Unfathomable pain and grief have turned into the biggest blessing we could ever hope for in our lives.

ERICA, MOM OF DOMINIC (7) WITH TSC
Throughout 2023, the TSC Alliance experienced incredible new frontiers in exploring scientific research, our community coming together to build coalitions and the power of our combined strength as we work together to achieve progress in the fight against tuberous sclerosis complex (TSC). Below are some new landmarks we achieved this year:

- Finding success in familiar territory with our signature events with the March on Capitol Hill securing $8 million in federal TSC research appropriations, Step Forward to Cure TSC® events raising more than $780,000, Comedy for a Cure® raising $460,000-plus and TSC families and individuals attending our International TSC Research Conference and four Regional TSC & LAM Conferences.
- Mapping out new scientific avenues that will radically change the direction of TSC, including gene therapy, reproductive/perinatal health and prevention of manifestations, as well as laying the groundwork to predict the severity of TSC-associated neuropsychiatric disorders (TAND), including autism and cognitive delay, and developing TAND-specific treatments.
- With guidance from our community and Board of Directors, the organization developed a new five-year strategic plan detailing how we will make progress toward changing the course of TSC by 2028 and updated our mission and vision statements.

William Faulkner stated, “You cannot swim for new horizons until you have courage to lose sight of the shore.” Emboldened by the strength of the TSC community, we have been able to make huge leaps and set sail on new adventures on the ever-changing tides of progress.

In the following pages, you learn much more about the map of TSC Alliance's vast 2023 research, clinical and community programs accomplishments; fund-raising victories; major donors; and our audited financials.

### About tuberous sclerosis complex

TSC is a rare genetic disease that affects people at all stages of life. Every individual's experience with TSC is different—many live independently while others require more complex care. We know at least two babies are born each day in the United States with the disease. In fact, nearly one million people worldwide are estimated to be living with TSC, with approximately 50,000 in the United States.

TSC causes tumors to grow in different organs and can impair their function, primarily the brain, heart, kidneys, skin and lungs. Changes in the brain caused by TSC have the biggest impact on quality of life, from seizures and developmental delays to intellectual disabilities, behavioral challenges and autism. In addition, TSC is the leading genetic cause of epilepsy and the leading symptomatic cause of infantile spasms. A strong correlation also exists between TSC and autism—an estimated 40-50% of individuals with TSC have autism spectrum disorder.

The more we understand about TSC, the more we understand about other diseases. TSC is a linchpin disease, meaning its genetic pathway also plays a role in other diseases and disorders. Advancements in TSC research have enhanced treatments for autism, epilepsy and cancer—diseases that affect nearly 26 million people in the United States alone.

### About the TSC Alliance

The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with tuberous sclerosis complex.

We are a source of hope and connection for all affected by TSC. We drive research, improve care quality, improve access and advocate with and for people affected by the disease. Through our collaboration and partnerships, we've advanced FDA-approved treatments and created support systems around the world, so no one has to navigate TSC alone. 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.

### Strategic planning leads to new vision and mission statements

Throughout 2023, members of the TSC Alliance Board of Directors, staff and community worked diligently and thoughtfully to write a five-year strategic plan. This plan was based on community needs and input, informed by a comprehensive online constituent survey and in-person discussions.

As part of that process, the organization updated its Mission and Vision Statements to better reflect the goals and objectives in the new plan. The organization’s new Vision Statement is to create a future where everyone with TSC has what they need to live their fullest lives. The new Mission Statement is: The TSC Alliance improves quality of life for everyone affected by tuberous sclerosis complex by catalyzing new treatments, driving research toward a cure and expanding access to lifelong support.

To read a summary of the new strategic plan, including updated objectives, goals, strategies and measures, visit tscalliance.org/strategicplan.
Research

The Science Department ensures researchers have the data and funds they need to discover breakthroughs in TSC. With support from the TSC community, researchers, and industry partners we are accelerating the development of new treatments by building resources and fostering collaborations at key points along the drug discovery pipeline.

Since 1984, the TSC Alliance has invested more than $37 million into TSC research projects through grants and contracts: $20.6 million in research grants and postdoctoral fellowships, $5.3 million into the Natural History Database and Biosample Repository, $9.6 million into the Preclinical Consortium, and $1.6 million into the Clinical Research Consortium.

In 2023, the TSC Alliance hosted our biennial International TSC Research Conference: Fueling the Future. The conference featured an Early Career Research Symposium, a keynote speech from Dr. Martina Bebin, 30 oral presentations, 59 posters, a TSC International workshop and a combined closing session with TSC & LAM Regional Conference participants. The conference also featured four breakout working group sessions (Transition from Pediatric to Adult, Neurodevelopment and Early Intervention, Cellular Energetics and Metabolism, and Big Data and Single Cell Approaches/Analysis) to allow time for attendees to meet with others in their field and work toward solutions for current issues in their area.

The TSC Natural History Database (NHD) captures clinical data to document the impact of the disease on a person's health over his/her lifetime. The database serves as a resource of information that helps TSC researchers better understand the progression of the disease, design hypothesis-driven questions to hasten the discovery of new treatments and identify persons with TSC who are eligible to participate in research studies. As of December 2023, 2,678 people with TSC were enrolled in the project from among 22 TSC Clinic sites and through the TSC Alliance. The TSC Alliance provides funding to participating clinics to perform data entry, monitors the integrity of the database, and makes data available to investigators to answer specific research questions and identify potential participants for clinical trials and studies.

The TSC Biosample Repository collects high-quality biosamples—such as blood, DNA and tissues—to help researchers understand why TSC is so different from person to person. Samples in the repository are linked to detailed clinical data in the NHD and are available to qualified researchers worldwide. As of December 31, 2023, the TSC Biosample Repository has acquired 2,654 biosamples: 1,012 blood samples from individuals with TSC enrolled in the NHD, 452 buccal samples from individuals with TSC enrolled in the NHD, 197 tissue samples from individuals with TSC enrolled in the NHD, 591 blood samples from the TSC Clinical Research Consortium collaborative projects, 389 DNA samples from the TSC Autism Center of Excellence Network Autism Biomarker study and 10 control samples.

Since the inception of our mobile phlebotomy initiative, we have acquired 473 blood samples via mobile phlebotomy. To encourage and enable more researchers to utilize biosamples, the TSC Alliance awarded three seed grants in 2023, totaling $60,000, to labs that submitted meritorious and innovative ideas for research on TSC biosamples.

The TSC Alliance’s whole-genome sequencing (WGS) initiative using DNA from blood samples in our biosample repository sequenced an additional 72 samples in 2023, totaling 115 samples since inception. This initiative supports clinical validation of variants found via WGS in either the TSC1 or TSC2 gene and genetic results are offered back to participants along with a genetic counseling session free of charge to the family to help them better understand their unique TSC diagnosis and provide valuable information for future decision making such as family planning.

In December 2021, the TSC Alliance added the TSC Self-Report Portal to the TSC Natural History Database. This portal permits the collection of patient-reported outcomes on how TSC affects individuals and families, which will complement medical data in the Natural History Database and helps the TSC Alliance and TSC researchers better understand the perspective of those affected by TSC to develop tools to measure improvement in areas most important to the TSC community. Eventually, these measurements can be used to identify endpoints for clinical trials and evidence-based guidelines for treatment.

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). At the end of 2023, 105 individuals were enrolled through the self-report portal.
In April 2023, the TSC Alliance hosted an innovation workshop to focus on furthering translational research on TAND. Outcomes from this research will be utilized to refine and develop PRO measures, investigate biomarkers, and develop preclinical TAND animal models to test candidate drugs.

In February 2023, the TSC Alliance hosted a community focus group during the Volunteer Leadership Summit in Washington, DC to gain insight into which TAND symptoms are most impactful to families. The long-term goal is to develop quantifiable patient-reported outcomes for those most impactful aspects of TAND utilizing the combined expertise of individuals and families living with TSC and clinical researchers. The focus group included nine caregivers of both children and dependent adults with TSC, and anxiety was identified as the most impactful TAND symptom, followed by sleep issues.

In April 2023, the TSC Alliance hosted an innovation workshop to establish a plan to identify blood-based biomarkers associated with behavioral and cognitive aspects of TAND. The participants of the workshop consisted of scientists, clinicians, community leaders, data analysts, and industry partners. This led to a prioritization of blood samples in the BSR/NHD and curated from TSC clinical trials including the second phase of a Developmental Synaptopathies Consortium (DSC) project and access to neurotypical controls. The strategy includes identifying potential protein, RNA, and DNA signatures that correlate with TAND manifestations.

The TSC Preclinical Consortium helps advance more drug candidates into clinical testing by providing the infrastructure to foster collaboration between academia and pharmaceutical industry researchers and for access to resources designed to help facilitate drug development in TSC. 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. Additional models for LAM are being developed in collaboration with The LAM Foundation. In 2023, two new industry members joined the consortium with a total of nine active industry members at the end of the year. The consortium tested 17 unique compounds in 2023, raising the total tested to 82 since 2016.

The TSC Preclinical Consortium helped raise the total tested to 82 since 2016. 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, TSC Clinical Research Consortium investigators have been awarded more than $40 million by the National Institutes of Health (NIH) and Food and Drug Administration through competitive grant processes.

The TSC Alliance also provides supplemental financial support to accelerate or expand NIH-funded studies. The PREVeNT trial—Preventing Epilepsy using Vigabatrin in Infants with TSC—was the first preventative trial in the United States for any form of epilepsy. Initial results from the study were reported this year and showed that preventative treatment with vigabatrin beginning when EEG biomarker changes were observed delayed the onset and lowered the overall occurrence of infantile spasms in infants with TSC. However, there was no significant difference between the treatment group and the placebo group in terms of drug-resistant epilepsy, focal seizures, or cognitive and behavioral outcomes at two years of age. In this trial, the biggest predictor of poorer developmental outcomes was the age at which the EEG biomarker changes occurred, suggesting that rapid diagnosis of TSC in infants, prior to having any seizures, followed by a close monitoring and rapid initiation of treatment when seizures begin is critical for ensuring the best outcomes possible.

Immediately after the PREVeNT trial enrollment completed, a similar clinical trial began enrolling newborns with TSC before the onset of seizures to test the effects of sirolimus on preventing or delaying seizure onset. The Stopping TSC Onset and Progression 2 (STOP-2) trial enrolled five infants at Cincinnati Children’s Hospital Medical Center as an initial safety study. The second stage of the trial is now called “Sirolimus TSC Epilepsy Prevention Study (TSC-STEPS)” and the TSC Alliance has contributed $200,000 to enable the trial to be expanded to additional sites across the country.

The TSC Alliance is also providing supplemental funding and collecting blood samples for the Developmental Synaptopathies Consortium (DSC), an NIH-funded project that includes studies of TSC and the related rare disorders Phelan-McDermid Syndrome and PTEN Hamartoma Syndrome. Researchers in this study are trying to find earlier signs of autism spectrum disorder (ASD) and intellectual disability (ID) to gain a better understanding of ASD/ID in individuals with TSC and enable effective treatments and interventions for ASD/ID to be found. The TSC Alliance funds a portion of clinical research coordinators’ salaries at five sites.
As a result, we provided 4,278 peer-to-peer support engagements and facilitated 50 school meetings, which involved TSC 101 training and Individualized Education Programs (IEPs) consultations. In addition, two “Ask an Advocate” webinars attracted 94 registrants.

Additionally, in 2023 the TSC Alliance continued supporting the following researchers:
- **Wong Family Foundation Research Award**: Lena Nguyen, PhD: “Translational control mechanisms in TSC-associated epilepsy” (University of Texas Dallas)
- **Postdoctoral Fellowship**: Stephanie Dooves, PhD: “The role of EGF signaling in astrocyte-neuron interactions in TSC” (VU University)
- **Keith Hall Award**: Postdoctoral Fellow Joohwan Kim, PhD: “Identify metabolite markers for diagnosis and treatment of TSC kidney tumor” (University of California Irvine)
- **Wong Family Foundation Research Award**: Luis Martinez, PhD: “Rescue of epilepsy using gene therapy in a mouse model of TSC” (Baylor College of Medicine)

Throughout 2023, $127,498 in Bcureful® travel and lodging funds were administered to 114 families through the National Organization for Rare Disorders (NORD), compared to 106 in 2022. This past year, these funds helped 78 families travel to TSC Clinics to receive the highest standard of TSC care and enabled 36 families to participate in TSC Clinical Trials to contribute to important research endeavors.

### Community support and resources

The TSC Alliance’s Community Programs team in coordination with our volunteer corps across the country ensure that no one is alone on their TSC journey. They offer outreach programs, support services, improved medical access and educational resources to empower those affected by this disease to overcome obstacles throughout their lives.

In 2023, the TSC Alliance implemented a new community support model that puts the TSC community center – focusing on local resources, support services, and access to medical care – in conjunction with energizing the current and future volunteer leaders to propel the TSC Alliance to the next level. This model united 36 Community Alliances consolidated into 14 Community Regions, led by more than 150 dedicated leaders throughout the United States.

The Community Programs team invested more than 900 training hours in our leaders to ensure they are well equipped to support and empower the TSC community.

### Awareness and education

**Awareness and education**

Everyone should know about tuberous sclerosis complex, so our Communications Department diligently works to increases awareness of TSC throughout the public to broaden the scope of support and understanding beyond TSC individuals and their families and to help reach the undiagnosed and newly diagnosed and connect them to resources and information.

During 2023, the TSC Alliance produced two issues of its national magazine, *Perspective*, which is mailed to about 18,500 constituents and posted on the website. The TSC Alliance’s podcast series, **TSC Now**, produced eight episodes with 2,180 total listens. Five issues of the electronic **TSC Matters** newsletter were distributed to 17,514 recipients. The TSC Alliance’s website increases awareness and provides extensive education through a monthly average of 26,916 page views.

The TSC Alliance also relies heavily on social media to educate constituents and promote new resources and events. Its private Facebook TSC Discussion Group boasts more than 10,800 members from around the world, while its X account has 2,684 followers and Instagram has 3,432 followers.

To increase public awareness, the TSC Alliance participated in the 11th Annual TSC Global Awareness Day on May 15 as well as TSC Awareness Month throughout May. The TSC Alliance also heavily promoted Infantile Spasms Awareness Week (December 1 to 7). These awareness campaigns along with the organization’s various news releases and social media outreach efforts culminated in more than 812 million cumulative impressions and engagements.
Professional education

Too many people go undiagnosed or misdiagnosed because of a lack of TSC awareness, which is why our professional education efforts 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 December, The TSC Alliance exhibited at the American Epilepsy Society annual meeting. Staff members and a volunteer shared educational materials with attendees who visited the booth. Staff also participated in the TSC Special Interest Group session, and the TSC Alliance hosted more than 100 people at a reception with presentations by parents of a child with TSC, by members of the TSC Alliance Science team, and by Dr. Angelique Bordey, who described how the TSC Alliance has impacted her research.

The TSC Alliance participated in or presented at 26 professional meetings in 2023 including Pretola course, Research!America Annual Advocacy Awards, Women at Bridge Leadership Speaking Series, Insitro Town Hall, Rare Disease Innovation and Partnering Summit, Anya's Accelerator Workshop, NORD, TSC Alliance of Mexico reunion, two Epilepsy Action Network Congressional Briefings, ATS Annual Meeting, Interagency Collaborative to Advance Research in Epilepsy (ICARE), Rare Diseases International World Health Assembly, UCP Annual Conference, Marinus Town Hall, TANDem Mini Symposium, ETSC workshop, NINDS Nonprofit Forum, Crisis Intervention Training International, TSCI Workshop, TSC Reproductive & Perinatal Task Force Meeting, LGS Meeting, Global Genes Rare Summit, PCORI Annual Meeting, RDCRN Fall Meeting and AES.

Global outreach

Our network of Global Alliances supports TSC communities around the world and we partner with them to create and implement plans to help better meet the needs of the international TSC community.

Our Global Outreach 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. 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 13 TSC Clinics in Global Alliance countries.

Government advocacy

Our Government Relations program advocates for state and federal funding of TSC research and clinical care—and give the TSC community the tools to do the same. Our voices are a powerful force for accelerating discoveries and through collaboration with government partners we are driving TSC research forward and improving clinical care and treatment options for individuals with TSC.

On the state level, the TSC Alliance advocated for state funding for TSC Centers in Alabama, Maryland and Missouri, resulting in at least $1.25 million 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 2023. Advocates met with more than 322 Congressional offices virtually and in person to ask for $10 million in funding for the TSCRP. The House TSCRP Dear Colleague Letter sponsored by Representatives Fitzpatrick (R-PA) and Raskin (D-MD) closed with 191 signers. The Senate letter sponsored by Senators Cramer (R-ND) and Heinrich (D-NM) closed with 41 signers.

Throughout my journey, my team of doctors has been nothing short of spectacular. Their dedication and efforts to save my life have been instrumental in my survival. The complexity of my condition required their expertise and unwavering commitment. I am alive today because of their exceptional skills and the care they have provided me.

NATACHA, ADULT WITH TSC
Fund development

Embarking on uncharted territories, the TSC Alliance sets sail with the unwavering support of thousands across the globe. Bound by a shared vision, our dedicated Development and Community Programs teams navigate these new horizons tirelessly. Empowered by the winds of our community, we rally funds for groundbreaking research and vital support services. Every contribution, no matter how modest, propels us forward. Our collective efforts forge a path of unprecedented progress.

Together, with the dedication of all involved, we continue to make significant strides towards advancing research and support for individuals and families affected by TSC.

Comedy for a Cure®

On April 2, the TSC Alliance hosted an incredible night of charity and comedy at the 22nd Annual Comedy for a Cure, with Jazz Pharmaceuticals as headliner sponsor, raising almost $465,000 at the Avalon Hollywood.

It was our honor to present the Courage in Leadership Award to The Holmes Family, who have been some of the organization’s most dedicated supporters since their daughter Seraphina was diagnosed with TSC. We were also thrilled to honor The Maginn Family with the TSC Champion Award for more than two decades of innovative investment in TSC research.

This exciting evening was led by Co-Chairs Anita Bhatia and Jill Hyman and emceed by two talented entertainers from our Comedian Committee, Mo Collins and Wendy Liebman. We were thrilled to feature the extraordinary talent of Special Guest Star Alonzo Bodden and Headliner Russell Peters after our auctioneer extraordinaire, Damon Casatico, orchestrated a record-breaking Fund a Cure and Live Auction that raised more than $135,000.

Step Forward to Cure TSC®

The Step Forward to Cure TSC walk series commenced on April 15 and concluded during the weekend of May 20-21. The remarkable success of these events speaks volumes about the exceptional dedication of the National Planning Committee, Walk Leads and the countless volunteers involved. Their steadfast commitment played a pivotal role in organizing and hosting 14 in-person events nationwide. Step Forward to Cure TSC saw active participation from 3,085 individuals, resulting in an outstanding fundraising achievement of $786,000.

We are immensely grateful for the support of our National Sponsors: Title Sponsor Nobelpharma, Marinus Pharmaceuticals, Jazz Pharmaceuticals, LivaNova, Neurelis, UCB, Upsher-Smith, SpecialCare, BridgeBio Gene Therapy, and Ovid Therapeutics. Additionally, we extend our appreciation to our Regional Sponsors: MN Epilepsy Group, Stanford Medicine Children’s Health, SOBOBA Foundation, TotalCareRX, CRD Associates, Orlando Health/Arnold Palmer Hospital for Children, Level Up Drywall, Klace & Company, Low Country Therapy and Nutricia.

Team TSC

The TSC Alliance is an official charity with the TCS New York City Marathon, a collaboration aimed at advancing the mission of the TSC Alliance. In 2023, Team TSC achieved a remarkable fundraising milestone, raising $56,023.14.

We extend our heartfelt congratulations and deepest gratitude to the dedicated runners who comprised the 2023 Team TSC: James Coyle, Phil Ifland, Holly Knight, Shelly Meitzler, Iris Mustich, Sarah Skelton, Catherine Tanner and Elizabeth Wilson. Their unwavering commitment and determination not only exemplify the spirit of Team TSC but also significantly contributed to the ongoing efforts to support individuals and families affected by TSC.

Other events raising more than $10,000

- Hope for Research | Research for Hope: $203,473
- Cure 4 Clara: $24,625
- 5th Annual Teeing off Fore TSC: $24,298
- Facebook Donations/Birthday Fundraisers: $13,651
- Luminate the Night: $13,375
- Adolfo and Sabine Orive Wedding: $12,626
- GivingTuesday: $12,358
Annual Fund: major donors and contract revenue
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Sandra and Ed Hyde-Swanson

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Research and modern medicine are what give me the most hope! Knowing that there are scientists out there looking for cures and new medicines to help those impacted by TSC is so relieving. As we’ve needed medicine, it was available.

WENDY, MOM OF DEXTER (15) WITH TSC
Luke gives me hope every day. He is such a tough boy, and I am blessed to be his mother.

BRITTANY, MOM OF LUKE (2) WITH TSC

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

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- BeautyMarcdd
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- April and David Bennett
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- Lisa and Tim Huddleston
- Irfan Mamdani
- Kaye Design Studios
- Bridgett Langstaff
- Kristi Lengyel
- Wendy Liebman
- LifeCell - South Beach Skincare
- Doug P. Loftus, CFP, Wealth Dimensions
- Lorin Backe Photography
- Jim Maginn
- Mehmooosh Architect
- Miss Bay Fly Fishing Co.
- Mobile World Logistics
- Dana and Bruce Holinka
- Neiman Marcus Group
- NewBeauty
- Nancy and Raymond Novotny, Sr.
- Jim O’Heir
- Russell Peters
- Melissa Peterman
- Rapaport Dermatology of Beverly Hills
- Joan and James Ridler
- Mary and Steve Roberds
- Kari Luther Rosbeck
- Craig Shoemaker
- Alex Skuby
- Jan Stevens
- Lisa and Robert Szilagyi
- Hal Tearse and Nicole Wright
- Tom Bercu Presents
- W Hollywood
- Paul Wang
- Adrienne and Daniel Wasserman

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
The late Magdalena Lutsky
Philip and Marion Winsor

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

Enrichment Society ($5,000 - $9,999)
Betty Lee
Justine Mullen
Paul and Pamela Waxlax

Investment Society ($500 - $4,999)
America Online Giving Foundation
Ron and Dorothy Cibulskis
Nick Gentry
Mark Hyman and Sheryl Neuman
Shonnie Johnson
David and Jill Light
Dennis and Joan Pidherny
The Rosa M Seemann Charitable Gift Fund

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 that 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
Jeffrey and Gloria* Benham
Matt Bolger
Treasa Bolger-Dunlap
William Bradley
Alice Brossart
Anthony Brundo*
Scott and Jan Burton
Marguerite Cleveland
John and Katherine Conrad
Kay and Will Cooper, Sr.
Richaand and Reiko Donato
Cindy Fowler
Richard and Rosemarie Gammache*
Jeffrey Ross Goldstein
Dawn B. Girard*
David and Laura Grimes
Robert W. and Kathryn A. Groves
Shannon Hackley
Keith Hall*
Jeffrey and Lisa Hargreaves
Clara Harwell
Anne Heilman*
Kay Herder
James and Amy Hobbs

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

I was diagnosed at 3 months old when I had infantile spasms. After multiple surgeries I was seizure-free for nine years until I turned 11. I have intellectual delay, but my family gives me hope.

SEBASTIAN (17) WITH TSC

Jaye Isham
Ken* and Shonnie Johnson
Arnold and Carol Kamm
Steve and Laura Kozisek
David and Kathy Krinsky
Mark Leal
Edward Lee
Betty C. Lee
Phyllis Leist
Glen Leiter*
Craig T. Lewis*
Doug and Linda Loftus
Magdalena Lutsky*
James Lynch
Glennwood Dale Maier*
Robert McBride*
Donna McGaha
Elizabeth McNamee*
David and Jan Mintz
William Morris*
Maria Sharon Munoz-Chargoy
Ottillit Nadel*
Jean Panther*
David and Penney Parkes
Jeffrey and Bonnie Rickert
Emma Rocco*
Pat and Jennifer Rofles
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
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

William Joseph, Chair
State College, PA
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Queens, NY

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CURE Epilepsy
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Senior Director, Customer Engagement
Jazz Pharmaceuticals
Ted Mastroianni
David Michaels
Senior Vice President
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Sean Shilling
Adamstown, MD
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Tara Zimmerman
Reno, NV

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Encoded Therapeutics, Inc.
Rebecca Anhang Price, PhD
Henry Shapiro
Chairman
MarketCast Group
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Owner
Relatively Speaking
John Thorpe Richards, Jr.
Bogorad and Richards, PLLC
Marc Shaples
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Chief Outreach Officer
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Chief of Staff
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Landon Cox
Development Coordinator
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Manager, Translational Research
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Carly Kaye
Community Programs Manager
Daniel Klein
Senior Director, Communications
Maddison Larrimore
Social Media & Content Coordinator
Justin Martucci
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Gail Saunders
Director, Community Programs
Elizabeth Skufka
Community Programs Manager
Katie Smith
Director, Government & Global Affairs
Anne Wolfe
Senior Manager, Strategic Projects

Community Leadership

Thank you to the TSC Alliance’s 2023 volunteer leaders.

Alaska
Lilian Ansari
Morgan Breit
Bridge Britt
Anna Galvin
Robert Grandia
Shannon Hanks-Grandia
Frances Harper
Viviana Hernandez-Ferrer
Kaycee Kincade
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

California
Terri Butler
Debora Moritz

Connecticut
Rebecca Thereault
Jennifer Waldron

Delaware
Andrea Beebe
Phyllis Brabender
Luzbeth Guzman
Lily Martinez

Florida
Sara del Valle
Michele Della Costa
Alisa Deltinger
Christine Montagne
Joyce Parks
Sara Sanchez
Megan Self
Vanessa Vazquez

Georgia
Michele Della Costa
Alisa Deltinger
Christine Montagne
Joyce Parks
Sara Sanchez
Megan Self
Vanessa Vazquez

Kentucky
Lisa Carlton

Massachusetts
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

New York
Lilian Ansari
Morgan Breit
Bridge Britt
Anna Galvin
Robert Grandia
Shannon Hanks-Grandia
Frances Harper
Viviana Hernandez-Ferrer
Kaycee Kincade
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Ohio
Lilian Ansari
Morgan Breit
Bridge Britt
Anna Galvin
Robert Grandia
Shannon Hanks-Grandia
Frances Harper
Viviana Hernandez-Ferrer
Kaycee Kincade
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Oregon
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Pennsylvania
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Tennessee
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Texas
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Virgin Islands

Washington
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Wisconsin
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Wyoming
Megan Newton
Tara Palage Spahr
Norma Vasquez Phan

Annual Report

2023
**Georgia**  
Lindsay Osborne

**Hawaii**  
Cindy Fowler
Maxx Kau

**Iowa**  
Wendy Andersen
Dawn Wagner

**Illinois**  
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Brett Gutth
Kristen Harris–Lohman
Karen Johnson
Paula Kristchel
Jackie Tallman
Phil Tallman
Samantha Tallman
Ashleigh Whittom

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Alanna Verdi
Krystal Watts
Kylee Watts

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Alexandria Dahlgren

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Melissa Bartley
Brianah Doeden
Kiersten O'Leary

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Jenelle Hitchcock

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Jocelyn Cenna
Lauren Shillinger

**Maine**  
Donny Wright

**Michigan**  
Mary Jo Cardona
Lachracha Handy
Tina Rossow

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Alanna Spotts

**Missouri**  
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Amy Dublinske
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Tarcisio Santos Moreira
Tammy Thorne
Nancy Weir

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Kristen Swain

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Jack Lyons
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Preston Fitzgerald
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Lee Triebenbach
Adrienne Wasserman

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Elizabeth Brown

**Wisconsin**  
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Lori Denzine
Nicole Dreier
Bridget Lucas
Anne-Marie McAnelly

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Baltimore, MD

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Bridgett Langstaff
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Penney Parkes
Greenwich, CT

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Pediatric Neurology and Epilepsy
Seattle, WA

**International Scientific Advisory Board**

Mustafa Sahin, MD, PhD, Chair  
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Children's Hospital/Harvard
Boston, MA

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Weill Cornell Medical College
New York, NY

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University of Maryland School of Medicine
Baltimore, MD

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Rondebosch, Cape Town, South Africa

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University of Virginia
Charlottesville, VA

Luciana Amaral Haddad, MD, PhD  
Departamento de Genética e Biologia Evolutiva
Universidade de São Paulo
São Paulo, Brazil

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Brigham and Women's Hospital
Harvard Medical School
Boston, MA

Gregory Holmes, MD  
Chair, Department of Neurological Sciences
University of Vermont School of Medicine
Burlington, VT

Chris Kingswood, MD  
Brighton & Sussex University Hospitals Trust
Renal Unit
Brighton, UK

David Kwiatkowski, MD, PhD  
Professor of Medicine
Brigham & Women's Hospital & Harvard Medical School
Boston, MA

Brendan Manning, PhD  
Department of Genetics and Complex Disease
Harvard School of Public Health
Boston, MA

David Mowat MBBS, MRCGP, FRACOG, FRACP  
Senior Staff Specialist
Clinical Geneticist
Sydney Children's Hospital
Sydney, Australia

Hope Northrup, MD  
Professor of Pediatrics
Director, Division of Medical Genetics
University of Texas–Houston
Houston, TX

Julian Sampson, DM, DM, FRCP, FMedSci  
Professor and Head of Department, Medical Genetics
Institute of Medical Genetics
Wales College of Medicine
Cardiff University
Cardiff, Wales, UK

Andrew Tee, PhD  
Medical Genetics
Institute of Medical Genetics
Wales College of Medicine
Cardiff University
Cardiff, Wales, UK

Michael Wong, MD, PhD  
Department of Neurology
Washington University School of Medicine
St. Louis, MO

Raymond Yeung, MD  
Department of Surgery
University of Washington
Seattle, WA

Hongbing Zhang, MD, PhD  
Institute of Basic Medical Sciences
Chinese Academy of Medical Sciences
Peking Union Medical College
Beijing, China
## National Tuberous Sclerosis Association & Affiliate

### Consolidated Statements of Financial Position

**As of December 31, 2023**

<table>
<thead>
<tr>
<th>Assets</th>
<th>2023</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$2,305,166</td>
<td>$2,440,085</td>
</tr>
<tr>
<td>Investments</td>
<td>7,898,056</td>
<td>5,577,848</td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>350,534</td>
<td>181,490</td>
</tr>
<tr>
<td>Promises to give</td>
<td>4,306,013</td>
<td>5,280,316</td>
</tr>
<tr>
<td>Prepaid expenses and other assets</td>
<td>283,821</td>
<td>279,571</td>
</tr>
<tr>
<td>Operating lease right of use asset, net</td>
<td>654,282</td>
<td>718,708</td>
</tr>
<tr>
<td>Property and equipment</td>
<td>393,961</td>
<td>463,272</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td><strong>$16,191,833</strong></td>
<td><strong>$14,941,290</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>$519,162</td>
<td>$599,548</td>
</tr>
<tr>
<td>Accrued compensation</td>
<td>310,445</td>
<td>298,339</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>189,493</td>
<td>285,264</td>
</tr>
<tr>
<td>Operating lease liability, net</td>
<td>1,084,988</td>
<td>1,189,842</td>
</tr>
<tr>
<td>Gift annuity obligations</td>
<td>90,397</td>
<td>113,451</td>
</tr>
<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>2,194,485</strong></td>
<td><strong>2,486,444</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>779,859</td>
<td>(158,002)</td>
</tr>
<tr>
<td>Board-designated</td>
<td>5,593,099</td>
<td>5,309,341</td>
</tr>
<tr>
<td><strong>Total without donor restrictions</strong></td>
<td><strong>6,372,958</strong></td>
<td><strong>5,151,339</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>With donor restrictions</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total net assets</td>
<td>13,997,348</td>
<td>12,454,846</td>
</tr>
</tbody>
</table>

| Total liabilities and net assets            | **$16,191,833** | **$14,941,290** |

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 2023 and 2022 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 2023 and 2022 there were net gains and losses, respectively, 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 $1,221,702 and $2,057,220 for 2023 and 2022, respectively.
# National Tuberous Sclerosis Association & Affiliate

## Consolidated Statement of Activities

<table>
<thead>
<tr>
<th>Revenue and Support</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>2023 Total</th>
<th>2022 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Events</td>
<td>$1,308,033</td>
<td>$130,107</td>
<td>$1,438,140</td>
<td>$1,559,148</td>
</tr>
<tr>
<td>Cost of direct benefits to donors</td>
<td>(164,132)</td>
<td>-</td>
<td>(164,132)</td>
<td>(125,478)</td>
</tr>
<tr>
<td>Contributions</td>
<td>1,302,612</td>
<td>3,676,704</td>
<td>4,979,316</td>
<td>5,504,298</td>
</tr>
<tr>
<td>Contributed nonfinancial assets</td>
<td>36,799</td>
<td>-</td>
<td>36,799</td>
<td>33,843</td>
</tr>
<tr>
<td>Contracts</td>
<td>2,548,976</td>
<td></td>
<td>2,548,976</td>
<td>1,906,672</td>
</tr>
<tr>
<td>Conferences</td>
<td>266,377</td>
<td></td>
<td>266,377</td>
<td>813,645</td>
</tr>
<tr>
<td>Interest and dividends</td>
<td>180,486</td>
<td>25,622</td>
<td>206,108</td>
<td>164,568</td>
</tr>
<tr>
<td>Memorials and honoraria</td>
<td>85,722</td>
<td>1,900</td>
<td>87,622</td>
<td>117,466</td>
</tr>
<tr>
<td>Federated funding</td>
<td>48,667</td>
<td>-</td>
<td>48,667</td>
<td>52,175</td>
</tr>
<tr>
<td>Other income</td>
<td>995</td>
<td>-</td>
<td>995</td>
<td>15,492</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>5,614,535</strong></td>
<td><strong>3,834,333</strong></td>
<td><strong>9,448,868</strong></td>
<td><strong>10,041,829</strong></td>
</tr>
</tbody>
</table>

Net assets released from restrictions: 3,616,501 (3,616,501) -

Total revenue and support: 9,231,036 (217,832) 9,448,868 (10,041,829)

## Expenses

### Program services

<table>
<thead>
<tr>
<th>Services</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>2023 Total</th>
<th>2022 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>5,022,281</td>
<td>-</td>
<td>5,022,281</td>
<td>3,794,438</td>
</tr>
<tr>
<td>Family services</td>
<td>895,227</td>
<td>-</td>
<td>895,227</td>
<td>1,701,754</td>
</tr>
<tr>
<td>Public health education</td>
<td>554,030</td>
<td>-</td>
<td>554,030</td>
<td>520,210</td>
</tr>
<tr>
<td>Government relations</td>
<td>188,742</td>
<td>-</td>
<td>188,742</td>
<td>162,771</td>
</tr>
<tr>
<td>Professional education</td>
<td>100,161</td>
<td>-</td>
<td>100,161</td>
<td>105,471</td>
</tr>
<tr>
<td><strong>Total program services</strong></td>
<td><strong>6,760,441</strong></td>
<td>-</td>
<td><strong>6,760,441</strong></td>
<td><strong>6,284,644</strong></td>
</tr>
</tbody>
</table>

### Supporting services

<table>
<thead>
<tr>
<th>Services</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>2023 Total</th>
<th>2022 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising</td>
<td>1,202,389</td>
<td>-</td>
<td>1,202,389</td>
<td>1,178,795</td>
</tr>
<tr>
<td>Management and general</td>
<td>580,436</td>
<td>-</td>
<td>580,436</td>
<td>672,392</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td><strong>1,782,825</strong></td>
<td>-</td>
<td><strong>1,782,825</strong></td>
<td><strong>1,851,187</strong></td>
</tr>
</tbody>
</table>

Total expenses: 8,543,266 -

Change in net assets from operations: 687,770 217,832 905,602 1,905,998

Net investment income (loss): 533,849 103,051 636,900 (1,060,139)

| Change in net assets | 1,221,619 | 320,833 | 1,542,502 | 845,859 |
| Net assets, beginning of year | 5,151,339 | 7,303,507 | 12,454,846 | 11,608,987 |

Net assets, end of year: $6,372,958 $7,624,390 $13,997,348 $12,454,846