Hope no matter how complex
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The TSC Alliance was founded on the core belief that community is a sustaining strength in the face of difficult challenges. In 1974 four mothers who shared the common bond of tuberous sclerosis complex (TSC) came together to provide fellowship, generate awareness, pursue more knowledge and offer hope to each other. That was the birth of the TSC Alliance, and the spirit and intention of those founders permeate everything we do to this day.

For most everyone as well as the TSC Alliance, 2020 started with so much hope and momentum. While those aspirations were soon eclipsed by an unforeseen pandemic, our partners, volunteers, donors and most importantly the TSC community at large worked in concert like never before to ensure the TSC Alliance was able to continue working toward a future where every person and family affected by TSC has what they need to live their fullest lives.

The TSC Alliance’s work wouldn’t be possible without the commitment of our community. Advancing research requires dedicated investigators, individuals with TSC, government and industry. Improving quality of and access to care demands healthcare professionals and dedicated volunteers. Raising awareness takes the work of families, individuals and volunteers.

Despite the challenges of COVID-19, the collaboration of individuals and families, along with the partnership of other organizations, fueled our efforts to ensure people navigating TSC always have support—and hope—every step of the way. Some 2020 highlights include:

- The 2020 March on Capitol Hill to advocate for TSC research led to 216 signatures in the House, 35 in the Senate and an $8 million appropriation for TSC Research Program through the Congressionally Directed Medical Research Program at the Department of Defense.

- To address TSC-Associated Neuropsychiatric Disorders (TAND), the TSC Alliance developed a series of informational webinars featuring hands-on practical tips especially pertinent during the pandemic.

- The TSC Alliance offered more than 30 COVID-19 Webinars, Virtual Townhalls and Open Forums to address needs and answer questions of TSC families and individuals.

- During May, the TSC community raised unparalleled awareness by joining the #TSCstrong social media campaign and supporting the TSC Awareness Month of Caring fundraising effort.

- The 2020 TSC & LAM Virtual Conference Series was another huge success, featuring leading experts discussing cutting-edge research and clinical care for children and adults living with TSC and LAM.

- In our ongoing quest to better understand how TSC affects each person differently, the TSC community continued to advance TSC research by participating in clinical trials and the Natural History Database, including a pivotal COVID-19 study. The Biosample Repository also grew as we began to collect samples through mobile collection.

- The historic Step Forward to Cure TSC® National Virtual Walk-Run-Ride included a weekend of events, attracting more than 1,750 participants from all across the country who joined together to celebrate our community, raise crucially needed funds and spread awareness.

This 2020 Annual Report provides additional information about these and other accomplishments, overviews of our programs and services, fundraising successes, donor acknowledgements and much more.

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 connects 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 and 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.
Fueling and funding collaborative TSC research

The TSC Alliance’s 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 the disease. Our research program 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. Since 1984, the TSC Alliance has invested $27.7 million into TSC research projects through our Research Grants program and contracts, including:

- $18.5 million in research grants and postdoctoral fellowships,
- $4.4 million into the Natural History Database and Biosample Repository, and
- $4.1 million into the Preclinical Consortium and $0.7 million into the Clinical Research Consortium.

For a complete list of currently funded projects and an archive of past awardees, visit tscalliance.org/grants.

The Natural History Database (NHD) captures clinical data to document the impact of the disease on people’s health over their lifetime. As of December 2020, 2,268 people with TSC were enrolled in the project from among 18 U.S.-based sites and through the TSC Alliance. In 2020, the TSC Alliance added a sub-project to address detailed questions about COVID-19 infection in individuals with TSC.

The Biosample Repository collects high-quality biosamples—such as blood, DNA and tissues—to understand why TSC is so different from person to person. By the end of 2020, the project housed 1,571 biosamples, including 421 blood, 358 buccal and 29 tissues samples from individuals with TSC enrolled in the NHD; 374 blood samples from the TSC Clinical Research Consortium collaborative projects; and 389 DNA samples from the TSC Autism Center of Excellence Network Autism Biomarker study. The TSC Alliance also funded three seed grants totaling $60,000 to labs who submitted meritorious and innovative ideas for research on them.

Ensuring no one is alone for the TSC journey

The TSC Preclinical Consortium works to advance more drug candidates into clinical testing and provides the infrastructure to foster collaboration between academia and pharmaceutical industry researchers and for access to resources designed to help facilitate drug development in TSC. Since inception, the consortium has helped advance the evaluation of drugs for TSC by conducting 54 studies, evaluating 44 candidate drugs. In 2020, the Preclinical Consortium evaluated 13 candidate drugs in mouse models and screened an additional 10 compounds in cell-based models of TSC.

The TSC Alliance also stimulates collaboration and innovation through convening experts and stakeholders within and outside the TSC field. The first Innovation Workshop was held in 2020 and focused on newborn screening. This workshop’s goals included: define the critical path of developing a screening assay to enable nomination of TSC to the Recommended Uniform Screening Panel; specify the immediate next steps needed along the critical path; recommend components of a funding opportunity announcement to elicit the best ideas and applicants to implement those next steps; and enable the TSC Alliance to fund the most meritorious applications.

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The TSC Alliance’s Community Programs team 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 as well as manages the organization’s volunteers and educational outreach efforts.

A wide array of TSC Connect volunteers including Adult Regional Coordinators, TSC Clinic Ambassadors, Dependent Adult Transition Resource Coordinators, Education Parent Mentors and Future Leaders worked in tandem to facilitate 28,447 support interactions in 2020. A network of 33 volunteer branches of the organization, called Community Alliances, provided local TSC education and personal support throughout the country to 4,988 families/individuals living with TSC.

To help our community navigate the challenges of COVID-19 throughout 2020, the TSC Alliance created tscalliance.org/COVID-19, dedicated to sharing important information about the pandemic specifically curated to meet the needs of those impacted by TSC. This web page gained 23,447 views on the COVID-19 landing page in 2020. The organization also launched a weekly educational series in March with programming lasting 11 weeks. This effort included five Virtual Town Halls, two World Forum...
webinars with Tuberous Sclerosis Complex International, 15 webinars on topics of relevance to TSC individuals and families, and nine open forums for caregivers, teens, siblings and adults with TSC to openly discuss issues related to COVID-19 and TSC. In total, 9,151 people participated in or watched recordings of these webinars and Town Hall series.

The TSC Alliance also co-hosted a three-part virtual Conference Series with The LAM Foundation, attracting 818 registered attendees, 1,106 subsequent video views and 424 visits to the virtual exhibit halls.

**Amplifying the voices of TSC**

The TSC Alliance’s Communications Department heightens awareness of TSC by telling stories of the TSC community and creates awareness campaign and educational tools and resources. During 2020, the organization’s website attracted an average of more than 22,300 unique visitors each month, working hand in hand with our social media channels to educate constituents and promote new resources and events. The private TSC Alliance TSC Facebook Discussion Group is the largest in the world with more than 10,000 members. Our Twitter and Instagram accounts both have 2,400-plus followers. Eleven TSC Now podcasts were downloaded 1,906 times, while our bi-monthly e-newsletter TSC Matters has 1,006 subscribers. In addition, the TSC Alliance’s online educational platform, TSC Academy, introduced three new courses covering the topics of CBD, FDA Review Process and State and Local Advocacy.

To both reach the undiagnosed and educate the public about TSC, the TSC Alliance participated in the Sixth Annual TSC Global Awareness Day on May 15 as well as TSC Awareness Month throughout May and heavily promoted Infantile Spasms Awareness Week, December 1 to 7. This awareness campaign included social media outreach and targeted national print publications, medical trade magazines and podcasts, resulting in 10 major media placements, 31.7 million-plus impressions and 550-plus social engagements. Finally, the TSC Alliance’s various news releases culminated in 694 million impressions throughout 2020.

**Educating professionals about TSC**

Everyone should know about TSC, especially health-care professionals. Too many people go undiagnosed or misdiagnosed for years because of a lack of awareness, even though TSC is as prevalent as ALS, cystic fibrosis and Huntington’s disease. Early diagnoses change lives because they enable early interventions, which may prevent symptoms like developmental delays. In addition to offering and supporting Professional Education programs about TSC targeted toward healthcare providers and educators, TSC Alliance staff members participated in and presented at 22 professional meetings in 2020. The TSC Alliance also has formal partnerships with The Arc USA and Parent Training Information Centers around the United States to help parents and individuals navigate a myriad of educational issues and challenges.

**Empowering the community through advocacy**

The TSC Alliance’s grassroots-driven Government Advocacy program focuses on increasing federal and state appropriations for TSC research, increasing awareness among lawmakers and collaborating with government partners to drive TSC research forward as well as improve clinical care and treatment options for individuals with TSC. The TSC community’s collective voice is a powerful force for accelerating discoveries.

On the state level, the TSC Alliance advocated for state funding for TSC Centers in Missouri and Maryland, resulting in at least $500,000 in state appropriations. The annual TSC Alliance March on Capitol Hill to advocate for federal TSC research funding was supported by more than 120 TSC community members who urged their Senators and Representatives to sign onto Dear Colleague letters in support of the Tuberous Sclerosis Complex Research Program (TSCRP) at the Congressionally Directed Medical Research Program.

The House Dear Colleague Letter, co-sponsored by Representatives Markwayne Mullin (R-OK) and Dave Loebsack (D-IA), closed with 216 signers, while the Senate Dear Colleague Letter, sponsored by Senators Kevin Cramer (R-ND) and Jon Tester (D-MT), closed with 35 signatures. For FY2021, the TSCRP received an $8 million appropriation—a $2 million increase over FY2020, bringing its cumulative funding to $97 million since 2002.
Making connections around the world

Our Global Outreach efforts work to address unmet needs of TSC communities around the world through our network of Global Alliances and as a member of Tuberous Sclerosis Complex International.

Dedicated volunteers work at every Global Alliance, and we partner with them to create and implement plans to help people navigating TSC outside of the United States. 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. In addition, the TSC Alliance recognizes 10 TSC Clinics in Global Alliance countries.

Raising support to fuel our mission

The TSC Alliance’s Development and Community Programs Departments work together, focused on raising funds to make sure no one is alone on their TSC journey. Special events, community fundraisers and personal donations, large and small, allow our organization to be a central hub for information about TSC care and treatment, offering resources and support for individuals, families, healthcare professionals and educators to ensure quality care from diagnosis onward.

In 2020, special events netted $1,227,326, representing 24% of the organization’s overall revenue.

Step Forward to Cure TSC® National Virtual Walk-Run-Ride

The inaugural and historic Step Forward to Cure TSC® National Virtual Walk Run Ride took place August 22-23, 2020 and raised $660,000.

The weekend kicked off Friday, August 21 and featured Kari Luther Rosbeck, President and CEO; Shelly Meitzler, Community Programs Manager, East; Dr. Peter Crino, Vice Chair of the TSC Alliance Board of Directors; Laura Wallker, Owner, Powerful Fitness; and guest speaker Bao Heffron, a young adult with TSC. Numerous virtual mixers held over the course of the weekend provided a platform for TSC community members to network, get live updates and watch interviews with TSC Champions Carly Kaye, Jill Hyman, Katie Martin and Amy Hightower. The wrap-up rally was co-hosted by long-time celebrity spokesperson Jim O’Heir, who announced our top prize winners with host Kari Luther Rosbeck, with closing remarks from Chris Russell, Chair of the TSC Alliance Board of Directors, and Philip Tallman, a TSC adult and parent.

The event also featured a Facebook Live challenge, called “Getting Saucy with Parker B for TSC,” hosted by Ryan and Andrea Beebe with Kari Luther Rosbeck and Chief Scientific Officer Steve Roberds, PhD, that raised $6,305. In addition, the first annual Step Forward to Cure TSC Virtual Auction raised more than $28,000.

The TSC Alliance thanks our National 2020 Step Forward to Cure TSC Walk-Run-Ride sponsors, outstanding planning committee, donors and the 1,758 participants who all made our first virtual major event one to remember.
National Step Forward to Cure TSC Walk-Run-Ride Sponsors
Greenwich, Mallinckrodt, Novartis, UCB, Upsher-Smith Laboratories LLC, LivaNova, MassMutual SpecialCare and Neurelis

Local Step Forward to Cure TSC Walk-Run-Ride Sponsors
Stanford Children's Health, Variety, Streamwood Fire Fighters, Cavarocchi Ruscio Dennis Associates, Fifth Third Bank, Level Up Drywall, Soboba Foundation and Seizure Tracker

Grand Prize Winner
Mike Gryzo, Little D's Heroes

Highest Fundraisers
1st Place: Amy Hightower, #teamarthur—$36,174
2nd Place: Kalyan O'hara, Bodies Buddies—$28,918
3rd Place: Jill Hyman and Katie Martin, Skyblue Crew—$22,128

Largest Teams
Corporate: Greenwich Bioscience (238 participants)
Non-Corporate: #teamarthur / Amy Hightower (125 participants)
TSC Clinic: Robert & Ann E. Lurie Children's Hospital (10 participants)

Most Spirited Team
Brynleigh's Believers: Lauren Shillinger, Captain

TSC Miles
Most Miles Walked: Kelly Simontacchi, Team Greenwich (21 miles)
Most Miles Biked: Kelly Andreas, Snoopy's Friends (73 miles) and Jack Lyons, Lyon's Pride (81 miles)
Most Miles Run: Kate Critchfield, Team Topher (15 miles)
Most Miles Completed by a Team: Kirsten Swain, Team Topher (95 miles)

19th Annual Comedy for a Cure®
In July and October, the TSC Alliance successfully hosted two virtual evenings of Comedy for a Cure. As one of our most celebrated events, we expanded what is usually one night of comedic performances and honors into Summer and Fall Editions, which together raised $179,000.

We are extremely thankful to Comedy for a Cure's 2020 sponsors: Greenwich Biosciences, Novartis, Mallinckrodt, Variety, CVS Health, Horizon Therapeutics, the Maginn Family, Neurelis, Saks Foundation, the Szilagyi Family, UCB, WNC & the Cooper Family, Upsher-Smith Laboratories LLC, Tim and Kathi Dills, the Keith A. Hall Family, Lauren and Richard Packard, Susie and Nolan Spencer, and Ted and Peggy Mastroianni.

During the Summer Edition, we were so grateful for our hilarious emcees—Jim O’Heir, Alex Skuby and Craig Shoemaker; our comedians—Ahmed Ahmed, Bruce Jingles, Sarah Halstead, and Ryan Niemiller; and our esteemed TSC Champion, Dr. Shafali Jeste, for her groundbreaking research in autism and TSC and setting the stage for preventative interventions.

The Fall Edition featured the same amazing emcees—Jim O'Heir, Alex Skuby and Craig Shoemaker—who were joined by auctioneer extraordinaire, Damon Casitico, and an incredible group of comedians—Ben Gleib, Adam Ray, Kira Soltanovich and headliner Jay Mohr. We presented the much-deserved Courage in Leadership Award to the Carroll Family for their unwavering generosity and dedicated service to the TSC community through their advocacy for Federal TSC research funding. We also paid tribute to TSC Champion Edina Kiss for her compassionate partnership over the past decade via cause-related marketing and in-kind support of Comedy for a Cure and other nationwide TSC Alliance events.

Virtual 4th Annual Sound Bites
On November 20, Melissa Peterman and Chris Hawkey co-hosted the TSC Alliance's 4th Annual Virtual Sound Bites, which raised $71,500. The event gave us the opportunity to present the Courage in Leadership Award to the Wiltscheck Family for their exceptional community support and to honor Kat Perkins with the TSC Champion Award for her partnership and years of spectacular music supporting the TSC Alliance. Backed by Eric Warner on guitar, Kat's beautiful voice kicked off the music for the evening, followed by the Erin and Jay Cabaret with Chris Hawkey bringing it home musically with his sincere passion for our cause.

We are extremely grateful for the support of our TSC community in Minnesota and sincerely thankful to the event's sponsor: Dr. Michael and Janie Frost, Greenwich Biosciences, the Maginn Family, Minnesota Epilepsy Group, Novartis, Upsher-Smith Laboratories LLC, Goodin Co., RW Baird, Ray Chan, WPT Industrial and Fairchild's FosterCare.
Other community campaigns

The TSC Alliance kicked off 2020 with two successful community events held in January with others planned throughout the year. However, everything changed in the wake of the COVID-19 pandemic. Despite challenges and cancellations of all in-person events planned after the first week in March, the TSC community and other supporters rallied around the TSC Alliance and created some unique virtual events to maintain the mission and strength of the organization.

3rd Annual Brewing for a Cure
January 18, 2020
Host: Heather Harden
Raised: $27,637

Krewe for a Cure
January 25, 2020
Host: Margaret Cox
Raised: $10,775

TSC Global Month of Caring
May 2020
Raised: $178,858

Getting Saucy with Parker B
May 2020
Host: Ryan and Andrea Beebe
Raised: $73,875

Step Forward to Cure TSC National Virtual Walk-Run-Ride
T-shirt Campaign
Host: Carly Kaye
Raised: $13,000

Team TSC
Raised: $17,491

2020 TCS New York City Marathon—Canceled
The 2020 New York City Marathon on November 1, 2020 was canceled due to coronavirus-related health and safety concerns. Race managers provided charity partners with an option for 2020 registered participants to defer their entries to 2021, 2022 or 2023. At the time of this determination, the TSC Alliance had eight of our ten entries registered. Of the eight contacted, six runners have elected to defer their entries to a later date. Special thanks to our official deferred 2020 team members: Amanda Alberts, Shalonda Alexander, Bridget Faria, Bridget Lucas, Shelly Meitzler and Sarah Skelton.

The TSC Alliance President’s Council

Founded in 2016, the TSC Alliance President’s Council is comprised of members of families impacted by TSC who work with the President & CEO and Board of Directors to ensure TSC researchers have the data and funds they need to deliver breakthroughs. President’s Council members give or get a minimum gift of $100,000 per year to fund research. President’s Council Members since its inception include:

- David Coit
- Cowlin Family
- Tim and Kathi Dills
- Christopher and Joy Dinsdale
- Engles Family Foundation on behalf of Engles Collaborative Research Fund
- Jim and Andrea Maginn, through the creation of the Abigail and Amelia Clinical Accelerator
- Jonathan Rothberg and Bonnie Gould Rothberg, Rothberg Family Charitable Foundation for Children’s Disease
- Brittany Smith and John Gottschall
- William Watts
- Lorne Waxlax, through the creation of the Waxlax Biosample Collection Initiative
Annual Fund – Major Donors and Contract Revenue
Fiscal Year 2020: January 1 to December 31

Chairman's Circle
($100,000 and Above)
Anonymous
Tim and Kathi Dills
Facebook Community Donations
Foglia Family Charitable Gift Fund
Gerry and Bill Cowlin Foundation
Greenwich Biosciences
GW Research Ltd.
Brittany and John Gottschall
Healx Limited
Jim and Andrea Maginn
Novartis Pharmaceuticals Corporation
Small Business Administration, Paycheck Protection Program
Tuberous Sclerosis Alliance Endowment Fund
UCB, Inc.
Lorne Waxlax

Benefactor
($50,000 - $99,999)
Hampton Fund
Carol and James Herscot
Doug and Linda Loftus
Lundbeck Pharmaceuticals, Inc.
Mallinckrodt Pharmaceuticals
Anonymous
Chris and Leslie Russell
Upsher-Smith Laboratories LLC
William Watts

Sponsor
($20,000 - $49,999)
Anonymous
Anonymous
Child Neurology Foundation
Kay and Will Cooper Sr., WNC & Associates
Prachee Devadas
Dravet Syndrome Foundation
Haag Family Foundation
Janice and Julian Gangolli Family Fund
Robert and Kathryn Groves
Amy and Kortney Hightower
Ingram, Yuzek, Gainen, Carroll, Bertolotti, LLP
Debra and William Joseph
LivaNova
Marinus Pharmaceuticals, Inc.
MassMutual SpecialCare
Nancy and David Michaels
Julianne Moore and Bart Freundlich
Ned Neely
Neurelis, Inc.
Nobelpharma
Regenxbio, Inc.
Pam and Pam Waxlax
Wong Family Foundation

Protector
($10,000 - $19,999)
Bcureful
David M. Coit
Chris and Joy Dinsdale Family Foundation
Michael and Janie Frost
Intensity Therapeutics
Carly and Andrew Kaye
Mary Ann Lamb
Louis Berkowitz Family Foundation
Montgomery County Economic Development Fund
Robert and Lisa Moss, Seizure Tracker LLC
The Pediatric Epilepsy Research Foundation
Allan and Carla Price
Irene Rothberg
John and Barbara Swanson
Karen White and Julie Geissman
Winifred M. Gordon Foundation

Defender
($5,000 - $9,999)
Steve and Lynn Aguiar
Amanda Alberts
Amazon Smile Foundation
Amneal Pharmaceuticals, Inc.
Rebecca Anhang Price and Matthew Price
Anonymous
Dorothy Barber
Estate of Barbara B. Bartlett
Thomas and Elizabeth Beattie
Linda Buchman
Ray Chan
Sara Chieffo and David Skillman
April and Alfred Cooper
Peter Crino
CVS Health
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Doe Family Foundation
EveryLife Foundation
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Taylor Foxwell
Kevin and Peggy Gaffney
Google, Inc.
Andrea Hall
Brenda Henry
Horizon Therapeutics
David and Maureen Kenna
David and Cathy Krinsky
Darcy Krueger
Bev LaSota
Estate of Glenn Leiter
Greg Linsin and Julie Blum
Adam and Irene Marton
Theodore and Peggy Mastroianni
Minnesota Epilepsy Group, P.A.
Jon and Patricia Myers
Jo Anne Nakagawa
Ovid Therapeutics
Proverbs 3:9 Foundation
Nancy Richards
Christopher and Kari Luther Rosbeck
Saks Fifth Avenue Chicago
Andrew Salter and Michele Gammer
Michele Smith
Stanford Children's Hospital
Annie Szilagyi
Timber Pharmaceuticals
TSC Alliance of Hungary
TSC Alliance of Israel
TSC Alliance of Mexico
Tuberous Sclerosis Canada Sclerose Tubereuse Variety - The Children's Charity
John Waterbury
Cliff and Deborah White, Cliff and Deborah White Family Foundation
Patrick Whitehead and Christine Page
The Whitten Family Fund
Gayle Wilson
Kevin and Sarah Wright
Saul Wyner

Advocate ($1,000 - $4,999)
A&A Banner
Abbvie
Earl Abramson and Sheila Schlaggar
Janice Akridge
Shalonda Alexander
The Alidina Family Fund
Paul and Patricia Anderson
Anonymous
Anonymous
Arborscapes LLC
Alex and Liz Argo
Michael and Milly Augustine
Frank Auman
Jeffrey Avansino
Aventria Health Group LLC
Baird Foundation, Inc.
Derek Bauer
Geoffrey Bauer
Nicole Bayless
Natasha Beck
Benevity Community Impact Fund
Biotechnology Innovation Organization
The Boston Foundation
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Walter and Mary Bradley
Breslow Family Foundation
Ray Brinson
Bridget and Jeremy Britt
Walter Brooks
Victor and Diane Brown
Elizabeth and Andrew Buchsbaum
Pablo Burbridge and Corina Crivelli
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John and Cathy Carlson
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Mark and Elizabeth St. Lezin  
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John and Janine Steenman  
David Stefanoni  
Linda Stewart  
Streamwood Firefighters Union  
Diana Sullivan  
Dirk and Kimberly Suringa  
Robert and Lisa Szilagyi  
Gene Tackett  
Stephen Tart  
Jeffrey and Wendy Thames  
Sean and Kelly Thomann  
Donna Thompson  
TIAA  
Eric Tittle  
Lee and Gloria Triebenbach  
U.S. Venture/Schmidt Family Foundation  
University of Alabama Birmingham  
Jeanne Vander Ploeg  
Vanguard Charitable  
Harvey and Theresa Varnet  
Lauri Veimer  
Ventas  
Nancy Vignola  
Christine Viola-Weiss  
Alan and Nancy Vogel  
Betty Vollmar, Betty Bohl Vollmar Foundation  
Joseph Walsh  
Victor Wang  
William and Corrine Ward  
Doug and Carol Watson  
Abba Welte  
Western & Southern Financial Fund  
Westinghouse Electric Company  
Westminster Police Memorial Moranville  
Jack and Jeanne Whitaker
Carol Wiley
Clark Williamson
Michael Wong and Cecilia Hsien-Tsing Yu
WPT Industrial REIT
Debra Wright
Joseph and Deborah Yohn
Andrea Zoppo

Champion
($500 - $999)
John and Janet Addison
Jon Alagem
Lisa and Dave Allis
America’s Charities
Arul and Gowri Arulmoli
Ashton Land Surveyor, Inc.
Kit-Sing Au
Theodora Bailey
Laurisa and Daniel Ballew
David and Naomi Balto
Bancare, Inc.
Stephen Bauer
Matt Bengloff
Robert and Kelly Best
Kevin Bittel
David Blake
Daniel Bloomstein and Kirscha Burgess
Patricia Bodnar
Brian and Jamie Boesiger
Tamara Bogojevic-Catanzano
Fred Bohlander
Matt Bolger and Maureen Watson-Bolger
Bonfire
Ryan Bovia
Ben and Gail Brancel
Marta Brenden
Shawn Briones
Mitzi Brock
Harry and Karen Broome
David Brown
Kenneth Brown
Joe and Donna Bryant
William and Alina Buchman
Pete Bullard
Marlee Cain
Brooke Call
Cane's Chicken Fingers
Frank and Barbara Capone
Joe and Sharon Cappadona
Trent Carlson
David and Brooke Carpenter
Bryce and Cassandra Carroll
Heather Case
Scott and Edie Catlin
Lisa Catto
Charles Cattrell
Michael Cavenee
Michele Cavenee Eller
Jeffrey Chernov
Children’s of Alabama
Mary Chow
The Chubb Corporation
Ron and Dorothy Cibulskis
Savannah Citron
Ken Cleveland
Kristie Cline
Michael Cohen

Paul and Susan Collins
Columbian Charities of Missouri, Inc.
Community Shares of Colorado
Linda Connors
Mike and Mary Cook
Steve Copeland
Kari Corey
Jessica Couillard
Andy Coyne
Brian and Mary Day
Stephen and Laurie Dennis
Kelly Desjardine
Gloria DeValle
Dr. Neal Suares Family Medicine
John Duffy
Charles and Bonnie Hogue Duffy
Anthony Earley
Eastport Trading Co, Inc.
Dean and Melissa Edmundson
Ralph Ellis
Martin Elspeth
Sejal Emerson
Rekha Epili
Carey Erin
Rusty and Kim Field
Maureen Filmer
First Presbyterian Church
Folk Design Group LLC
Gloria Garbutt
Alfred and Johanna Garzino
Don and Nancy Germano
Matt and Jennifer Geyso
Scott Giacobello
Bojan Gligorijevic
John Golden
Marc Goldstein
Reese Grafft
Robert and Shannon Grandia
Hattie Gresham
Joseph and Margaret Griscti
Andrew Gross
Michael Grygo
Beatrice Gurwitz
Karen Gustafson
Michael and Kathleen Gutto
Henry and Lucy Hahn
David and Heidi Hahne
Raymond and Nancy Hall
Lee and Susan Hammontree
Carter Hampton
Joe and Debby Harden
Frances Harper
Ron and Ann Heffron
Linda and Tom Held Charitable Fund
Rick Heltzel
Theresa Hemp-Hall
Craig and Allison Henning
Mark Borman and Karen Hermelin
Michael Hicks and Megan Big John
Dorsey Hightower
Sandra Hightower
The Hillary Family Foundation
William and Francine Hillier
Ralph and Carol Honderd
Dena Hook and Santo Pino
Hope Christian Reformed Church
Curtis and Carolyn Hull
Sheri Hyland
Jaye Isham and Larry Rocha
Steven Jasper
Wayne and Emiko Jasper
John and Renee Charitable Fund
Shonnie and the late Ken Johnson
Johnson & Johnson
Elizabeth Johnstone
Carol Jordan
Matt and Susan Jorski
Noby Joseph
JP Morgan Chase Bank, NA
Anthony Kay
Curtis Kelly
David and Sari Kelly
Craig and Sally Kieny
Chris and Alicia Kisselburgh
Ronald Klein
Dennis and Sandra Kollmann
Fred and Norma Kozisek
Russell and Merry Kraft
Jon Kralik
Jeff Krol
Frances Kuehn
Lise Lagace
James Lamb
Tom and M.E. Langbein
Frank Lansford
Justin and Carey Largent
Johnny and Chinny Law
Wynonia Lazaro
Joia Lee
Renee Leeb
Rodney and Caroline Lenz
Stan Lloyd
Douglas Loock
Brandi and Jason Lowe
Aida Lucero
Judy Luther
Laura Macinnis
Barbara Malatesta
Arien Malec and Kristin Barr
Edward and Judith Malecki
Audrey Malesky
Jo Neil Malloy
Lawrence and Joya Marks
Marsh & McLennan Shared Services Corporation
Katie Martin
Susan Mazahteri
Courtney McBride
Charles and Theresa McFadden
Toby McClain
Andrew McIntyre
Patrick and Mary McKiernan
Virginia McKiernan
Greg Meier
Robert and Mary Melcher
Michael Miller
Clark and Linda Moore
Laurie Morrow
Scott and Faith Moskowitz
Ernesto Moules
Thomas and Joyce Murphy
Music Theory Society of the Mid-Atlantic
Lytton and Elizabeth Musselman
Jason Davis and Jenny Nassal
Kirk Neely and Holly Myers
Gerald and Jill Nerheim
Shane Novacek and Molly Ruggles
Robert O'Reilly
Dan and Kaylan O'hara
Dennis O'Hara
Oracle
Michael and Diane Oravecz
Lily O'Rielly
Sharon Palm
Lydia Palumpon
Ali and Shamsuddin Panjwani
Howard Pattis
Paypal Charitable Giving Fund
Vincent Pedre
Sandra Perlmutter
Kellyann Petrucci
Daniel and Tracey Pilone
Jen Pooley
Pure Salon
Raechelle Raimondo
David and Kathy Rauch
Nathalie Richard
Stephanie Ricke
Patrick and Maureen Roche
Stephanie Rogone
Diane Rose
Kelley Sadlowski
Mildred Sanders
Raman and Oonagh Sankar
Thomas and Deborah Schaefer
Thomas and Nancy Schaefer
Dale and Colleen Schleich
David Sharon
Sheila Shillinger
Seth and Rebecca Short
Betty Smith
Lytle Smith
Melvin Smith
Mike Smith and Patricia Hagins
Mallory South
Garrett Spahr and Tara Palage-Spahr
Hans and Joanne Hans Spiecker
Lora Spizzirri
Elizabeth Stafford
Lanae Steen
Cynthia Sterling
Warren Stewart
Nadav Streett
Robert and Karin Sullivan
Lofa Tatupu
Hal Tarse
Paul Thomas
Michael Thompson
Todd Family Charitable Foundation
Melaura Tomaino
Autumn Tompkin
Armen and Vicky Toroian
Harvey Triebwasser
Andrew and Helen Triemer
Amy Trittipo
Kelly Tufts
James Tuite
Jed Turner
Keith Turner
Thomas Tylman
United Way of Central Indiana
United Way of Greater Cleveland
United Way of Greater Portland
United Way of San Diego County
John Uster
Dan Vannice
Ana Vasquez  
Norma Vasquez  
Patrilla Vigil  
Rita Vinnicombe  
Tim Walker  
Miriam Warshauer-Cohen  
Dick and Evy Kay Washburne  
Krystal Watts  
Christina Waxlax and James Paine  
Westbury Fire Dept Hose Co. No. 1  
Westvale Road Runners Club  
Carolann White  
Hayes Williams  
Joan Williams  
Matthew Wilson  
Scott Wilson  
Kallan Windham  
Terence Wingert  
Joel Wojnilower  
Sheila Wolff  
John and Laurel Wrynn  
Joyce and Allan Wu  
David and Marilyn Yeamans  
Marlin Yoder  

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

Ahmed Ahmed  
Anonymous  
Farzana Ali  
Michael and Jennifer Bailey  
Laurisa and Daniel Ballew  
Bob’s Watches  
Bragg Properties LLC  
Patricia Brontman  
Damon Casatico  
David Coit  
Kay and Will Cooper Sr.  
Jennifer and Will Cooper, Jr.  
April and Alfred Cooper  
Cypress Design Studio & Framing LLC  
Carol Ann White and Lori DiStefano  
Neil and Amy Dublinske  
EBoost  
Edina Kiss Jewelry  
EOS Estate Winery  
Jay Fuchs  
Giovinezza Laser Medical Group  
Ben Glieb  
Tiffani Goff  
Grenn Pilot  
Jason Gulliot  
Sarah Halstead  
Jimmy Place  
Jonathan and Heather Harden  
Frances Harper  
Chris Hawkey  
Amy Hightower  
Rhett Hobart  
Mark Hobart  
Christy Hobart  
Dana and Bruce Holinka  
Hong Kong Tailers  
Bruce Jingles  
Kaye Design Studios  

Edina Kiss  
Wendy Liebman  
Douglas P. Loftus, CFP, Wealth Dimensions  
Loren Backe Photography  
Patrick and Lisa Mills  
David and Jan Mintz  
Hasib and Malinda Mobh  
Jay Mohr  
Ryan Niemiller  
Ocean Properties Hotel, Resorts and Affiliates  
Jim O’Heir  
Jeanette Page  
Kat Perkins  
Melissa Peterman  
Adam Ray  
Erin Schwab  
Craig Shoemaker  
Alex Skuby  
Jan Snyder Stevens  
Kira Soltanovich  
Southern Ag Credit  
Stagetime Productions  
John Stone  
Stonebridge Country Club  
Robert and Lisa Szilagyi  
Taylor Rental  
Tearse Photography  
The Newport Harbor Hotel Marina  
The Pantry, Inc.  
Total Wine & More  
Trout Mouth Charters  
Variety Magazine  
Vanessa Vazquez and Max Bertolotti  
Eric Warner  
David Webb  
Gayle Wilson  

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.

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)
Andrea Hall and the late Keith Hall
Robert and Joan Appleby Foundation

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

Investment Society ($500 - $4,999)
Farrar Family Charitable Fund
Jason and Brandi Lowe
Network for Good
Laura Wilson-Brown

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 join the Eternal Flame Society. If you or a loved one has designated the TSC Alliance through a planned gift and are currently not listed in the Eternal Flame Society, please let us know so we can add you. We are pleased to honor the following distinguished Eternal Flame Society members:

Harry Alcorn*
Anonymous
David Armijo
Michael and Millicent Augustine
Harold and Barnice* Belfer
Jeffery and Gloria* Benham
Matt Bolger
Treasa Bolger-Dunlap
Alice Brossart
Anthony Brunno*
Scott and Jan Burton
Marguerite Cleveland
John and Katherine Conrad
Kay and Will 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
Craig T. Lewis*
Doug and Linda Loftus
Magdalena Lutsky
James Lynch
Glennwood Dale Maier*
Robert McBride*
Donna McGaha
David and Jan Mintz
William Morris*
Maria Sharon Munoz-Chargoy
Ottilitt Nadel*
Jean Panther*
David and Penney Parkes
Jeffrey and Bonnie Rickert
Pat and Jennifer Rolfes
Kari Luther Rosbeck
Dave and Nancy Scott
Robert and Mary Ellen Scott
Joan Smardan*
Fred and Ilse Smith
John and Janine Steenman
Mark Stromberger*
Rob Thurston
Kathy Trapp
Alma A. Tutrone*
Jim and Nancy Weir
Philip and Marion Winsor
Barbara Witten and William Bradley
Frieda Zimmerman*

*Deceased

Endowment Named Funds

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

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

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

Operating Board of Directors
Chris Russell, Chair
Coppell, TX
Peter Crino, MD, PhD, Vice Chair
Moorestown, NJ
William Joseph, Treasurer
State College, PA
Laura Marks, Secretary
Queens, NY
Timothy Dills, Immediate Past Chair
Great Falls, VA
Julie Blum
Potomac, MD
Matt Bolger
Lansing, MI
Cassandra Carroll
Oakland, CA
Mark Carroll
Saratoga, CA
Sara Chieffo
Washington, DC
David Coit
Cape Elizabeth, ME
Margaret Cox
Vestavia, AL
Andrew Duffy, International Partner Member
Toronto, ON
Bonnie Hogue Duffy
Chevy Chase, MD
Steven Goldstein, CPA, FFS
Westport, CT
Rob Grandia
Riverside, CA
Dana Holinka
Northglenn, CO
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
Judy Shoulak
Corcoran, MN
Matthew Simonian
Humble, TX
Vanessa Vazquez
Miami, FL
Paul Waxlax
Denver, CO
Tara Zimmerman
Reno, NV

Endowment Fund Board of Directors
Doug Loftus, Chair
Cincinnati, OH
Michael Augustine, JD, Secretary
San Gabriel, CA
Hal Tearse, Treasurer
Independence, MN
Marion Adams
Mobile, AL
Mark Carroll
Saratoga, CA
Robert Groves
Leander, TX
William Joseph
State College, PA
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
Julian S. Gangolli
Independent Advisor
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
Vice President, International Operations
Dairy Queen
Mary Jane Mudd
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
Richard Gollub, CPA
Chief Financial Officer
Steven Roberds, PhD
Chief Scientific Officer
Dean Aguari, PhD
Director, Preclinical Research
Lilian Ansari
Community Programs Resource Advisor
Taylor Bates
Development Associate
April Cooper
Vice President, Community Programs
Zoë Fuchs  
Science Project Coordinator  

Emebet G/Micheal  
Senior Accountant  

Jaye Ishaw  
Senior Vice President, Strategic Communications  

Daniel Klein  
Director, Digital Platforms  

Justin Martucci  
Development Systems Manager  

Shelly Meitzler  
Regional Program Manager, East  

Lisa Moss  
Vice President, Donor Relations  

Jo Anne Nakagawa  
Director, Clinical Projects & TSC Clinic Liaison  

Ashley Pounders, MSN, FNP-C  
Director, Medical Affairs  

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  

TSC Alliance of Alabama  
Margaret Cox, Chair  

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

TSC Alliance of Arizona  
Debora Moritz, Chair  

TSC Alliance of Austin  
Shalonda Alexander, Chair  

TSC Alliance of Connecticut  
Jennifer Waldron, Chair  

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

TSC Alliance of Delaware/Lehigh Valley  
Liz Saadoun, Co-Chair  
Devon McCollum, Co-Chair  

TSC Alliance of the Delta Region  
Heather Harden, Chair  

TSC Alliance of Florida  
Amy Hightower, Co-Chair  
Vanessa Vazquez, Co-Chair  

TSC Alliance of Georgia  
Wendi Scheck, Chair  

TSC Alliance of Greater Chicago  
Geri Greenberg, Chair  

TSC Alliance of Greater Kansas City  
Amy Dublinske, Chair  

TSC Alliance of Hawaii  
Trisha Kam, Chair  

TSC Alliance of the Heartland  

TSC Alliance of Houston  
Heather Little, Chair  

TSC Alliance of Indiana  
Laura Marlin, Co-Chair  
Cassie Souder, Co-Chair  

TSC Alliance of the Intermountain West  
Kelli Sutherland, Chair  

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

TSC Alliance of Maryland  
Lauren Shillinger, Chair  

TSC Alliance of Michigan  
Carly Kaye, Chair  

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

TSC Alliance of New England  

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

TSC Alliance of North Carolina  
Karen Johnston, Chair  
Virginia Musseleman, Vice Chair  

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

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

TSC Alliance of Oklahoma  
Heather Lens, Chair  

TSC Alliance of the Pacific Northwest  
Gloria Triebenbach, Chair  
Debbie Rothwell, 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 Tennessee  

TS 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  

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  
Brooke Simsa  

Region 6: Tennessee, Kentucky, Georgia, Alabama, Mississippi, Florida  
Kate Crosett  

Region 7: Connecticut, Vermont, Maine, Rhode Island, New Hampshire, New York, New Jersey, Massachusetts  
Phillip Tallman  

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, 2020**

<table>
<thead>
<tr>
<th>Assets</th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$2,370,947</td>
<td>$2,093,560</td>
</tr>
<tr>
<td>Investments</td>
<td>5,913,426</td>
<td>5,941,995</td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>113,491</td>
<td>10,243</td>
</tr>
<tr>
<td>Promises to give</td>
<td>1,578,285</td>
<td>2,033,626</td>
</tr>
<tr>
<td>Prepaid expenses and other assets</td>
<td>403,498</td>
<td>262,620</td>
</tr>
<tr>
<td>Operating lease right of use asset, net</td>
<td>833,830</td>
<td></td>
</tr>
<tr>
<td>Property and equipment</td>
<td>510,367</td>
<td>80,221</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td><strong>$11,723,844</strong></td>
<td><strong>$10,422,265</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Liabilities and Net Assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Liabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$181,331</td>
<td>$333,196</td>
</tr>
<tr>
<td>Accrued compensation</td>
<td>254,553</td>
<td>200,306</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>422,226</td>
<td>54,700</td>
</tr>
<tr>
<td>Operating lease liability, net</td>
<td>1,336,433</td>
<td>7,176</td>
</tr>
<tr>
<td>Gift annuity obligations</td>
<td>66,740</td>
<td>70,300</td>
</tr>
<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>2,261,283</strong></td>
<td><strong>665,678</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Net assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Without donor restrictions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undesignated</td>
<td>189,609</td>
<td>(214,362)</td>
</tr>
<tr>
<td>Board-designated</td>
<td>5,764,868</td>
<td>5,936,709</td>
</tr>
<tr>
<td><strong>Total without donor restrictions</strong></td>
<td><strong>5,954,477</strong></td>
<td><strong>5,722,347</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>With donor restrictions</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3,508,084</td>
<td>4,034,240</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total net assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9,462,561</td>
<td>9,756,587</td>
</tr>
</tbody>
</table>

| **Total liabilities and net assets**      | **$11,723,844** | **$10,422,265** |

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 2020 and 2019 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 2020 and 2019 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 negative ($271,742) and a positive $355,028 for 2020 and 2019, respectively.
# National Tuberous Sclerosis Association & Affiliate

## Consolidated Statement of Activities

### Revenue and Support

<table>
<thead>
<tr>
<th></th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>2020 Total</th>
<th>2019 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Special Events</strong></td>
<td>$ 1,160,425</td>
<td>$ 126,886</td>
<td>$ 1,287,311</td>
<td>$ 2,706,594</td>
</tr>
<tr>
<td><strong>Cost of direct benefits to donors</strong></td>
<td>(59,986)</td>
<td>(59,986)</td>
<td>(285,156)</td>
<td></td>
</tr>
<tr>
<td><strong>Special events, net</strong></td>
<td>1,100,439</td>
<td>126,886</td>
<td>1,227,325</td>
<td>2,421,438</td>
</tr>
<tr>
<td><strong>Contributions</strong></td>
<td>1,353,452</td>
<td>1,422,050</td>
<td>2,775,502</td>
<td>3,021,932</td>
</tr>
<tr>
<td><strong>Contracts</strong></td>
<td>791,210</td>
<td></td>
<td>791,210</td>
<td>247,384</td>
</tr>
<tr>
<td><strong>Conferences</strong></td>
<td>1,475</td>
<td></td>
<td>1,475</td>
<td>174,381</td>
</tr>
<tr>
<td><strong>Interest and dividends</strong></td>
<td>113,341</td>
<td>17,838</td>
<td>131,179</td>
<td>191,528</td>
</tr>
<tr>
<td><strong>Memorials and honoraria</strong></td>
<td>107,148</td>
<td>2,949</td>
<td>110,097</td>
<td>102,250</td>
</tr>
<tr>
<td><strong>Federated funding</strong></td>
<td>38,743</td>
<td></td>
<td>38,743</td>
<td>45,664</td>
</tr>
<tr>
<td><strong>Other income</strong></td>
<td>-</td>
<td></td>
<td></td>
<td>714</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>3,505,808</td>
<td>1,569,723</td>
<td>5,075,531</td>
<td>6,205,291</td>
</tr>
</tbody>
</table>

### Expenses

**Program services**

<table>
<thead>
<tr>
<th></th>
<th>2020 Total</th>
<th>2019 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research</strong></td>
<td>2,591,582</td>
<td>2,590,463</td>
</tr>
<tr>
<td><strong>Family services</strong></td>
<td>765,051</td>
<td>929,277</td>
</tr>
<tr>
<td><strong>Public health education</strong></td>
<td>503,125</td>
<td>439,992</td>
</tr>
<tr>
<td><strong>Government relations</strong></td>
<td>149,610</td>
<td>165,225</td>
</tr>
<tr>
<td><strong>Professional education</strong></td>
<td>24,320</td>
<td>92,979</td>
</tr>
<tr>
<td><strong>Total program services</strong></td>
<td>4,033,688</td>
<td>4,217,936</td>
</tr>
</tbody>
</table>

**Supporting services**

<table>
<thead>
<tr>
<th></th>
<th>2020 Total</th>
<th>2019 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fundraising</strong></td>
<td>1,085,941</td>
<td>1,135,609</td>
</tr>
<tr>
<td><strong>Management and general</strong></td>
<td>517,311</td>
<td>542,410</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td>1,603,252</td>
<td>1,678,019</td>
</tr>
</tbody>
</table>

**Total expenses**

<table>
<thead>
<tr>
<th></th>
<th>2020 Total</th>
<th>2019 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Change in net assets from operations</strong></td>
<td>8,816</td>
<td>(561,409)</td>
</tr>
<tr>
<td><strong>Net investment income (loss)</strong></td>
<td>223,134</td>
<td>767,563</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8,937,390</td>
<td>309,336</td>
</tr>
</tbody>
</table>

**Change in net assets**

<table>
<thead>
<tr>
<th></th>
<th>2020 Total</th>
<th>2019 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net assets, Beginning of Year</strong></td>
<td>5,722,347</td>
<td>8,679,688</td>
</tr>
</tbody>
</table>

**Net assets, End of Year**

<table>
<thead>
<tr>
<th></th>
<th>2020 Total</th>
<th>2019 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net assets, End of Year</strong></td>
<td>$ 5,954,477</td>
<td>$ 9,462,561</td>
</tr>
</tbody>
</table>

---

NOTE: These are the stand-alone revenues of the TSC Alliance.
Hope no matter how complex