A transformative year of generosity
A transformative year of generosity
2021 marked the most successful year in the 47-year history of our organization. It was a year of transformative, foundational change, epitomized in the evolution of our name to the TSC Alliance® and reflected in every facet of what we do. Here are just a few examples of how this change manifested across our organization:

- **We reimagined how we accelerate research** by investing more in researchers than ever before, testing more potential treatments to lay the foundation for future clinical trials and incorporating cutting-edge science to help us better understand the variability and progression of tuberous sclerosis complex (TSC).

- **We reshaped how we educate and mobilize our constituents** to meet people where they are, empowering more community members to advocate for federally funded TSC research, connect and learn from leading TSC researchers and clinicians and participate virtually in TSC Alliance events from anywhere in the world.

- **We redefined how we provide support** through updating guidelines and standards to ensure the highest quality of care for those affected, developing new tools to provide resources for every stage of life and recommitting to reaching more people with TSC, including those from underrepresented groups.

What makes these feats even more impressive is the backdrop in which they took place. Facing another year impacted by the COVID-19 pandemic, we built upon lessons learned from the year before and continued to find new ways to innovate, collaborate and inspire. And at every turn our success was spurred by the overwhelming support of our community of volunteers, researchers, clinicians, donors and partners.

Our challenge now is to not rest on the laurels of our success, but to carry this momentum forward and continue to innovate and transform to meet the changing needs of our community, so we can realize our vision of a world where everyone affected by TSC can live their fullest lives.

This 2021 Annual Report provides additional information about these and other accomplishments, overviews of our programs and services, fundraising successes, donor acknowledgements and much more.

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**About tuberous sclerosis complex**

Tuberous sclerosis complex (TSC) is a rare genetic disease that affects people at all stages of life. TSC causes tumors to grow in different organs and can impair their function, primarily the brain, heart, kidneys, skin, eyes and lungs. TSC is the leading genetic cause of epilepsy, including infantile spasms. A strong correlation also exists between TSC and autism—an estimated 40-50% of individuals with TSC have autism spectrum disorder. Every individual’s experience with TSC is different—many live independently while others require complex care.

Too often, TSC goes undiagnosed. But we know at least two babies born each day in the United States will have it. Nearly one million people worldwide are estimated to be living with TSC, with approximately 50,000 in the United States. The TSC Alliance helps connect them.

**About the TSC Alliance**

The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with TSC. We drive research, improve quality care, increase access and advocate for all affected by the disease. The TSC community is our strongest ally. The collaboration of individuals and families, along with the partnership of other organizations, fuels our work to ensure people navigating TSC have support—and hope—every step of the way. Join us at tscalliance.org or contact us at info@tscalliance.org.
Research

The TSC Alliance ensures TSC researchers have the data and funds they need to discover breakthroughs. Our Science and Medical Department stimulates and supports basic, translational and clinical research on the various manifestations of tuberous sclerosis complex to further the development of clinical therapies and, ultimately, a cure for TSC. The department builds and fosters collaborations between basic and clinical researchers by collecting and distributing TSC natural history data and biosamples, through collaborative preclinical and clinical research programs and by hosting biennial International TSC Research Conferences.

In 2021, the TSC Alliance invested more in TSC research than ever before: $3.9 million. Since 1984, the TSC Alliance has spent $31 million on innovative TSC research through our grants and contracts funding mechanisms.

"I sincerely thank the TSC Alliance for supporting and trusting my TSC research project as it’s not easy to describe how important this funding has been for my professional path. Thanks to you I became aware of the importance of TSC pathology, and this really pushed me to give my best for this important research."

Ilaria Barone, PhD, Postdoctoral Research Fellow, Boston Children's Hospital

Implemented in 2006, the TSC Natural History Database captures clinical data to document the impact of the disease on a person's health over his or her lifetime. As of December 2021, 2,357 people with TSC were enrolled in the project from among 18 U.S.-based sites and through the TSC Alliance.

Building upon the Natural History Database, the TSC Biosample Repository will impact research over the next 10 years or more. High-quality biosamples—such as blood, DNA and tissues linked to detailed clinical data—are critical for researchers to understand why TSC is so different from person to person. As of December 31, 2021, the TSC Biosample Repository has acquired 2,000 biosamples. The organization continues to grow the Biosample Repository by collecting blood samples annually from participants who volunteer to do so, enabling researchers to study changes in proteins and other molecules in the blood over time; adding additional TSC Clinics as participating Biosample Repository collection sites; and collecting blood using mobile phlebotomy, enabling people to donate samples regardless of where they live in the United States and whether they are seen at a TSC Clinic. In 2021, portions of 456 of these samples were shared with 13 distinct researchers and since inception, 1,290 samples have been distributed to 34 different researchers for 39 distinct projects to further scientific advances.

In 2021, the TSC Alliance also completed a Whole-Genome Sequencing (WGS) pilot study using DNA from blood samples in our Biosample Repository to demonstrate the feasibility of this approach. The TSC Alliance submitted 20 DNA samples that had not been previously analyzed to the Translational Genomics Research Institute for WGS. Results confirmed disease-causing variants in 13 of 20 samples while 6 were newly discovered as likely disease-causing variants and demonstrated feasibility of WGS to deliver valuable information to both patients and researchers.

In December 2021, the TSC Alliance added the TSC Self-Report Portal to the TSC Natural History Database. This new portal will permit the collection of patient-reported outcomes on how TSC affects individuals and families, which will complement medical data in the Natural History Database. One of the most impactful aspects of TSC on the quality of life for people living with TSC is TSC-Associated Neuropsychiatric Disorders (TAND). Therefore, the TSC Alliance's first use of the portal is through collaboration with the TANDem project (Empowering Families through Technology: a mobile-health project to reduce the TAND identification and treatment gap) by allowing the community to complete the self-quantified TAND checklist (TAND-SQ). The TSC Alliance is helping the TANDem project team validate the utility of the TAND-SQ for future use in a mobile application.

The TSC Alliance launched the TSC Preclinical Consortium in 2015 to help advance more drug candidates into clinical testing. Collaborating with the TSC community, the consortium has identified and implemented robust and reproducible cell and animal models for TSC manifestations including tumors, epilepsy and TAND. As of December 2021, 10 companies were active members of the consortium. Since inception, the consortium has helped advance the evaluation of drugs for TSC by conducting 90 studies, evaluating 57 candidate drugs.
In 2012, the TSC Alliance helped create the TSC Clinical Research Consortium in partnership with investigators running clinical studies to ensure clinical research in TSC is as efficient and effective as possible. Since then, consortium investigators have been awarded more than $39 million by the National Institutes of Health (NIH) and Food and Drug Administration (FDA) through competitive grant processes. TSC Alliance personnel serve on the leadership team for the consortium, actively track enrollment and raise community awareness to help identify potential participants for clinical studies. TSC Alliance also provides supplemental financial support to accelerate or expand NIH-funded studies.

The TSC Alliance stimulates collaboration and innovation through convening experts and stakeholders within and outside the TSC field. The first Innovation Workshop topic was newborn screening, held in late 2020 and culminating in a Zoom meeting on January 29, 2021. Following peer-review by experts in TSC and screening research, the TSC Alliance fully funded two proposals totaling $164,856 for hypothesis-driven research in assay development for early detection of TSC.

The 2021 Virtual International TSC & LAM Research Conference: Driving Discoveries Beyond Boundaries, presented by Greenwich Biosciences and The Rothberg Institute for Childhood Diseases, held October 28-30, 2021, welcomed 179 people from 18 countries. Co-sponsored by the TSC Alliance and The LAM Foundation, the conference featured three plenary sessions with 17 oral presentations and two poster sessions with 14 posters.

Support services

No one is alone on their TSC journey with the TSC Alliance. Our Community Programs Department develops programs and services that provide individuals with TSC direct access to information, resources and specialists experienced in the diagnosis, treatment and management of TSC.

In 2021 the TSC Alliance facilitated 8,742 peer-to-peer supports from Adult Regional Coordinators (12 volunteers in 8 regions nationwide), Clinic Ambassadors (16 volunteers in 19 TSC Clinics and TSC Centers of Excellence nationwide), Dependent Adult Transition Resource Coordinators (31 volunteers in 26 states and Puerto Rico), Education Parent Mentors (29 volunteers in 21 states) and Community Alliance Leaders (47 volunteers in 33 regions across the United States) with active Future Leaders (8 Volunteers) and Past Future Leaders (6 volunteers) who have agreed to remain as leaders for other young adults with TSC.

Until I became involved in the TSC Alliance peer-to-peer support programs as an Adult Regional Coordinator, I had never met anyone else with TSC. Being able to connect with other adults with TSC has provided me with a sense of community and helped me realize I am not alone, which has been invaluable to me, especially during the pandemic when it has been easy to feel isolated.

Iris Mustich, MPH, Volunteer

The TSC Alliance works to ensure school systems understand and adapt to the learning needs of students with TSC. Education Parent Mentors attended 55 school meetings (IEPs, Evaluation Team Meetings, 504 Plan Meetings, Resolution Meetings and Mediations) in person, through SKYPE/Zoom and via conference calls to support families in attaining educational services for their children throughout the country. Several school systems also requested “TSC 101” in an effort to help them understand the complexities of TSC and learning issues for children with TSC.

Our nationwide network of Community Alliances supports individuals and families affected by TSC at the local level. Every branch is run by caring and welcoming volunteers—parents, grandparents, adults and friends—who host educational meetings, raise awareness and fundraise, foster local connections and serve as a resource in their communities.

To ensure the TSC community continues to receive updated information about TSC, TSC-Associated Neuropsychiatric Disorders (TAND), transition and research, the TSC Alliance developed an e-Webinar series. In 2021, we hosted 27 e-Webinars with 1,219 cumulative live attendees, 5,567 cumulative recording views and 3,123 cumulative landing pages visits. Additionally, we held the following webinars: April COVID Vaccine Town Hall – 66 live attendees, 304 video views; ABC to SAP Webinar – 50 live attendees, 458 video views; August COVID Update Town Hall – 307 live attendees, 463 video views. Adding in live attendees with additional webinars total live audience for webinars is 1,642, total cumulative recording views is 6,636 and 3,123 cumulative landing page visits.
In 2021, the TSC Alliance launched **TSC Navigator**, an easy-to-use, interactive online tool to help guide individuals and families through the complexities of TSC across the lifespan, proactively manage their care and live their fullest lives. Users can access information based on the age of one's diagnosis, such as prenatal, childhood or adult, to help determine which steps will help empower them throughout their individual journeys, regardless of age. The TSC Navigator launched October 14 and received more than 2,700 visits by year end. In addition, 587 individuals and families were assisted directly by the Director of Medical Affairs and team members acting as Support Navigators. Of the assistance provided, 78 were medication-related, 60 were TAND-related, 88 were new diagnosis and 252 were for assistance with access to care with 46 COVID-19 related. The remainder served a variety of other needs.

"Our hope is for the TSC Navigator to serve as a central guide for newly-diagnosed families and individuals, as well as those encountering new areas of concern along the TSC journey. Having a wealth of information, resources and support all in one place is invaluable for our community."

Lesley Holmes, Parent

**Awareness and education**

The more people know about TSC, the faster it can be diagnosed and treated. The TSC Alliance's Communications Department heightens awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families.

One major project in 2021 was changing the organization's name to TSC Alliance. The change was formally announced Sunday, May 16, after almost two years of planning by staff and members of the TSC community.

During 2021, the TSC Alliance also produced two issues of its national magazine, *Perspective*, which is mailed to approximately 17,900 constituents as well as posted on the website. The TSC Alliance's podcast series, called *TSC Now*, produced 12 episodes with 2,186 downloads. Six issues of the electronic *TSC Matters* newsletter were distributed to 1,340 subscribers. The TSC Alliance's website increases awareness and provides extensive education through an average of more than 24,000 unique visitors each month.

The TSC Alliance also relies heavily on social media to educate constituents, provide online support and promote new resources and events. Our private Facebook TSC Discussion Group boasts more than 10,000 members, while our Twitter account has 2,579 followers and Instagram has 2,762 followers.

To increase public awareness, the TSC Alliance participated in the Ninth Annual TSC Global Awareness Day on May 15 as well as TSC Awareness Month throughout May. The TSC Alliance also heavily promoted the inaugural Seizure Action Plan Awareness Week (February 8-14) and Infantile Spasms Awareness Week (December 1 to 7). These awareness campaigns along with the organizations various news releases culminated in more than 1 billion cumulative impressions.
Advocacy

We advocate for state and federal funding of TSC research and clinical care—and give the TSC community the tools to do the same. Our Government Relations efforts focus on increasing government appropriations for TSC research, raising awareness and collaborating with partners to drive TSC research.

On the state level, the TSC Alliance advocated for state funding for TSC Centers in Missouri and Maryland, resulting in at least $750,000 in state appropriations. The annual TSC Alliance March on Capitol Hill to advocate for federal funding for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense’s (DoD) Congressionally Directed Medical Research Program (CDMRP) took place in early March 2021.

TSC research funding at the state and federal levels is very important to my brother Frank and our family! State funding enabled the setup of the first adult TSC Clinic in Maryland. Federal funding enabled research in treatments, including an FDA-approved facial cream for all TSC patients. Using cutting-edge research, we want to one day find a cure for this rare disease.

Jocelyn Cenna, Sibling

More than 135 advocates made virtual appointments with 75 Senate and 280 House offices to advocate for a continuation of $8 million in funding for the TSCRP. The House TSCRP Dear Colleague Letter sponsored by Representatives Mullin (R-OK) and Raskin (D-MD) closed with 202 signers. The Senate letter sponsored by Senators Cramer (R-ND) and Heinrich (D-NM) closed with 34 signers. Total funding for the TSCRP has been $105 million since 2002. Research performed through the TSCP has led to multiple clinical trials. The TSCRP also funded research to develop animal models of TSC that have seizures, enabling a better understanding of the etiology of TSC.

Global outreach

The TSC Alliance works to address unmet needs within the global TSC community. Our Global Alliance program provides the opportunity for the TSC Alliance to share experiences and assist in the start-up of support of TSC-related organizations in other countries.

“TSC Alliance India is grateful to the Global Alliance program for jumpstarting our organization with a good governance plan, devising a strategy and mentoring our activities. We are indebted to the TSC Alliance for helping us achieve much progress in a short time.

Rahul Vipparthi, President, TSC Alliance of India

A Global Alliance is a structured group of empowered and caring volunteers who work closely with the TSC Alliance to facilitate local connections for individuals and families affected by TSC and raise revenue and awareness while supporting the mission of the organization. The TSC Alliance has six global partnerships, including TSC Alliance of Israel, TS Canada ST, TSC Alliance of Mexico, TSC Alliance Foundation (in Thailand), Hungarian Foundation for Tuberous Sclerosis and TSC Alliance of India. The TSC Alliance recognizes 10 TSC Clinics in Global Alliance countries.

The TSC Alliance is also active in Tuberous Sclerosis Complex International (TSCI), a consortium of TSC organizations around the world. TSCI provides a forum to share information, exchange ideas and methods, co-fund research projects and promote increased international awareness of TSC. In 2021, TSCI wrote a paper entitled, “Beyond the Guidelines: How We Can Improve Healthcare for People with TSC Around the World,” which examines the state of TSC care around the world, identifies gaps in TSC care and makes recommendations for how TSC organizations and key stakeholders can work together to overcome barriers in TSC care.
Professional education

Everyone should know about TSC, especially healthcare professionals. Our Professional Education activities expand programs to target researchers and healthcare providers caring for individuals with TSC, medical students, genetic counselors and educators to minimize the consequences of ignorance and misinformation.

In August, two new publications were accepted by *Pediatric Neurology*, “Updated International TSC Diagnostic Criteria and Surveillance and Management Recommendations” and “Beyond the Guidelines: How We Can Improve Healthcare for People with TSC Around the World.” The new papers provide the first significant updates to the international guidelines since 2013 because of new medications and advances in treatments. To address the changes, a working group led by Darcy A. Krueger, MD, PhD, Cincinnati Children's Hospital Medical Center, and Hope Northrup, MD, McGovern Medical School, University of Texas Health Science Center at Houston, included 80 participants from 16 countries.


Fund development

Thousands of supporters, TSC community members and other partners work together to help fuel the TSC Alliance's mission. Our Development and Community Programs Departments focus on raising funds for research, programs and support for individuals, families, healthcare professionals and educators. Special events, community fundraisers and personal donations—large and small—help underwrite these initiatives and allow the TSC Alliance to work hand-in-hand with the TSC community to ensure people navigating TSC have hope and support every step of the way.

"One of the things that impresses me about the TSC Alliance is their ability to identify research needs and collaborate effectively with researchers. Donating to this organization means they can get results faster."

Lorne Waxlax

Second Annual Step Forward to Cure® TSC Global Virtual Walk-Run-Ride

The TSC Alliance hosted its second annual Step Forward to Cure TSC Global Virtual Walk-Run-Ride on May 15-16, raising more than $805,000! We also hosted our second annual Step Forward to Cure TSC Virtual Auction.

This year’s event schedule started on May 10 and featured Kari Luther Rosbeck, TSC Alliance President and CEO, and Lisa Moss, Vice President, Donor Relations, hosting Facebook Live lunch-and-learn interviews with national sponsors and members of the TSC community members. The Facebook Live Kick-Off Ceremony was held May 15 with Kari Luther Rosbeck; Dr. Peter Crino, Chair, TSC Alliance Board of Directors; and special guest, Althea Grace, American Idol Season 19 contestant and TSC mom.

The Wrap-Up Rally was hosted by Jim O’Heir, TSC Alliance Champion and celebrity spokesperson, and Kari Luther Rosbeck, TSC Alliance President & CEO, who announced our top prize winners. The opening remarks were presented by Bill Joseph, Vice Chair of the TSC Alliance Board of Directors. Bill graciously acknowledged the strength and support of the TSC community and thanked this year’s planning committee members and TSC Alliance staff for all of their work behind the scenes and throughout the event weekend. We were thrilled to end our Wrap-Up Rally with the official launch of the new TSC Alliance name, logo and tagline.

Again, we want to thank our National 2021 Step Forward to Cure TSC Global Virtual Walk-Run-Ride sponsors, our outstanding planning committee, donors and the 2,112 supporters and 202 teams who registered to make our second virtual walk a stellar event.
National Sponsors
Greenwich Biosciences; Marinus; Nobelpharma; Novartis, UCB, Inc.; Upsher-Smith Laboratories, LLC; MassMutual SpecialCare; LivaNova

Regional Sponsors

Participating TSC Clinics and Centers of Excellence
Atrium Health (NC), Beaumont Health (MI), Boston Children's Hospital, Boston Children's Hospital Physicians, Children's Hospital of Los Angeles, Children's National Medical Center, Cincinnati Children's Hospital, Cooke Children's Hospital, Dell Children's Hospital, Duke University, Herscot Center for TSC at Massachusetts General Hospital, Institute of Neurology at St. Barnaba, Le Bonheur Children's, Lurie Children's Hospital, MN Epilepsy Group, Seattle Children's Hospital, Stanford Children's Health, Texas Children's Hospital, Texas Scottish Rite Hospital for Children, University of Alabama/Birmingham, UCLA, University of Iowa, University of Maryland Medical Center, Virginia Commonwealth University, Washington University/St. Louis

Top Fundraisers
1. Ryan and Andrea Beebe, Parker's Phantics: $40,951
2. Jill Hyman and Kate Martin, Team SkyBlue Crew: $40,793
3. Mary Ann Lamb, Team Jay: $33,425

19.5 Comedy for a Cure®

The TSC Alliance hosted a wildly successful hybrid edition of Comedy for a Cure, which raised $143,000 on October 17. The show was live-streamed to online viewers from Feinstein's at Vitello's in Studio City, CA with a sold-out in-person audience.

We were thrilled to present the much-deserved Courage in Leadership Award to Althea Grace, a singer-songwriter who gained national attention as a top contestant on American Idol Season 19. We were also pleased to honor Wendy Liebman, who has been a significant behind-the-scenes contributor to Comedy for a Cure and the mission of the TSC Alliance for many years, with a TSC Champion Award. The magical night included musical entertainment by Althea Grace and a piano performance by Emily Phan, TSC Alliance Future Leader. The event featured an action-pack lineup of hilarious comedians: Jodi Miller, Marty Ross, Taylor Williamson and headliner Drew Lynch. We are thankful to our fabulous co-hosts Jim O’Heir and Wendy Liebman who, together with auctioneer extraordinaire Damon Casatico, hosted another stellar event.

Comedy for a Cure sponsors included Greenwich Biosciences; Horizon; The Maginn Family; Neurelis; The Szilagyi Family; WNC/Cooper Family; Upsher-Smith Laboratories, LLC; UCB, Inc.; Ray Chan; Tim and Kathi Dills; The Keith A. Hall Family; Ted and Peggy Mastroianni; and Regenxbio.

Other events raising more than $10,000
- Facebook Donations/Birthday Fundraisers: $97,775
- Getting Saucing with Parker B., hosted by Ryan and Andrea Beebe: $24,464
- Bcureful Valentine's Day Campaign—Show Your Heart, Send a Heart: $11,590

Team TSC

The TSC Alliance and Team TSC were proud to be an Official Charity Partner with the 50th TCS New York City Marathon, held Sunday, November 7, 2021. Team TSC raised $53,939 to fund the mission of the TSC Alliance. Congratulations and thanks to Team TSC runners: Raymond Capogna, Claire Blyth, Katherine Chapman, Maureen Elliott, Kristin Burkhalter, Chip Burkhalter, Ryan Kennedy and Amanda Alberts.

The President’s Council

The TSC Alliance founded the President’s Council in 2016, bringing together members of families impacted by TSC who work with the President & CEO and the Board of Directors to fund and fuel research. Members contribute a minimum gift of $100,000 per year to fund research. President’s Council members since its inception include:

- David M. Coit
- Kay and Will Cooper, through the creation of the Kay and Will Cooper TSC Mental Health Fund
- Cowlin Family
- Tim and Kathi Dills
- Christopher and Joy Dinsdale
- Engles Family Foundation on behalf of Engles Collaborative Research Fund
- Foglia Family Charitable Gift Fund, through the Bcureful Travel Fund
- Julian and Janice Gangolli
- Brittany and John Gottschall
- Jim and the late Andrea Maginn, through the creation of the Abigail and Amelia Clinical Accelerator
- Diane McSwain
- Jonathan and Bonnie Rothberg, Rothberg Charitable Foundation of Children's Disease
- William Watts
- Lorne Waxlax, through the creation of the Waxlax Biosample Collection Initiative
- Wong Family Foundation
Chair’s Circle
($100,000 and Above)
Anonymous
Anonymous
BridgeBio Pharma, Inc.
David M. Coit
Kay and Will Cooper Sr., WNC & Associates
Facebook Community Donations
Foglia Family Foundation
Gerry and Bill Cowlin Foundation
Janice and Julian Gangolli Family Fund
Jazz Pharmaceuticals
Jim and Andrea Maginn Memorial Trust
Diane McSwain
Ovid Therapeutics
Small Business Administration, Paycheck Protection Program
TSC Alliance Endowment Fund
UCB, Inc.
Lorne Waxlax
Wong Family Foundation

Benefactor
($50,000 - $99,999)
Anonymous
Brittany and John Gottschall
Novartis Pharmaceuticals Corporation
Emma J. Rocco Living Trust
Jonathan Rothberg and Bonnie Gould
Rothberg, Rothberg Institute for Childhood Diseases
Upsher-Smith Laboratories, LLC
William Watts

Sponsor
($20,000 - $49,999)
Anonymous
Edward and Kristin Burkhalter
Child Neurology Foundation
Haag Family Foundation
Ingram, Yuzek, Gainen, Carroll, Bertolotti, LLP
Mallinckrodt Pharmaceuticals
Marinus Pharmaceuticals, Inc.
MassMutual SpecialCare
Neurel, Inc.
Nobelpharma
Allan and Carla Price
Irene Rothberg

Protector
($10,000 - $19,999)
Accurate Healthcare, Inc.
Amazon Smile Foundation
Anonymous
Juan Carrión
Mark and Kelly Carroll
Dravet Syndrome Foundation
David Farrar
Nick Gentry
Karen White and Julie Geissman
Horizon Therapeutics
Carly and Andrew Kaye
Cathy and David Krinsky
Darcy Krueger
Kuehn Family Foundation
Mary Ann Lamb
LivaNova
Doug and Linda Loftus
Louis Berkowitz Family Foundation
Theodore and Peggy Mastroianni
Nancy and David Michaels
Rachel and David Nachbar
Ned Neely
O’Friel Family Foundation
Adolfo Orive
PeerView Institute for Medical Partnership
Rebecca Anhang Price and Matthew Price
Leslie and Chris Russell
Joshua and Cheryl Samuels
Lacinda and Douglas Scott
Heidi and Jerrill Sprinkle
Barbara and John Swanson
Tetra Laval
Winifred M. Gordon Foundation

Defender
($5,000 - $9,999)
Steve and Lynn Aguiar
America’s Charities
Anonymous
Jeffrey Avansino
Susan and Dale Bennett
Biototechnology Innovation Organization
Linda Buchman
Cassandra and Bryce Carroll
Cliff and Deborah White, Cliff and Deborah White Family Foundation
Margaret and Jared Cox
Peter Crino
Cornelius and Linda DenHarder
Prachee Devadas
Tim and Kathi Dills
Chris and Joy Dinsdale Family Foundation
Doe Family Foundation
Nick Giardina
Robert and Kathryn Groves
Tyler Guettler
The Hall Family
Lori and James Hartge
Dorsey Hightower
Hightower Dermatology
Douglas and Margaret Hinkle
Alex and Lesley Holmes
James Huntington Foundation
Scott and Emily Johnson
Debra and William Joseph
Shannon and Nick Landt
Lundbeck Pharmaceuticals, Inc.
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Jonathan and Judith Marshall
Irene Marton
Stuart and Carina Marton
Michael P. Wilson, Inc.
Robert and Staciellen Mischel
Mischel Family Charitable Fund
Jon and Patricia Myers
Noema Pharma AG
James Norman
Chris Parker
Jo Anne Nakagawa
Premier Research International, LLC
Mark Reich
Nancy Richards
Michele Smith
Michael Sorenson
Stanford Children’s Hospital
The late Mary Lou Thurston-Smoot
TSC Alliance of Hungary
TSC Alliance of Israel
TSC Alliance of Mexico
Tuberous Sclerosis Canada Sclerose Tubereuse
John Waterbury
Paul and Pamela Waxlax
Adam Wayne
Sarah and Kevin Wright
Wurwand Foundation
Deborah and Joseph Yohn
Advocate ($1,000 - $4,999)
A&A Banner
Norman Abazoris
Abbvie
Howell Adams
Adobe Systems Inc.
Janice Akridge
Allstate Foundation
Paul Patricia Anderson
Anonymous
Stephen and Erin Antosh
Arborscapes, LLC
Alex and Liz Argo
Ascension Ministry Service
Robert Baker
Laurisa and Daniel Ballew
Richard Barnett
Derek Bauer
Stephen Bauer
Nicole Bayless
Tammie and Robert Beatty
Martina Bebin
Andrea and Ryan Beebe
Jeffery Benham
Marti Berry
Anita Bhatia
Brenda and Robert Biddle Jr.
Phyllis and Josef Bismanovsky
John Blake
Martha Blakejacobson
Carl Blyth
Fred Bohlander
Robert Bowling
Mary and Walter Bradley, Jr.
Breslow Family Foundation
Bridget and Jeremy Britt
Lisa and Peter Bryan
Joe and Donna Bryant
Elizabeth and Andrew Buchsbaum
Pablo and Corina Burbridge
Diane and Warren Burgess, III
Christopher Capone
James and Diane Caserta
Ben Cattanach
Cavarocchi Ruscio Dennis Associates, LLC
Michael Cavenee
CDW Corporation
Ray Chan
Kim Chang
Cindy and Dan Chernow
Sara Chieffo and Dan Skillman
Vincent Chieffo
Mardel Chinburg
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Susan and Richard Clack
Connie and Richard Cockerham
Ned and Susan Coen
Saundra and Harvey Cohen
Kimberly and Mark Colby
Craig and Margie Colby
George and Susan Conlon
Kathleen and Steve Conrad
April and Alfred Cooper
Jennifer and Wilfred Cooper, Jr.
Jason and Michelle Cox
Marshall and Nathalie Cox
Frank Criniti
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Laurie and Stephen Dennis
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Marcia Hecht
Dennis and Lynn Heieie
Kathleen and Thomas Herndon
Craig Hesch
Lisa Hidaybaca
Melanie and Daniel Hileman
Butch and Kathie Hitchcock
Karen and Jeff Hoersch
Lesley and Jay Hoffarth
Jeffrey and Lori Hoffmann
Dana and Bruce Holinka
John Horns
Lorraine Houchin
Scott Howe
John and Alice Hulbert
Laurie Hutton
Sandra Hyde-Swanson
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Richard and Linda Keister
Kendra Scott, LLC
Kaci Kennedy
David and Maurine Kesner
Dwight Kines
Alan Kines
Josh Kiplinger
Edina Kiss, Edina Kiss Jewelry
Stewart and Grace Krakover
Jeff Krol
Peter and Jeannette La Forte
Merili Laks
James and Chelsea Lamb
Bev LaSota
Calvin and Michele Lau
Casey Law
William and Barbara Lee
Angelique Lee-Rowley
Heather and Christopher Lens
Matt Leone
Wai-Man Leung
Linda and Tom Held Charitable Fund
Linda G Porter Charitable Fund of Waccamaw Community Foundation
Renee Lindo
Greg Linsin and Julie Blum
Jim Lloreta
Thomas and Nancy Lofredo
Richard Lotz
Bridget Lucas
Richard Lucett
Nick MacDonald
Elizabeth MacDonald
MacPherson Fund, Inc.
Nikki and Michael Mandile
Jeff Krol
Mary Rose and Carey Davis Giving Fund
Mark and Kathy Mayrsohn
David McKinnon
Latane Meade
Shelly and Matthew Meitzler
Robert and Mary Ann Melcher
Esther Messing
Harry and Donna Meyer
Carol Michael
Jan and David Mintz
Arshen Mirzoiann
Debora Moritz
Robert and Lisa Moss, Seizure Tracker, LLC
Tamar Bogojevic-Catanzano
Arham Muhammad
William and Susan Nasser
Mark Hyman and Sheryl Neuman
Tri Nguyen
Robert and Jennifer Nicholson
Norgren Family Fund
Norman and Susan Abazoris Foundation
Jess and Michael Noviski
NVIDIA
Jim O’Heir
Oracle Corporation Matching Gifts Program
Sharon Palm
Jim and Maryann Paskell
Muriel Pattis
Howard Pattis
Paypal Charitable Giving Fund
Mark Perlmutter
Dennis Ehrler and Penny Perna-Ehrler
Diana Petroff
Marcia Philips
Joel Pingel
Andrew and Maureen Piotrowski
Jeanne Vander Ploeg
Harold and Mary Jane Podgorski
Theodora Polamalu
Jen Pooley
Portage Public Schools General Fund
Prospera Financial Services
Ronnie and Linda Pyle
Pzena Investment Management
Ilana Ratner
David and Kathy Rauch
Steve and Mary Roberts
James Rodgers
Debbie and John Roeser III
Christopher and Kari Luther Rosbeck
John and Peggy Ruckauf
Allen and Gayle Ruplinger
Brian Ruttenberg
Angela Saar
Mildred Sanders
Ian Saunders
Timothy Scanlan
Jennifer Schillig
Earl Abramson and Sheila Schlaggar
Robert and Mary Ellen Scott
Julie and Dave Scroggins
Jeffrey Seabold
Kenneth Seip
James Seith
Mahendra Sekaran
Seyfarth Shaw Charitable Foundation
Elysia and Thomas Seymour
Shawn Gaffney Memorial Fund Inc.
Stephany Sherman
Sheila Shilling
Judy and James Shoulak
Maria Skowron
Mary and Don Smith
Johnny and Vianne Smith
Candace Smith
Kathleen and Joseph Smith III
David Smith
Soboba Foundation Inc.
Arlene and Ralph Sonday
Denise Soucy
Steven and Mari Sparagana
Tyna Sprecher
Namit Srivastava
Elizabeth and Mark St. Lezin
Kate Staples
Starr H. Clark Endowment Fund
John and Janine Steenman
Dirk and Kimberly Suringa
Synergy Enterprises, Inc.
Annie Szilagyi
Eldon Tackett
The Aldina Family Fund
Michael Bill Avner Memorial Fund of The Pittsburgh Foundation
The Schaefer Foundation
Sean and Kelly Thomann
Paul Thomas
Total Care Rx, Inc.
UScellular
Vanguard Charitable
Theresa and Harvey Varnet
Christine Viola-Weiss
Nancy and Alan Vogel
Betty Vollmar, Betty Bohl Vollmar Foundation
Tara Wagner
William and Corinne Ward
Michael Ward
Gary and Ann Wasserman
Emily Waterbury
Krystal Watts
Robert Welker
Western & Southern Financial Fund
Patrick Whitehead and Christine Page
William and Beverley Mansfield Charitable Fund
Donna Williams
Gerald and Edna Willis
Ben and Angie Windham
Michael Wong and Cecilia Hsien-Tsing Yu
Doug Wright and Chad Cortes
Kirby and Jennie Woodard
Debra Wright
Kevin and Paige Yost

Champion ($500 - $999)
Shalonda Alexander
Ali Amiri
Anonymous
Aru and Gowri Arulmoli
Chris Bachman
Alina Baciu
Patricia and John Badorf
James and Bettianne Barash
Marissa Bedini
Tara Bell
Joel Bernheim
Megan Big John and Michael Hicks
Kevin Bittel
Byron Elaine Bixiones
Sarah Blyth
Sherry Blyth
Katie Blyth
Stephanie and Ian Bobbermin
Patricia Bodnar
Brian and Jamie Boesiger
Tyras Bookman
Charles Booth
Jim Bough
William Bowman
Bryan Boye
Marta Brenden
Karen and Harry Broome Jr.
Daniel Bloomstein and Kirscha Burgess
Ajna Burke
Clay Burkhalter
Trisha and Tom Burt
Jim and Margaret Burt
Ashton Butcher
Christine Byars
Raymond Capogna
Frank and Barbara Capone
Carolina Tailwinds Bicycle Vacations
Nancy Carver
Mary Sue Catlett
Erin Catto
James and Nancy Caufield
Rebecca Cervantez
The Chelsea Hutchison Foundation
Chevron Corporation
Ron and Dorothy Cibulskis
Savannah Citron
Elaine Clancy
Danielle Clark
Andrew Clark
George Clemens III
Susan and Paul Collins
Community Shares of Colorado
Jim and Marilyn Conner
Linda Connors
Jerry Cordova
Kari Corey
Jessica Couillard
Andy Coyne
Ashley Crary
Raghunath D
Cheryl Dashiell
Dale Davis
Al and Jamie Debauche
Meredith Delich
Gloria DeValle
Dayna Donaldson
Janette Dooley Swift and Martin Dooley
Alla Dragoun
Stephanie Dreyer
Malik Ducard
John Duffy
Bonnie and Charles Duffy
Joelle Dumas
Arnold and Janice Eckelman
Michael Eisner
Skip Elliott
Todd and Teresa Embury
Donna and Robert English
Steven and Lauren Erickson
Katherine and Ronald Espalin
Marcia Farrar
Rusty and Kim Field
Brian and Patricia Finn
First Presbyterian Church
David and Jeannine Fitzmaurice
Nancy Flaherty
Jennifer Flannery O’Connor
Jane Foster
Jeff and Debra Foster
Paul and Susie Franke
Hal and Pat Fredrickson
Gloria Garbutt
Johanna and Alfred Garzino
Sheila Gaschen
Jennifer Segal Geetter
Michael Ghozland
Donald Lorusso and Judith Gilbert
Douglas and Nancy Glass
Jonathan Goldstein
Martin Goodhart
Google Matching Gifts Program
Google, Inc.
Blayne Grady
Reese Grafft
Benjamin Greenberg
Andrew Gross
Michael Grygo
Carl and Clarinda Guarino
Charles and Diane Gulas
Barbara Gurski
Shannon Hackley
Raymond and Nancy Hall
Lee and Susan Hammontree
Carter Hampton
Melinda and William Hanks
Debby and Joe Harden
Frances Harper
Maria Hart
Heather Joy Memorial Fund
Theresa Hemp-Hall
Dave and Mary Henke
Michelle Henslin
The Hillary Family Foundation
William Hillier
Christy Hobart and Henry Shapiro
Gerrick Hodge Sr.
Marilyn Holt-Smith
Aaron Howes
Ann Huber
Kimberly Hyers
International Monetary Fund
Van and Jennifer Isley
Evelyn and David Isley
Shirley Israel
Jan Jaffe
Charles Joanesid
Amy Johnson
James Johnson
Johnson & Johnson
Jollyville Sertoma Club, Inc.
Deborah and Jay Julow
Troy Kay
Bill Kearney
Karima Khawja
Sally and Craig Kiency
Klase & Company
Ronald Klein
Merry and Russell Kraft
The Krantz Family
Brette Kranz
Frances Kuehn
Patricia Kuehn
Robert and Cynthia Kupper
Lise Lagace
Paul Lalka
Maria Lamb
Sarah Lambrose
Tom Langbein
Dane Larsen
Kelsey Larson
Johnny and Chinny Law
Ellen Lerner
Layne Levine
Lindsay Lidlow
Michelle and Jason Litsky
Douglas Loock
Cody Low
Laura Lubbers
Scott Lucas
Richard Lucas
Judy Luther
Monica Mafia
Barbara Malatesta
Edward and Judith Malecki
Audrey Malesky
Jo Nell Malloy
Lawrence and Joya Marks
Katie Martin
Frederic Marton and Nina Zubkoff
Greg McCollum
Kevin McCray
Michelle McDonald
Charles and Theresa McFadden
John and Berni McFadden
Toby McIlwain
Virginia McKiernan
McNeely Foundation
Greg Meier
Barbara Meitzler
Maggie Mikolay
Michael Miller
Jessica Minton
Timothy and Anne Mooney
Brittany Moore
Linda and Clark Moore
Scott and Faith Moskowitz
Frances and Kathleen Mulvey
James and Margot Mustich
Kirk Neely and Holly Myers
Dhruv Nair
Gerald and Jill Nerheim
Jennifer Northrup
Stephen O’Brien
Sharon and Leon Oberlander
Terry Odonnell
Matt and Amanda Olear
Omni Cable Foundation
Michael and Diane Oravecza
Lily Orielly
Georgia Dealey Paine
Elizabeth and Vincent Palagiano
Lydia Palumpon
Stephanie Paulson
Sandra Perlmutter
Lindsay Perraud
Raymond and Carolyn Peterson
Kellyann Petrucci
Laura Pope
Janice Primus-Wickett
Rabobank New York Branch
Rajsekar Rajaraman
Bob and Brenda Ramirez
Raytheon
Major Gifts in Kind
(Value of $500 or more, as identified on received in-kind forms)

Farzana Ali
Anonymous
Shane Brady
Patricia Bronfman
Damon Casatico
Kristie Cline
David Coit
Mo Collins
April and Alfred Cooper

Derma Medical Spa
Tony Dunlap and Treasa Bolger-Dunlap
Edina Kiss Jewelry
Kate Flannery
Tiffani Goff
Althea Grace
Shawn Briones and Frances Harper
John Henson
Dana and Bruce Holinka
Alex and Lesley Holmes
Jill and Jonathan Hyman
Kaye Design Studios
Kent and Yvonne Kahlen
Wendy Liebman
Doug P. Loftus, CFP, Wealth Dimensions
Heather and Christopher Lens
Drew Lynch
Jim O’Heir
Irfan Mamdani
Jodi Miller
Misson Bay Fly Fishing Co.
Virginia Musselman
Jeanine and Steven Page
Amin Panjwani
Melissa Peterman
Kim and Lauren Phan
Steve and Mary Roberds
Christopher and Kari Luther Rosbeck
Marty Ross
Lauren and Sean Shillinger
Craig Shoemaker
Alex Skuby
Cassie Souder
Lisa and Robert Szilagyi
Hal Tearse
Supreme Wireless
Taylor Williamson
XIV Karats LTD

The TSC 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 TSC 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 TSC Alliance. The Endowment Fund ensures the TSC Alliance has an ongoing source of funding to better serve those touched by TSC through education, support services and research.

Founders Society
($100,000 and above)
Michael and Milly Augustine

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

Century Society
(10,000 - $24,999)
Mark and Judy Fox
Andrea Hall and the late Keith Hall
Robert and Joan Appleby Foundation

Enrichment Society
($5,000 - $9,999)
Doug and Linda Loftus
James Norman
Paul and Pamela Waxlax

Investment Society
($500 - $4,999)
Jill and Randy Banks
Michael Durrant
Ever Loved, Inc.
Frank and Laura Gallagher
Pay and Carl Godman
Nancy and Robert Graham
Judy Graves
Phil and Karen Johnson
Arnold and Carol Kamm
Michael and Karen Loulakis
Network For Good
Kenneth and Julie Ostrowski
Parsons Corporation
Paypal Charitable Giving Fund
Richard Solomon
Louis and Joan Sudholz
Virginia and Robert Swain
Paul Xavier

The Eternal Flame Society

When individuals and families inform the TSC Alliance of a designated planned gift through a will or estate plan to the TSC Alliance Endowment Fund or the TSC Alliance they become part of the Eternal Flame Society. If you or a loved one has designated the TSC 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
Barbara Bartlett*
Harold and Bernice* Belfer
Jeffery and Gloria* Benham
Matt Bolger
Treasa Bolger-Dunlap
Alice Brossart
Anthony Bracco*
Scott and Jan Burton
Marguerite Cleveland
John and Katherine Conrad
Will and Kay Cooper
Richard and Reiko Donato
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
Glenn Leiter*
Craig T. Lewis*
Doug and Linda Loftus
Magdalena Lutsky
James Lynch
Glennwood Dale Maier*
Robert McBride*
Donna McCaha
David and Jan Mintz
William Morris*

*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
Ken Johnson Memorial Fund
Lauren E. Krinsky Fund
The Lawler Fund
Cade Scott Fund
Jeb Ward Legacy Fund

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

Operating Board of Directors

Peter Crino, MD, PhD, Chair
Moorestown, NJ

William Joseph, Vice Chair
State College, PA

Paul Waxlax, Treasurer
Denver, CO

Laura Marks, Secretary
Queens, NY

Chris Russell, Immediate Past Chair
Grapevine, TX

Derek Bauer, MD
Charlottesville, VA

Julie Blum
Potomac, MD

Matt Bolger
Lansing, MI

Chip Burkhalter
Alexandria, VA

Mark Carroll
Saratoga, CA

Sara Chieffo
Washington, DC

David Coit
Cape Elizabeth, ME

Margaret Cox
Vestavia, AL

Timothy Dills
Great Falls, VA

Andrew Duffy, International Partner Member
Toronto, ON

Bonnie Hogue Duffy
Chevy Chase, MD

Tanjala Gipson, MD
Cordova, TN

Steven Goldstein, CPA, FFS
Westport, CT

Rob Grandia
Riverside, CA

Dana Holinka
Northglenn, CO

Jessica Krefting, BSN, RN
Madison, AL

Darcy Krueger, MD, PhD
Mason, OH

Heather Lens
Westville, OK

Jim Maginn
Manhattan Beach, CA

Diane McSwain
Crystal Lake, IL

Mustafa Sahin, MD, PhD
Needham, MA

Sean Shillinger
Adamstown, MD

Matthew Simonian
Humble, TX

Vanessa Vazquez
Miami, FL

Tara Zimmerman
Reno, NV

Endowment Fund Board of Directors

Marion Adams, Chair
Mobile, AL

Michael Augustine, JD, Secretary
San Gabriel, CA

Hal Tearse, Treasurer
Independence, MN

Rita DiDominico
Staten Island, NY

Robert W. Groves, III
Leander, TX

Bill Joseph
State College, PA

Brittany Smith
Kenilworth, IL

Paul Waxlax
Denver, CO

Corporate Advisory Board

Wilfred Cooper, Sr., Honorary Chair
Chairman
WNC & Associates

Julianne Moore, Honorary Chair
E. Martina Bebin, MD, MPA
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

Gail Gershon
Ken Kocher
Former President
LIDS Sports Group

Laura S. Lubbers, PhD
Chief Scientific Officer
CURE Epilepsy

Alan Marshall
Director, Customer Engagement
Greenwich Biosciences

Ted Mastroianni
David Michaels
Senior Vice President
Wells Fargo Bank, NA

Darren Miles
Chairman, International Operations
Dairy Queen

Mary Jane Mudd
John P. Nicholson, MD, MBA
Crapboard Ridge Consulting, LLC

Sean C. Nolan
Chairman
Encoded Therapeutics, Inc.

Rebecca Anhang Price, PhD
Henry Shapiro
Chairman
MarketCast Group

Judy Shoulak
Owner
Relatively Speaking

John Thorpe Richards, Jr.
Bogorad and Richards, PLLC

Marc Shapses
Executive Managing Director
Savills Studley

Staff

Kari Luther Rosbeck
President & Chief Executive Officer

Cynthia Arcuri, CPA
Chief Financial Officer

Steven Roberds, PhD
Chief Scientific Officer

Dean Aguilar, PhD
Vice President, Translational Research

Ryan Beebe
Manager, Annual Giving & Partnerships

Christen Bell
Grant Writer Consultant

April Cooper
Vice President, Community Programs

Landon Cox
Development Coordinator

Zoë Fuchs
Science Project Manager

Emebet G/Micheal
Senior Accountant

Jaye Isham
Senior Vice President, Strategic Communications

Carly Kaye
Community Programs Manager
Dan Klein
Director, Digital Platforms
Justin Martucci
Development Systems Manager
Shelly Meitzler
Director, Community Education & Resources
Lisa Moss
Vice President, Donor Relations
Jo Anne Nakagawa
Director, Clinical Projects
Ashley Pounders, MSN, FNP-C
Director, Medical Affairs
Gabrielle Rushing, PhD
Director, Research
Gail Saunders
Senior Associate Director, Community Programs
Katie Smith
Director, Government & Global Affairs
Rachel Wojnilower
Executive Assistant
Anne Wolfe
Senior Community Programs Manager

Community Alliances

TSC Alliance of Alabama
Margaret Cox, Chair
TSC Alliance of Alaska
Rebecca Racenet, Chair
TSC Alliance of Arizona
Debora Moritz, Chair
TSC Alliance of Connecticut
Jennifer Waldron, Chair
TSC Alliance of Dallas/Fort Worth
Leslie Russell, Chair
TSC Alliance of Delaware/Lehigh Valley
Liz Saadoun, Co-Chair
TSC Alliance of the Delta Region
Heather Harden, Chair
TSC Alliance of Florida
Amy Hightower, Co-Chair
TSC Alliance of Georgia
Wendi Scheck, Chair
TSC Alliance of Chicago
Geri Greenberg, Chair
TSC Alliance of Greater Kansas City
Amy Dublinske, Chair
TSC Alliance of Hawaii
Trisha Kam, Chair
TSC Alliance of Indiana
Laura Marlin, Co-Chair
Cassie Souder, Co-Chair
TSC Alliance of the Intermountain West
Kelli Sutherland, Co-Chair
Brittani Rich, Co-Chair
TSC Alliance of Kentucky/West Virginia
Melissa Bartley, Chair
TSC Alliance of Maryland
Lauren Shillinger, Co-Chair
Kristy Nunley, Co-Chair
TSC Alliance of Michigan
Carly Kaye, Chair
TSC Alliance of Nevada
Kathleen Kingston, Co-Chair
Tara Zimmerman, Co-Chair
TSC Alliance of New York/New Jersey
Laura Marks, Co-Chair
Rhiannon Schade, Co-Chair
TSC Alliance of North Carolina
Karen Johnston, Chair
Virginia Musselman, Vice Chair
TSC Alliance of Northern California
Lilian Ansari, Co-Chair
Jennifer Yeamans, Co-Chair
TSC Alliance of Ohio
Tammy Thorne, Chair
TSC Alliance of Oklahoma
Heather Lens, Chair
TSC Alliance of the Pacific Northwest
Gloria Triebenbach, Chair
Debbie Rothweiller, Vice Chair
TSC Alliance of the Rocky Mountain Region
Dana Holinka, Chair
TSC Alliance of South Carolina
Amy Bredeson, Chair
TSC Alliance of Southern California
Tara Palage, Chair
Lesley Holmes, Vice Chair
TSC Alliance of St. Louis/Southern Illinois
Jackie Grena, Chair
TSC Alliance of the Upper Midwest
Alanna Spotts, Chair
TSC Alliance of Washington, DC/Virginia
Kathi Dills, Chair
Adrianne Cohen, Vice Chair
TSC Alliance of Western Pennsylvania
Kelsey Hudson, Chair
TSC Alliance of Wisconsin
Kristin DeGueme, Chair
Nicole Galarmo, Vice Chair

Adult Regional Coordinators
Rob and Shannon Grandia, supported by Daniel Price
Region 2: California, Arizona, Nevada, New Mexico, Utah
Rob and Shannon Grandia, supported by Daniel Price
Region 3: Colorado, Nebraska, South Dakota, North Dakota, Iowa, Minnesota, Wisconsin
Danielle Clark, supported by Melyssa McDonough
Region 4: Texas, Oklahoma, Kansas, Missouri, Arkansas, Louisiana
Jake Irby, supported by Emilie Peters and Foster Hyde
Region 5: Illinois, Michigan, Indiana, Ohio, Pennsylvania
Phillip Tallman
Region 6: Tennessee, Kentucky, Georgia, Alabama, Mississippi, Florida
Kate Crosett
Region 7: Connecticut, Vermont, Maine, Rhode Island, New Hampshire, New York, New Jersey, Massachusetts
Iris Mustich, MPH
Region 8: Delaware, Virginia, West Virginia, Maryland, North Carolina, South Carolina, Washington DC
Kathy Henkel
Social Media: Danielle Clark

View members of the TSC Alliance’s Professional and International Scientific Advisory Boards at tscalliance.org.
National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Financial Position

As of December 31, 2021

<table>
<thead>
<tr>
<th>Assets</th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$2,843,269</td>
<td>$2,370,947</td>
</tr>
<tr>
<td>Investments</td>
<td>6,691,013</td>
<td>5,913,426</td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>99,173</td>
<td>113,491</td>
</tr>
<tr>
<td>Promises to give</td>
<td>2,698,495</td>
<td>1,578,285</td>
</tr>
<tr>
<td>Prepaid expenses and other assets</td>
<td>620,148</td>
<td>403,498</td>
</tr>
<tr>
<td>Operating lease right of use asset, net</td>
<td>778,371</td>
<td>833,830</td>
</tr>
<tr>
<td>Property and equipment</td>
<td>437,169</td>
<td>510,367</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td><strong>$14,167,638</strong></td>
<td><strong>$11,723,844</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Liabilities and Net Assets</th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$186,010</td>
<td>$181,331</td>
</tr>
<tr>
<td>Accrued compensation</td>
<td>290,487</td>
<td>254,553</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>676,798</td>
<td>422,226</td>
</tr>
<tr>
<td>Operating lease liability, net</td>
<td>1,285,691</td>
<td>1,336,433</td>
</tr>
<tr>
<td>Gift annuity obligations</td>
<td>119,665</td>
<td>66,740</td>
</tr>
<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>2,558,651</strong></td>
<td><strong>2,261,283</strong></td>
</tr>
<tr>
<td>Net assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without donor restrictions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undesignated</td>
<td>(20,618)</td>
<td>189,609</td>
</tr>
<tr>
<td>Board-designated</td>
<td>6,601,224</td>
<td>5,764,868</td>
</tr>
<tr>
<td><strong>Total without donor restrictions</strong></td>
<td><strong>6,580,606</strong></td>
<td><strong>5,954,477</strong></td>
</tr>
<tr>
<td>With donor restrictions</td>
<td>5,028,381</td>
<td>3,508,084</td>
</tr>
<tr>
<td><strong>Total net assets</strong></td>
<td><strong>11,608,987</strong></td>
<td><strong>9,462,561</strong></td>
</tr>
<tr>
<td><strong>Total liabilities and net assets</strong></td>
<td><strong>$14,167,638</strong></td>
<td><strong>$11,723,844</strong></td>
</tr>
</tbody>
</table>

The TSC Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization’s 2021 and 2020 financial statements to the TSC Alliance Board of Directors. The complete audited financials are on file with the TSC Alliance or available on its website. To obtain a copy, please call (800) 225-6872 or download at tscalliance.org. This summary was prepared from the audited consolidated statements of the TSC Alliance and the TSC 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 TSC Alliance and the TSC Alliance Endowment Fund. The Endowment Fund may experience gains or losses on its investments. In 2021 and 2020 there were net gains, 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 TSC Alliance Endowment Fund, the change in net assets of the TSC Alliance was a positive $1,328,199 and a negative ($271,742) for 2021 and 2020, respectively.
### Consolidated Statement of Activities

<table>
<thead>
<tr>
<th>Revenue and Support</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>2021 Total</th>
<th>2020 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special Events</td>
<td>$1,169,138</td>
<td>$55,434</td>
<td>$1,224,572</td>
<td>$1,287,311</td>
</tr>
<tr>
<td>Cost of direct benefits to donors</td>
<td>(46,439)</td>
<td>(46,439)</td>
<td>(59,986)</td>
<td></td>
</tr>
<tr>
<td>Special events, net</td>
<td>1,122,699</td>
<td>55,434</td>
<td>1,178,133</td>
<td>1,227,325</td>
</tr>
<tr>
<td>Contributions</td>
<td>1,198,857</td>
<td>3,330,407</td>
<td>4,529,264</td>
<td>2,775,502</td>
</tr>
<tr>
<td>Contracts</td>
<td>2,120,485</td>
<td>2,120,485</td>
<td>791,210</td>
<td></td>
</tr>
<tr>
<td>Conferences</td>
<td>113,777</td>
<td>113,777</td>
<td>1,475</td>
<td></td>
</tr>
<tr>
<td>Interest and dividends</td>
<td>108,717</td>
<td>18,843</td>
<td>127,560</td>
<td>131,179</td>
</tr>
<tr>
<td>Memorials and honoraria</td>
<td>135,221</td>
<td>1,018</td>
<td>136,239</td>
<td>110,097</td>
</tr>
<tr>
<td>Federated funding</td>
<td>54,696</td>
<td>54,696</td>
<td>38,743</td>
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</tr>
<tr>
<td><strong>Total revenue</strong></td>
<td><strong>4,854,452</strong></td>
<td><strong>3,405,702</strong></td>
<td><strong>8,260,154</strong></td>
<td><strong>5,075,531</strong></td>
</tr>
<tr>
<td><strong>Net assets released from restrictions</strong></td>
<td>2,026,987</td>
<td>(2,026,987)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total revenue and support</strong></td>
<td><strong>6,881,439</strong></td>
<td><strong>1,378,715</strong></td>
<td><strong>8,260,154</strong></td>
<td><strong>5,075,531</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program services</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>3,939,924</td>
<td>3,939,924</td>
<td>2,591,582</td>
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<tr>
<td>Family services</td>
<td>726,768</td>
<td>726,768</td>
<td>765,051</td>
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<td>Public health education</td>
<td>524,284</td>
<td>524,284</td>
<td>503,125</td>
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<td>Government relations</td>
<td>154,139</td>
<td>154,139</td>
<td>149,610</td>
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<tr>
<td>Professional education</td>
<td>122,600</td>
<td>122,600</td>
<td>24,320</td>
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<tr>
<td><strong>Total program services</strong></td>
<td><strong>5,467,715</strong></td>
<td>-</td>
<td><strong>5,467,715</strong></td>
<td><strong>4,033,688</strong></td>
</tr>
<tr>
<td><strong>Supporting services</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fundraising</td>
<td>990,443</td>
<td>990,443</td>
<td>1,085,941</td>
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<tr>
<td>Management and general</td>
<td>549,013</td>
<td>549,013</td>
<td>517,311</td>
<td></td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td><strong>1,539,456</strong></td>
<td>-</td>
<td><strong>1,539,456</strong></td>
<td><strong>1,603,252</strong></td>
</tr>
<tr>
<td><strong>Total expenses</strong></td>
<td><strong>7,007,171</strong></td>
<td>-</td>
<td><strong>7,007,171</strong></td>
<td><strong>5,636,252</strong></td>
</tr>
<tr>
<td><strong>Change in net assets from operations</strong></td>
<td>(125,732)</td>
<td>1,378,715</td>
<td>1,252,983</td>
<td>(561,409)</td>
</tr>
<tr>
<td><strong>Net investment income (loss)</strong></td>
<td>751,861</td>
<td>141,582</td>
<td>893,443</td>
<td>267,383</td>
</tr>
<tr>
<td><strong>Change in net assets</strong></td>
<td>626,129</td>
<td>1,520,297</td>
<td>2,146,426</td>
<td>(294,026)</td>
</tr>
<tr>
<td><strong>Net assets, beginning of year</strong></td>
<td>5,954,477</td>
<td>3,508,084</td>
<td>9,462,561</td>
<td>9,756,587</td>
</tr>
<tr>
<td><strong>Net assets, end of year</strong></td>
<td><strong>$6,580,606</strong></td>
<td><strong>$5,028,381</strong></td>
<td><strong>$11,608,987</strong></td>
<td><strong>$9,462,561</strong></td>
</tr>
</tbody>
</table>
A transformative year of generosity

Hope no matter how complex™