

inspiration

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innovation



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2019
45
YEARS OF
CHANGING
THE FUTURE

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YEARS OF
CHANGING
THE FUTURE
Fibrous Sclerosis Alliance
TSC Champion
Elizabeth Trinkle, MD, PhD
In appreciation for your unwavering
dedication, passion and commitment
to those living with rare and complex

inspiration innovation hope

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:

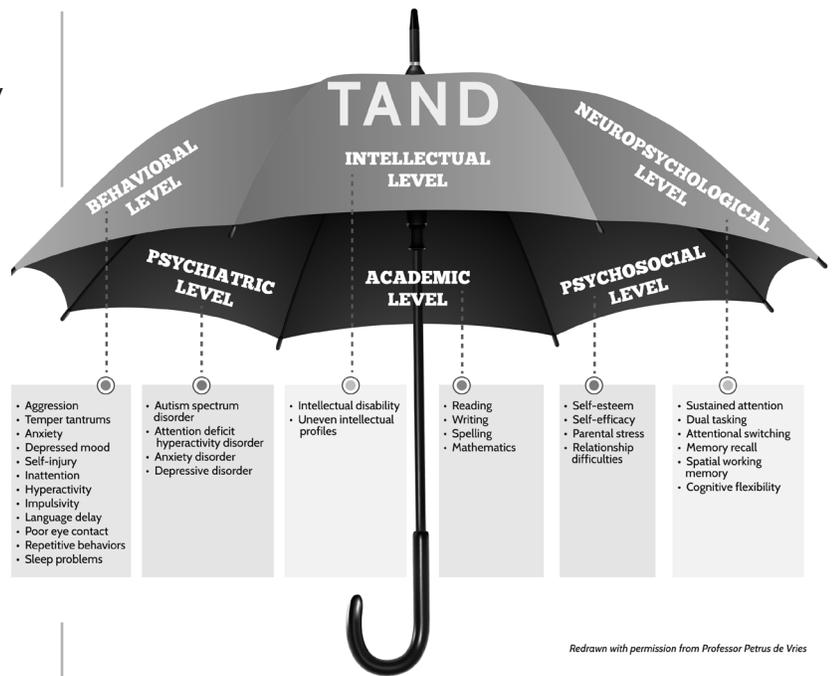
- Continued to make history with the PREVeNT trial – Preventing epilepsy using vigabatrin in infants with tuberous sclerosis complex, the first preventative trial for any form of epilepsy in the US, which has expanded the consortium to 13 sites.
- Received more than \$35 million cumulatively in competitive 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 (TSCRCP) at the Department of Defense's Congressionally Directed Medical Research Program, which resulted in a \$6 million appropriation bringing the cumulative TSCRCP 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.

Together in 2019, they:

- Facilitated 32,932 peer-to-peer support interactions.
- Recruited 60 new volunteers for the Support Services program and 117 new volunteers overall.
- Provided 1,429 training hours to our volunteers.
- Attended 128 school meetings to support families in attaining educational services for their children.
- Helped develop three new publications: *Early Childhood in Education*, *TSC-Associated Neuropsychiatric Disorders (TAND) and Education*, and *The Body of Sample Letters: Everything You Need to Build a Paper Trail for Your Child's Special Education Career*.
- Collaborated with 14 advocacy organizations in order to enhance support services to the TSC community.

Additionally, a network of 37 volunteer branches called Community Alliances provide localized help, social gatherings and fundraising activities across the country. Our **Community Programs** team supports these Community Alliances in two regions: East and West. A Community Programs Manager is assigned to each region to manage the day-to-day activities within their communities. This team also helps coordinate and plan Step Forward to Cure TSC and other fundraisers as well as educational programs. In 2019:

- 503 people from 29 states attended one of five regional educational conferences, co-hosted by the TS Alliance and The LAM Foundation.
- 1,405 people attended at Community Alliance meetings with 31% held virtually.
- 97 people served in Community Alliance leadership positions.

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.

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 \$2,421,4239, 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.



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 ground-breaking *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.



- The much-deserved Leadership in Courage Award was presented to the Szilagyi Family and a TSC Champion award to Dr. Joyce Wu of UCLA.
- Special thanks to the generous event sponsors: Mallinckrodt Pharmaceuticals, MarketCast Group, The Szilagyi Family, *Variety*, C&C Market Research, CVS Health, The Dills Family, Greenwich Biosciences, Horizon Therapeutics, The Maginn Family, Novartis, R&R Electric, Saks Fifth Avenue, WNC & Associates, UCB, eWorks International, Lauren & Richard Packard, Neurelis and Upsher-Smith Laboratories, LLC.
- 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 Tearse-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, Santori 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.
- Special thanks to the generous event sponsors: The Engles Family, Drs. Bonnie and Jonathan Rothberg and Family, Cindy Engles Advisory Fund, Greenwich Biosciences, Pat and Pete Schenkel, The Tlappek Fund, Capitol Peak Partners, Joe and Beverly Hardin, WNC & Associates, Greg and Ashley Arnold, Chris and Joy Dinsdale, Friends of Lucy Engles, Natalie, Brooke, Bunny and Harold Ginsburg, Stephen Green, The Maginn Family, Laurence and Anthony Magro, Novartis, OPL Charities, Friends of Eric Parkes, Leslie and Chris Russell, Marla and Marc Shapses, Engage Therapeutics, Inc., Friends of John Fitzmaurice, Keith and Dianna Flanigan, Horizon Therapeutics, Doug and Linda Loftus, Lundbeck LLC, Mallinckrodt, Ovid Therapeutics, Rebecca Anhang Price and Matthew Price, The Theodoredis Family, Tolleson Family Foundation, Cavarocchi Ruscio Dennis Associates, Julie Blum and Greg Linsin, Ray Chan, Tim and Kathi Dills, FACES,

Dr. Michael and Janie Frost, Family of Keith Hall, Hobart Shapiro Family, The Johnson Family, Lawler Family / Glenn N. Howatt Foundation, Massachusetts General Hospital, Abe and Celia Mastbaum, Ted and Peggy Mastroianni, Blaine and Anne McPeak, Carol Brown Michael, Nobelpharma, Muriel Pattis, Psychogenics, TheBloc Partners, UCB Inc., Upsher-Smith Laboratories, LLC, Mickey Williams, Amneal Pharmaceuticals, Inc., Bcureful, Chemistry RX, Child Neurology Foundation, Hollingsworth LLP, Inspire, William and Deborah Joseph, Jeremy and Robin Krantz, LGS Foundation, Shaun and Chantel Mara and Seizure Tracker.



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 Suresh 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

Step Forward to Cure TSC® walks took place in 31 cities across the United States, collectively raising \$902,981.

- The walks are both fundraisers and community gatherings that bring the TSC community together to connect and share experiences.
- Special thanks to the generous walk sponsors: Novartis, Aquestive, Greenwich Biosciences, Upsher-Smith Laboratories, LLC, LivaNova and MassMutual.
- **Step Forward to Cure TSC Walks Raising More than \$10,000**
 - Arizona - Debora Moritz and Terri Butler
 - Carolinas - Heather Morris
 - Chicago - Jacqueline Wolak
 - Cincinnati - Nathalie Mortine
 - Connecticut - Jennifer Waldron
 - Dallas/Ft Worth - Sylvia Sparby and Cassie Jimenez
 - Denver - Aida and Abel Lucero
 - Houston - Rachael Jackson
 - Indiana - Pat Schmutte
 - Metro DC - Lauren Shillinger and Michal Cepler
 - Nashville TN - Sandy Ewing
 - New England - Stacie Verrill
 - New York (Long Island) - Carol Ann White and Lori DiStefano
 - Northern California - Bridgett Britt
 - Oklahoma - Heather Lens and Kirsten Swain
 - Pennsylvania East - Jack and Fran Lyons
 - Seattle (Pacific NW) - Gloria Triebenbach and Adrienne Wasserman
 - Southern California - Shannon and Rob Grandia
 - Tampa Bay - Amy Hightower and Jamie Jodoin



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**

Chairman's Circle (\$100,000 and Above)

Aeovian Pharmaceuticals
Bcureful
David M. Coit
Christopher and Joy Dinsdale
Engles Family Foundation on Behalf of
Engles Collaborative Research Fund
Facebook Community Donations
Gerry and Bill Cowlin Foundation
Greenwich Biosciences
James and Andrea Maginn
Novartis Pharmaceuticals Corporation
OPL Charities
Jonathan Rothberg and Bonnie Gould
Rothberg, Rothberg Institute for
Childhood Diseases
Tuberous Sclerosis Alliance Endowment
Fund
UCB, Inc.
Lorne and Heidi Waxlax
William Watts

**Benefactor
(\$50,000 - \$99,999)**
Mallinckrodt Pharmaceuticals
Upsher-Smith Laboratories, LLC

**Sponsor
(\$20,000 - \$49,999)**
Aquestive Therapeutics
The Friends of Lucy Engles
Cindy Engles Advisory Fund
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Haag Family Foundation
Judith Henke
Ingram, Yuzek, Gainen, Carroll,
Bertolotti, LLP
LivaNova
MassMutual Financial Group
Julianne Moore and Bart Freundlich
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.
Irene Rothberg
Pat and Pete Schenkel
Judy and James Shoulak, The Shoulak
Family Fund
The Tlapek Fund
Wong Family Foundation

**Protector
(\$10,000 - \$19,999)**
Sandeep Alva
Greg and Ashley Arnold
Capitol Peak Partners
Ray Chan
Craig and Cindy Cunningham, C&C
Market Research
Stephen Green
Joe Hardin
Horizon Therapeutics
Robert Kamenski
David and Cathy Krinsky
Mary Ann Lamb
Doug and Linda Loftus
Louis Berkowitz Family Foundation
Laurence and Anthony Magro
MarketCast Group
Alan Marshall
James and Cindy Megginson
Nancy and David Michaels
Ned Neely
John and Carol Nicholson
Pharmaceutical Research and
Manufacturers of America
Allan and Carla Price
Christopher and Kari Luther Rosbeck
Chris and Leslie Russell
Haydn and Jillian Scarr
Marc and Marla Shapses
Annie Szilagyi
John Waterbury
Karen White and Julie Geissman

**Defender
(\$5,000 - \$9,999)**
Earl Abramson and Sheila Schlaggar
Naveera Ali
Amazon Smile Foundation
Rebecca Anhang Price and Matthew Price
Anonymous
Chad and Alicia Austin
Jeff Avansino
Bob Bouchard
Jim and Margaret Burt
Mark and Kelly Carroll
Rebecca and George Carroll
Charles & Mildred Schnurmacher
Foundation, Inc.
Jennifer and Will Cooper, Jr.
Ed and Dori Crofts
CVS Health
Cornelius and Linda Denharder
Tim and Kathi Dills
Doe Family Foundation
Engage Therapeutics, Inc.
Keith and Dianna Flanigan
Ed Fugger
Goldman, Sachs & Co. Matching Gift
Program
Michelle Goolsby
Lynn and Kelly Haecker
Andrea Hall
Dan and Tricia Hase
Brenda Henry
Amy Hightower
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James and Amy Hobbs
Bill and Sheri Hyland

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William and Debra Joseph
Lundbeck Pharmaceuticals, Inc.
Stuart and Carina Marton
Theodore and Peggy Mastroianni
Mischel Family Charitable Fund
Jon and Patricia Myers
Ovid Therapeutics
Pakpour Consulting Group
Clark and Temple Poche
Proverbs 3:9 Foundation
Psychogenics, Inc.
R & R Electric
SAKS, Inc.
Jacob Shoup
David Smith
Stanford Children's Hospital
Steve and Sarah Terrell
The Theodoredis Family
Tolleson Family Foundation
Tuberous Sclerosis Alliance of Israel
Tuberous Sclerosis Alliance of Mexico
Tuberous Sclerosis Canada Sclerose
Tubereuse
Variety - The Children's Charity
Velocity Ventures Group, LLC
Cliff and Deborah White, Cliff and
Deborah White Family Foundation
Winifred M. Gordon Foundation
Kevin and Sarah Wright
Saul Wyner
Yost Charitable Fund
Thomas Zanetich

**Advocate
(\$1,000 - \$4,999)**
21GRAMS
A. Sturm & Sons Foundation Inc.
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Accurus Aerospace Tulsa, LLC
Marion and Laura Adams
Jim and Lee Ann Addison
John and Janet Addison
Steve and Lynn Aguiar
Ariff and Laila Mobh Alidina
Scott Almeida
Paul and Patricia Anderson
Anonymous
Arborscapes, LLC
Helen Arlinghaus
Margaret Arnold
Ascension Ministry Service
Michael and Milly Augustine
AWH Partners
Adrian Banner
James and Betteanne Barash
Barmmer Family Charitable Gift Fund
Jeff Barnes
Lucy Hahn, Bayonne Glass Co.
BDB Company
Thomas and Elizabeth Beattie
Ryan and Andrea Beebe
Jay Bennett
Berkshire Heights Fire Co.
Biotechnology Innovation Organization
Greg Linsin and Julie Blum
William Bowman
Breslow Family Foundation
Bright Funds Foundation
Bridget and Jeremy Britt

Teresa Brockwell
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The TS Alliance strives to correctly recognize all our 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 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.

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 (\$25,000 - \$99,999)
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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:

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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

Community Alliances

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

TS Alliance of the Pacific Northwest
Gloria Triebenbach, Chair
Debbie Rothweiler, Vice Chair

TS Alliance of the Rocky Mountain Region
Dana Holinka, Chair

TS Alliance of South Carolina
Amy Bredeson, Chair

TS Alliance of Southern California
Tara Palage, Chair
Leslie Holmes, Vice Chair

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

Region 1: Washington, Oregon, Idaho,
Montana, Wyoming, Alaska
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.*

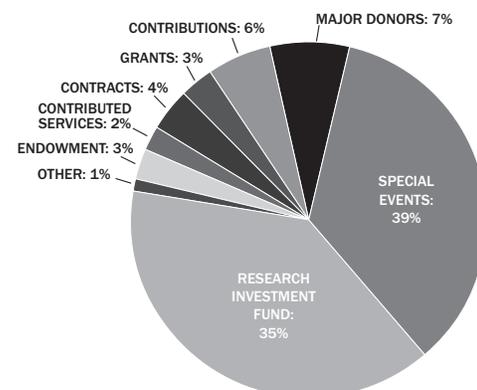
National Tuberosclerosis Association & Affiliate

Consolidated Statements of Financial Position

As of December 31,	2019	2018
Assets		
Cash and cash equivalents	\$ 1,045,437	\$ 1,304,824
Investments	6,990,118	6,209,943
Accounts receivable	10,243	158,782
Promises to give	2,033,626	1,249,706
Prepaid expenses and other assets	262,620	263,093
Property and equipment	80,221	169,346
Total assets	\$ 10,422,265	\$ 9,355,694
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	4,034,240	3,654,811
Total net assets	9,756,587	8,679,688
Total liabilities and net assets	\$ 10,422,265	\$ 9,355,694

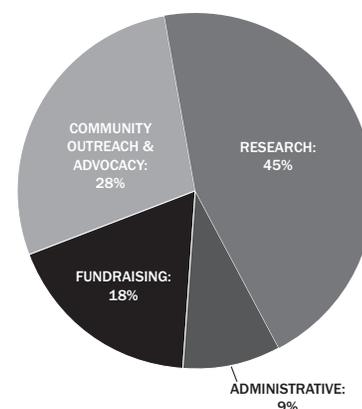
The TS Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The current year's auditors completed their 2019 audit and submitted an unmodified opinion to the TS Alliance Board of Directors. The complete audited financials are on file with the 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.

TS Alliance Revenue Sources 2019



NOTE: These are the stand-alone revenues of the TS Alliance.

TS Alliance Expenses 2019



NOTE: These are the stand-alone expenses of the TS Alliance.

National Tuberos Sclerosis Association & Affiliate

Consolidated Statements of Activities

	Without Donor Restrictions	With Donor Restrictions	2019 Total	2018 Total
Revenue and Support				
Special Events	\$ 2,318,140	\$ 388,454	\$ 2,706,594	\$ 1,660,285
Cost of direct benefits to donors	(285,156)		(285,156)	(141,001)
Special events, net	2,032,984	388,454	2,421,438	1,519,284
Contributions	725,432	2,296,500	3,021,932	2,463,731
Contracts	247,384		247,384	1,126,302
Conferences	174,381		174,381	743,427
Interest and dividends	168,000	23,528	191,528	142,146
Memorials and honoraria	101,864	386	102,250	77,552
Federated funding	45,664		45,664	44,107
Other income	714		714	15,118
	3,496,423	2,708,868	6,205,291	6,131,667
Net assets released from restrictions	2,443,437	(2,443,437)	-	-
Total revenue and support	5,939,860	265,431	6,205,291	6,131,667
Expenses				
Program services				
Research	2,590,463		2,590,463	2,463,285
Family services	929,277		929,277	770,313
Public health education	439,992		439,992	322,973
Government relations	165,225		165,225	149,340
Professional education	92,979		92,979	128,621
World TSC Conference	-		-	767,575
Total program services	4,217,936		4,217,936	4,602,107
Supporting services				
Fundraising	1,135,609		1,135,609	781,502
Management and general	542,410		542,410	528,655
Total supporting services	1,678,019	-	1,678,019	1,310,157
Total expenses	5,895,955	-	5,895,955	5,912,264
Change in net assets from operations	43,905	265,431	309,336	219,403
Net investment income (loss)	653,565	113,998	767,563	(596,495)
Change in net assets	697,470	379,429	1,076,899	(377,092)
Net assets, Beginning of Year	5,024,877	3,654,811	8,679,688	9,056,780
Net assets, End of Year	\$ 5,722,347	\$ 4,034,240	\$ 9,756,587	\$ 8,679,688

WE'LL GIVE EVERYTHING. BUT UP.



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