reaching Out Across the World**

While we're based in the US, our Global Outreach program works with TSC organizations in other countries and to meet the unmet needs of the world-wide TSC community in general. The TS Alliance is an active participant in Tuberous Sclerosis Complex International (TSCi), a consortium of 38 existing TSC organizations around the world. TSCi hosts the annual TSC Global Awareness Day on May 15 and completed its groundbreaking Improving Care Resources White Paper in 2019.

Through our Global Alliances, we are also able to share our expertise and provide limited financial support in some countries to start their own organizations. By the end of 2019, the TS Alliance established six of these global partnerships, including TS Alliance of Israel, TS Canada ST, TS Alliance of Mexico, TS Alliance Foundation (in Thailand), Hungarian Foundation for Tuberous Sclerosis and TS Alliance of India.

**Raising Critical Funding**

Every day the TS Alliance's Development and Community Programs Departments work to fund our efforts to provide meaningful programs and services, increase awareness and drive TSC research forward. Luckily, the TSC community serves as an active partner by helping stage national events, walks and other local fundraisers as well as making personal contributions. These volunteers and supporters embody our mission to find a cure for TSC while improving the lives of those affected.

In 2019, Special Events netted $2,421,423, representing 39% of the organization's overall revenue.

The 18th Annual Comedy for a Cure® in Hollywood was held at Academy LA on April 7, 2019 and raised $225,000.

- The night included music by Kate Flannery and the Tony Guerrero Quintet and a bit of magic with Shane Brady.
- Laughter filled the room because of three hilarious comedians: Karen Rontowski, John Henson and the evening's headliner Orny Adams.
- Attendees were also amused by the fabulous and always entertaining co-hosts Jim O'Heir and Alex Skuby, who made the night extra special.

- Co-hosted a reception with the University of Maryland during the annual American Epilepsy Society meeting, where more than 100 attended including the Larry Hogan, Maryland's Governor.
- Collaborated with national educational networks, including The Arc USA and Parent Training Information Centers around the US.

- The much-deserved Leadership in Courage Award was presented to the Szilagyi Family and a TSC Champion award to Dr. Joyce Wu of UCLA.
- The evening was made possible due to the efforts of the fabulous Comedy for a Cure planning committee, Ingram Design Studio, Traci Hoffberg Events and Tom Bercu Presents.
The Third Annual Minnesota Sound Bites was held at the Metropolitan in Golden Valley, MN on May 10, with the sold-out crowd raising $108,000.

- The night was kicked off by DJ Jake Rudh who spun while all enjoyed the sponsored food and beverages donated by Baba’s Catering, Charlie’s on Prior, Caribou Coffee, Davanni’s, Dough Dough, Du Nord Craft Spirits, Eileen’s Colossal Cookies, Fulton Beer, The Loop Bar + Restaurant, Papa Murphy’s, Red Rabbit and Red Cow.
- The evening program was emceed by the wonderfully hilarious Melissa Peterman.
- The much-deserved Leadership in Courage Award was presented to the Spotts Family, who became powerful TSC advocates in honor of their young son, Sawyer.
- Carol Hoskin, RN, was honored for her commitment to the TSC community as the nurse coordinator for the TSC Clinic Without Walls serving the Upper Midwest since its inception, while Minnesota’s own Upsher-Smith Laboratories LLC was honored because of its remarkable commitment to the patient and their outstanding partnership with the TS Alliance.
- The highlight of the evening’s entertainment was an intimate acoustic concert led by the event’s Honorary Co-Hosts Chris Hawkey and Kat Perkins; they were joined by local rising stars Michael Shynes and Erin Grand and supported by Alexander Fredrick and Tony Williams.
- Special thanks to the generous event sponsors: Dr. Michael and Janie Frost, Novartis, Upsher-Smith Laboratories, LLC, Minnesota Epilepsy Group, Greenwich Biosciences, Goodkin Company, RBC Wealth Management – The Tease-Wright Group, WPT Industrial REIT, The Shoulak Family and Relatively Speaking, Mathnasium, Bach to Rock, e2 Electrical Services, Fairchild’s Foster Care, Eric and Kat Katzenmeyer, Larry and Lindsey Mason, Santorii Mortgage, Ralph and Arlene Sunday, Jim and Mabel Tarlton, Ron and Cheryl Wagner and Wee Willy Walkers.

The 45th Anniversary Gala, held at The Edison Ballroom in New York City on October 3, raised a record-breaking $1 million!

- The outstanding planning committee was co-chaired by David and Jeannine Fitzmaurice and included a diverse team from the TSC community, including: Erinmary Barrett, Donnie and Rebecca Bilbrey, Julie Blum, Alexis, Andy and Emily Bott, Katrina Caban, Rita DiDomenico, Lori DiStefano, Lauren Gottlieb, Heather Harden, Carly Kaye, Robin Krantz, Peggy Lindsey, Laura Marks, Laurie Marshall, Celia Mastbaum, David Michaels, David and Penney Parkes, Mary Roberds, Haydn Scarr, Rhiannon Schade, Sean and Lauren Shillinger, Lucy Tart and Carol Ann White.
- The event’s “Blue Brick Road Video Series” made possible by Greenwich Biosciences, beautifully highlighted both the rich history of the TSC community as well as several individuals who made significant contributions over the past 45 years.
- The evening was kicked off beautifully by Nathan Carlisle, member of the Metropolitan Opera.
- Throughout the night, we were entertained by host Mo Collins and co-emcees Jim O’Heir and Alex Skuby.
- The crowd was moved by Kat Perkins who partnered with the Sing Me A Story Foundation and Horizon Therapeutics to compose and perform an original song written with young John Fitzmaurice.
- Dr. Elizabeth Thiele and Greenwich Biosciences were presented with TSC Champion Awards.
- The Engles Family was presented with the Courage in Leadership Award for the tremendous impact they have had in advancing of TSC research, increasing TSC knowledge and helping pave the way for new treatments.
- Everyone was most dazzled by Kat’s evening-ending rendition of Somewhere Over the Rainbow, which left most everyone speechless and many in tears.

Team TSC endurance events raised $71,823, with TSC community members demonstrating their athletic abilities while raising awareness and funds for the TS Alliance.

- For the third year, the TS Alliance had a dedicated group of 11 individuals running in the 2019 TCS New York City Marathon.
- Special thanks to our 2019 Team TSC members: Marko Albrecht, Shalonda Alexander, Jennifer Ballance, Joseph Cervantez, Joshua Kimerling, DeAnne Lau, Kristen Maday, Lauren McKenna, David Miller, David Reinhardt and Suress Thomas.
- We were grateful to have Celia Mastbaum and Liz Buchsbaum host what has become an annual Rooftop Celebration the day before the marathon, where a small group of local TSC family members came together to eat, make signs and celebrate Team TSC.

Other Community Events Raising More Than $10,000

- 10th Annual Western Pennsylvania Tournament of Champions – Lori Shoup
- Brewing for a Cure - Heather Harden
- Facebook Donations – TSC Community
- Kick TSC to the Curb – Laurisa Ballew
- Krewe for a Cure – Margaret Cox
- Annual TS Alliance Dinner - Temple Pouche

The TS Alliance President’s Council, introduced in 2016, is comprised of members of families impacted by TSC who work with the President & CEO and Board of Directors to dramatically advance scientific progress by ensuring resources exist to make strategic results possible, thereby improving the quality of life for those living with TSC today and in future generations. President’s Council members give or get a minimum gift of $100,000 per year to fuel research. Current TS Alliance President’s Council Members include:

- David M. Coit
- Cowlin Family
- Christopher and Joy Dinsdale
- Gregg and Molly Engles, Engles Family Foundation on behalf of Engles Collaborative Research Fund
- James and Andrea Maginn through the creation of the Abigail and Amelia Clinical Accelerator
- Jonathan Rothberg and Bonnie Gould Rothberg, Rothberg Institute for Childhood Diseases
- William Watts
- Lorne and Heidi Waxlax through the creation of the Waxlax Biosample Collection Initiative
Major Donors and Contract Revenue

Fiscal Year 2019: January 1 to December 31

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- The National Institutes of Health: the National Heart, Lung, and Blood Institute; the National Center for Advancing Translational Sciences; the Eunice Kennedy Shriver National Institute of Child Health and Human Development; the National Institute of Arthritis and Musculoskeletal and Skin Diseases; and the National Institute of Diabetes and Digestive and Kidney Diseases.
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- Saul Wyner
- Yost Charitable Fund
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Elizabeth and Andrew Buchsbaum
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Bridget Lucas
Abel Lucero
Richard Lucett
Marjorie Luke
Maria Lund
John and Frances Lyons
Elizabeth Macdonald
MacPherson Fund, Inc.
Elizabeth Mahoney
Christopher Mahoney
Arien Malec and Kristin Barr
Shaun and Chantal Mara
Jennifer Marble
Judith Marshall
Mary Mclimid Financial Advising
Christopher Mason
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WE'LL GIVE EVERYTHING. BUT UP.

Shirley Moore
Clark and Linda Moore
Brenda Moore
Ashley Morrison
Laurie Morrow
Nathalie Mortine
Mount Sinai Medical Center
Mark and Barbara Murphy
Mickey Murray
James and Janis Musselman
Lynton and Elizabeth Musselman
Kerri Myatt
National Association of Theatre Owners
National Information Solutions Cooperative
James Nelson and Nan Martin
Robert and Jennifer Nicholson
Delia Nickolaus
Noah Nierenberg
Leila Noel
Hope Northrup and Ed Bonura
O-Ring Sales & Service, Inc
Joseph O'Connell
Lily O'Rielly
Leon and Sharon Oberlander
Anthony Oliva
Sofia Orive Garza
Vincent and Elizabeth Palagiano
Vincent and Ashley Palmisano
Michael and Nancy Parkes
Dwain and Rita Parrish
Bharat Patel
Danielle Peller
David and Ria Peters
Kevin and Anastasia Pike
Mary Ellen Pilkington
Jeremy Pipkin
John Poutasse and Mara Flynn
Daniel Price
Miguel Pujana
Paul and Shannon Quistorff
Kimberly Raab-Graham
Justin Racinowski
Jeremy Radisch
Ognjen Rakita
Alan and Bili Rakov
Ilana Horowitz Ratner
Regions Bank
Scott Reinker
Shannon Richter
Charles and Lana Rivers
Steve and Mary Roberds
John and Alice Robin
Patrick and Maureen Roche
Andrew Rooke
Diane Rose
Susan Royles
Al and Gayle Rushler
Tom Ruskin and Donna Vitale
Harriet Rust
Fabrice and Elisabeth Saadoun
William Sadowski
Abel Sanchez
Raman and Oonagh Sankar
Willie Sarver
Nathan Schaefer
Jeremy and Ann Schaefer
Dale and Colleen Schleich
Lynda Schweibish
Michael and Sonja Schwien
Don Sciorillo
Paul and Mary Seward
Marina Shindell
Shawn Short
Raymond and Susan Silhan
Bruce Simmons
Anne Skillin
Mike Smith and Patricia Hagins
Ronald and Dorothy Smith
Richard Smith
Betty Smith
Mary Smoot
Maria Soler
Timothy and Samantha Soule
Eric and Adelynn Specker
Hans and Joanne Specker
Barbara Spotts
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John and Janine Steenman
Michael and Alana Steinberg
Cynthia Sterling
Richard and Sharon Stewart
Zigurts Straus
Neal Suares
Kirsten Swain
Minhdung Ta
Vickie Tankersley
Tamara Tanner
Peter Tart
Dorothy Tebetts
The David Patti Memorial Foundation
The Medical Roundtable
The Mistler Charitable Trust
Paul Thomas
Nancy Thornton
James Tolley
Town of Mint Hill
Trident Watercraft Consulting LLC
Harvey Triebwasser
Andrew and Helen Triemer
James and Heather Trimm
Kelly Tufts
James and Cynthia Tuite
Alex and Kelli Tzouras
United Way of Greater Portland
United Way of San Diego County
University of California San Francisco
Tina Urv
Stephen and Norma Volz
Jennifer Waldron
John and Christine Walker
Joseph Walker
Jai Wall
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Erich Wasserman
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C.L. and Rachel Werner
Carol Whitmer
Carl and Sheila Wiezalis
Hayes Williams
Tracee Williams
Joan Williams
Scott Wilson
Alan and Kathy Windham
Amanda Woodford
Thomas and Eleanor Woods
Jesse and Julie Wright
John and Laurel Wynn
Robert Yaeggi
Judy Yoder
Elizabeth Yu
Maria Zak
Zebra Technologies Corporation

Major Gifts in Kind
(Value of $500 or more, as identified on received in-kind forms)

21GRAMS
Orny Adams
Jim and Lee Ann Addison
Babas Catering
Tom Bercu
Brag Properties LLC
Shane Brady
Bob’s Watches
Patricia Brontman
Mary Brucker
Buffalo Wild Wings
Caribou Coffee
Nathan Carlisle
Indira Challa
Charlies on Prior
Cindys Jumpers
Clippers
Mo Collins
April Cooper
Will and Kay Cooper
Ed Crofts
Cypress Design Studio & Framing LLC
Bobby Dadlani
Davanni’s
Delta Meat Market LLC
Derma Medical Spa
Jeffrey Doolittle
Dough Dough
The Dr. Oz Show
Du Nord Craft Spirits
Eileen’s Colossal Cookies
Fab City Toys
Kate Flannery
Friends of TS Alliance
Janie and Michael Frost
Eileen’s Colossal Cookies
Eric and Tricia Gerum
Louis and Tiffani Goff
Goldbar/Sweetwater Social
Erie Grand
Greenwich Biosciences
Jason Guillot
Hapi Art and Pattern LLC
Chris Hawkey
Christy Hobart and Henry Shapiro
John Henson
Rhett Hobart
Ann Hollowell
Lela Restaurant
Leonetti Confetti
Doug Loftus
The Loop Bar + Restaurant
The Mistler Charitable Trust
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Maria Zak
Zebra Technologies Corporation

Major Gifts in Kind
(Value of $500 or more, as identified on received in-kind forms)

21GRAMS
Orny Adams
Jim and Lee Ann Addison
Babas Catering
Tom Bercu
Brag Properties LLC
Shane Brady
Bob’s Watches
Patricia Brontman
Mary Brucker
Buffalo Wild Wings
Caribou Coffee
Nathan Carlisle
Indira Challa
Charlies on Prior
Cindys Jumpers
Clippers
Mo Collins
April Cooper
Will and Kay Cooper
Ed Crofts
Cypress Design Studio & Framing LLC
Bobby Dadlani
Davanni’s
Delta Meat Market LLC
Derma Medical Spa
Jeffrey Doolittle
Dough Dough
The Dr. Oz Show
Du Nord Craft Spirits
Eileen’s Colossal Cookies
Fab City Toys
Kate Flannery
Friends of TS Alliance
Janie and Michael Frost
Eileen’s Colossal Cookies
Eric and Tricia Gerum
Louis and Tiffani Goff
Goldbar/Sweetwater Social
Erie Grand
Greenwich Biosciences
Jason Guillot
Hapi Art and Pattern LLC
Chris Hawkey
Christy Hobart and Henry Shapiro
John Henson
Rhett Hobart
Ann Hollowell
Lela Restaurant
Leonetti Confetti
Doug Loftus
The Loop Bar + Restaurant


Endowment Fund

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

Advancement Society ($25,000 - $99,999)
Ken and Shonnie Johnson
Magdalena Lutsky
Philip and Marion Winsor

Century Society (10,000 - $24,999)
Andrea Hall and the late Keith Hall
The Maffei Family Charitable Fund
Robert and Joan Appleby Foundation

Enrichment Society ($5,000 - $9,999)
Michael and Millicent Augustine
Paul and Pam Waxlax

Investment Society ($500 - $4,999)
Anonymous
Gordon and Katherine Buntrock
Farrar Family Charitable Fund
Susan Franz
Doug and Sandra Hill
Linda Meints
Network for Good
Parsons Corporation
Walter and Sharon Smith
Laura Wilson-Brown

The Eternal Flame Society

When individuals and families inform the TS Alliance of a designated planned gift through a will or estate plan to the TS Alliance Endowment Fund or the TS Alliance, they become part of the Eternal Flame Society. If you or a loved one has designated the TS Alliance through a planned gift and are currently not listed on The Eternal Flame Society, please let us know so we can add you.

We are pleased to honor the following distinguished members of the Eternal Flame Society:

Harry Alcorn*  
Anonymous  
David Armijo  
Michael and Millicent Augustine  
Harold and Barnice* Belfer  
Jeffery and Gloria* Benham  
Matt Bolger  
Treasa Bolger-Dunlap  
Alice Bostrom  
Anthony Bruno*  
Scott and Jan Burton  
Marguerite Cleveland  
John and Katherine Conrad  
Will and Kay Cooper  
Richard and Reiko Donato  
Treasa Bolger-Dunlap  
Cindy Fowler  
Richard and Rosemarie Gammache*  
Jeffrey Ross Goldstein  
David and Laura Grimes  
Robert W. and Kathryn A. Groves  
Shannon Hackley  
Keith Hall*  
Jeffrey and Lisa Hargreaves  
Clara Harwell  
Anne Heilman*  
James and Amy Hobbs  
Jaye Isham  
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  
Magdalena Lutskey  
James Lynch  
Glennwood Dale Maier*  
Robert McBride*  
Donna McGaha  
David and Jan Mintz  
William Morris*  
Maria Sharon Munoz-Chargoy  
Ottillit Nadel*  
Jean Panther*  
David and Penney Parkes  
Jeffrey and Bonnie Rickert  
Pat and Jennifer Rolfe  
Kari Luther Rosbeck  
Dave and Nancy Scott  
Robert and Mary Ellen Scott  
Joan Smardan*  
Fred and Ilse Smith  
John and Janine Steenman  
Mark Stromberger*  
Rob Thurston  
Kathy Trapp  
Alma A. Tutrone*  
Jim and Nancy Weir  
Philip and Marion Winsor  
Barbara Witten and William Bradley  
Frieda Zimmerman*

*Deceased

Endowment Named Funds

On 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  
Augustine Family Fund  
John A. Conrad Jr. Memorial Fund  
Carrie Cooper Memorial Fund  
Matthew J. Fox Fund  
Lauren E. Krinsky Fund  
The Lawler Fund  
Cade Scott Fund  
Jeb Ward Legacy Fund

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

Operating Board of Directors

Beth Dean, Chair (through June 2019)
Grayslake, IL

Chris Russell, Chair (starting July 2019 and Vice Chair through June 2019)
Coppell, TX

Cassandra Carroll, Vice Chair (starting July 2019)
Oakland, CA

Darren Miles, Treasurer
Edina, MN

Tara Zimmerman, Secretary
Reno, NV

Timothy Dills, Immediate Past Chair
Great Falls, VA

Matt Bolger
Lansing, MI

John Bissler, MD
Memphis, TN

Sara Chieffo
Washington, DC

David M. Coit
Cape Elizabeth, ME

Margaret Cox
Vestavia, AL

Peter Crino, MD, PhD
Mooresstown, NJ

Andrew Duffy, International Partner Member
Toronto, ON

Bonnie Hogue Duffy
Chevy Chase, MD

Steven Goldstein, CPA, FFS
Westport, CT

Rob Grandia
Riverside, CA

Tom Gwinn
Parkland, FL

Dana Holinka
Northglenn, CO

Heather Lens
Westville, OK

Darcy Krueger, MD, PhD
Mason, OH

Jim Maginn
Manhattan Beach, CA

Brendan Manning, PhD
Boston, MA

Diane McSwain (beginning December 2019)
Crystal Lake, IL

Adolfo Orive (through June 2019)
Dallas, TX

Mustafa Sahin, MD, PhD
Needham, MA

Sean Shillinger
Adamstown, MD

Judy Shoulak (beginning July 2019)
Corcoran, MN

Matthew Simonian
Humble, TX

Endowment Fund Board of Directors

Doug Loftus, Chair
Cincinnati, OH

Michael Augustine, Secretary
San Gabriel, CA

Hal Tearse, Treasurer
Independence, MN

James Achterhof
Palos Park, IL

Marion Adams
Mobile, AL

Mark Carroll
Saratoga, CA

William Joseph
State College, PA

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Chairman
WNC & Associates

Julianne Moore, Honorary Chair
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Co-Director
University of Alabama TSC Clinic

Rita DiDomenico
Vice President
MUFG Bank

Orrin Devinsky, MD
Director
NYU Epilepsy Center

Rusty Field
CEO
Upsher-Smith Laboratories, LLC

David Fitzmaurice
Director of Business Development
Sealed Air

Julian S. Gangolli
Independent Advisor

Gail Gerchon

Ken Kocher
Former President
LIDS Sports Group

Laura S. Lubbers, PhD
Chief Scientific Officer
Citizens United for Research in Epilepsy (CURE)

Alan Marshall
Director, Customer Engagement
Greenwich Biosciences

Ted Mastroianni

David Michaels
Senior Vice President
Wells Fargo Bank, NA

Darren Miles
VP International Operations – Dairy Queen

Mary Jane Mudd

Sean C. Nolan
Chairman
Encoded Therapeutics, Inc.

Rebecca Anhang Price, PhD

Henry Shapiro
Chairman
MarketCast Group

John Thorpe Richards, Jr.
Bogorad and Richards, PLLC

Marc Shapses
Executive Managing Director
Savills Studley

Staff

Kari Luther Rosbeck
President & Chief Executive Officer

Richard Gollub, CPA
Chief Financial Officer

Steven Roberds, PhD
Chief Scientific Officer

Dean Aguiar, PhD
Director, Preclinical Research

Taylor Bates
Development Associate

Dany Brunner, PhD
Senior Scientific Advisor/Preclinical Research Leader
April Cooper  
Director, Community Programs

Zoe Fuchs  
Science Project Coordinator

Ernebet G/Micheal  
Senior Accountant

Dena Hook  
Vice President, Support Services

Jaye Isham  
Vice President, Communications Strategy

Daniel Klein  
Director, Digital Platforms

Justin Martucci  
Development Services Manager

Shelly Meitzler  
Regional Program Manager, East

Lisa Moss  
Senior Director, Donor Relations

Jo Anne Nakagawa  
Director, Clinical Projects & TSC Clinic Liaison

Gabrielle Rushing, PhD  
Associate Director, Research

Gail Saunders  
Senior Associate Director, Community Programs

Julie Scroggins  
Regional Program Manager, West

Katie Smith  
Director, Government & Global Affairs

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TS Alliance of Alabama  
Margaret Cox, Chair

TS Alliance of Alaska  
Rebecca Racenet, Chair  
Erica Chilla, Vice Chair

TS Alliance of Arizona  
Debora Moritz, Chair

TS Alliance of Arkansas  

TS Alliance of Connecticut  
Jennifer Waldron, Chair

TS Alliance of Dallas/Fort Worth  
Leslie Russell, Chair  
Lauren Sims, Vice Chair

TS Alliance of Delaware/Lehigh Valley  
Liz Saadoun, Chair  
Devon McCollum, Vice Chair

TS Alliance of the Delta Region  
Heather Harden, Chair

TS Alliance of Florida  
Amy Hightower, Co-Chair  
Vanessa Vasquez, Co-Chair

TS Alliance of Georgia  
Wendi Scheck, Chair

TS Alliance of Greater Chicago  
Geri Greenberg, Chair

TS Alliance of Greater Kansas City  
Amy Dublinske, Chair

TS Alliance of Hawaii  
Trisha Kam, Chair

TS Alliance of the Heartland  

TS Alliance of Houston  
Heather Little, Chair

TS Alliance of Indiana  
Laura Marlin, Chair

TS Alliance of the Intermountain West  
Kelli Sutherland, Chair

TS Alliance of Kentucky/West Virginia  
Tammy Kouns, Co-Chair  
Melissa Pennington, Co-Chair

TS Alliance of Maryland  
Lauren Shillinger, Chair

TS Alliance of Michigan  
Carly Kaye, Chair

TS Alliance of Nevada  
Kathleen Kingston, Co-Chair  
Tara Zimmerman, Co-Chair

TS Alliance of New England  

TS Alliance of New York/New Jersey  
Laura Marks, Co-Chair  
Rhiannon Schade, Co-Chair

TS Alliance of North Carolina  
Karen Johnston, Chair  
Virginia Musselman, Vice Chair

TS Alliance of Northern California  
Lilian Ansari, Co-Chair  
Jennifer Yeamans, Co-Chair

TS Alliance of Ohio  
Rebecca and Donnie Bilbrey, Co-Chairs

TS Alliance of Oklahoma  
Heather Lens, Chair

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Gloria Triebenbach, Chair  
Debbie Rothweiler, Vice Chair

TS Alliance of the Rocky Mountain Region  
Dana Holinka, Chair

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Amy Bredeacon, Chair

TS Alliance of Southern California  
Tara Palage, Chair  
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TS Alliance of St. Louis/Southern Illinois  
Jackie Grenia, Chair

TS Alliance of Tennessee  

TS Alliance of the Upper Midwest  
Alanna Spotts, Chair

TS Alliance of Washington, DC/Virginia  
Kathi Dills, Chair  
Adrienne Cohen, Vice Chair

TS Alliance of Western Pennsylvania  
Kelsey Hudson, Chair

TS Alliance of Wisconsin  
Kristin DeGueme, Chair

Adult Regional Coordinators

Rob and Shannon Grandia

Region 2: California, Arizona, Nevada, New Mexico, Utah,  
Rob and Shannon Grandia

Region 3: Colorado, Nebraska, South Dakota, North Dakota, Iowa, Minnesota,  
Wisconsin  
Danielle Clark

Region 4: Texas, Oklahoma, Kansas, Missouri, Arkansas, Louisiana  
Jake Irby

Region 5: Illinois, Michigan, Indiana, Ohio, Pennsylvania  
Brooke Simsa

Region 6: Tennessee, Kentucky, Georgia, Alabama, Mississippi, Florida  
Mark Martin

Region 7: Connecticut, Vermont, Maine, Rhode Island, New Hampshire, New York,  
New Jersey, Massachusetts  
Scott Moskowitz

Region 8: Delaware, Virginia, West Virginia, Maryland, North Carolina, South Carolina, Washington DC  
Kathy Henkel

To view members of our Professional Advisory Board and International Scientific Advisory Board, visit tsalliance.org.
National Tuberous Sclerosis Association & Affiliate
Consolidated Statements of Financial Position
As of December 31, 2019 2018

<table>
<thead>
<tr>
<th>Assets</th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$ 1,045,437</td>
<td>$ 1,304,824</td>
</tr>
<tr>
<td>Investments</td>
<td>6,990,118</td>
<td>6,209,943</td>
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<tr>
<td>Accounts receivable</td>
<td>10,243</td>
<td>158,782</td>
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<tr>
<td>Promises to give</td>
<td>2,033,626</td>
<td>1,249,706</td>
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<tr>
<td>Prepaid expenses and other assets</td>
<td>262,620</td>
<td>263,093</td>
</tr>
<tr>
<td>Property and equipment</td>
<td>80,221</td>
<td>169,346</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td>$ 10,422,265</td>
<td>$ 9,355,694</td>
</tr>
</tbody>
</table>

| Liabilities and Net Assets                                          |             |             |
| Liabilities                                                          |             |             |
| Accounts payable and accrued expenses                                | $ 333,196   | $ 196,626   |
| Accrued compensation                                                 | 200,306     | 255,560     |
| Deferred revenue                                                     | 54,700      | 114,499     |
| Deferred rent and lease incentive                                    | 7,176       | 35,378      |
| Gift annuity obligations                                             | 70,300      | 73,943      |
| **Total liabilities**                                                | 665,678     | 676,006     |

| Net assets                                                           |             |             |
| Without donor restrictions                                          |             |             |
| Undesignated                                                        | (214,362)   | 235,336     |
| Board-designated                                                    | 5,936,709   | 4,789,541   |
| **Total without donor restrictions**                                 | 5,722,347   | 5,024,877   |

| With donor restrictions                                             |             |             |
| **Total net assets**                                                | 9,756,587   | 8,679,688   |

| Total liabilities and net assets                                    | $ 10,422,265| $ 9,355,694 |

The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year’s auditors completed their 2019 audit and submitted an unmodified opinion to the TS Alliance Board of Directors. The complete audited financials are on file with the TS Alliance or available on our website. To obtain a copy, please call (800) 225-6872 or download at www.tsalliance.org. This 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 generally accepted accounting principles in the United States. Supporting services reflected in the consolidated statement of activities include services for both the TS Alliance and the TS Alliance Endowment Fund. The Endowment Fund may experience gains or losses on its investments. In 2019 there was a net gain, contributing to the total change in net assets on a consolidated basis for the year. On a stand-alone basis, excluding investment gains from the TS Alliance Endowment Fund, the change in net assets of the TS Alliance was a positive $355,028 for the year.
## National Tuberous Sclerosis Association & Affiliate

### Consolidated Statements of Activities

#### Revenue and Support

<table>
<thead>
<tr>
<th></th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>2019 Total</th>
<th>2018 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Events</td>
<td>$2,318,140</td>
<td>$388,454</td>
<td>$2,706,594</td>
<td>$1,660,285</td>
</tr>
<tr>
<td>Cost of direct benefits to donors</td>
<td>(285,156)</td>
<td>(285,156)</td>
<td>(285,156)</td>
<td>(141,001)</td>
</tr>
<tr>
<td>Special events, net</td>
<td>2,032,984</td>
<td>388,454</td>
<td>2,421,438</td>
<td>1,519,284</td>
</tr>
<tr>
<td>Contributions</td>
<td>725,432</td>
<td>2,296,500</td>
<td>3,021,932</td>
<td>2,463,731</td>
</tr>
<tr>
<td>Contracts</td>
<td>247,384</td>
<td>247,384</td>
<td>1,126,302</td>
<td></td>
</tr>
<tr>
<td>Conferences</td>
<td>174,381</td>
<td></td>
<td>743,427</td>
<td></td>
</tr>
<tr>
<td>Interest and dividends</td>
<td>168,000</td>
<td>23,528</td>
<td>191,528</td>
<td>142,146</td>
</tr>
<tr>
<td>Memorials and honoraria</td>
<td>101,864</td>
<td>386</td>
<td>102,250</td>
<td>77,552</td>
</tr>
<tr>
<td>Federated funding</td>
<td>45,664</td>
<td></td>
<td>45,664</td>
<td>44,107</td>
</tr>
<tr>
<td>Other income</td>
<td>714</td>
<td></td>
<td>714</td>
<td>15,118</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total revenue and support</td>
<td>$3,496,423</td>
<td>2,708,868</td>
<td>6,205,291</td>
<td>6,131,667</td>
</tr>
</tbody>
</table>

#### Expenses

<table>
<thead>
<tr>
<th>Program services</th>
<th>2019 Total</th>
<th>2018 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>2,590,463</td>
<td>2,463,285</td>
</tr>
<tr>
<td>Family services</td>
<td>929,277</td>
<td>770,313</td>
</tr>
<tr>
<td>Public health education</td>
<td>439,992</td>
<td>322,973</td>
</tr>
<tr>
<td>Government relations</td>
<td>165,225</td>
<td>149,340</td>
</tr>
<tr>
<td>Professional education</td>
<td>92,979</td>
<td>128,621</td>
</tr>
<tr>
<td>World TSC Conference</td>
<td>-</td>
<td>767,575</td>
</tr>
<tr>
<td></td>
<td>4,217,936</td>
<td>4,602,107</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supporting services</th>
<th>2019 Total</th>
<th>2018 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising</td>
<td>1,135,609</td>
<td>781,502</td>
</tr>
<tr>
<td>Management and general</td>
<td>542,410</td>
<td>528,655</td>
</tr>
<tr>
<td></td>
<td>1,678,019</td>
<td>1,310,157</td>
</tr>
</tbody>
</table>

| Total expenses           | 5,895,955  | 5,912,264  |

| Change in net assets from operations | 309,336 | 219,403 |
| Net investment income (loss)         | 767,563 | (596,495) |
| Net assets, Beginning of Year        | 8,679,688 | 9,056,780 |

<table>
<thead>
<tr>
<th>Net assets, End of Year</th>
<th>2019 Total</th>
<th>2018 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>$5,722,347</td>
<td>$9,756,587</td>
<td>$8,679,688</td>
</tr>
<tr>
<td>$4,034,240</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
WE’LL GIVE EVERYTHING. BUT UP.