

「navigating new horizons」



ANNUAL
REPORT
2023



navigating new horizons



“ 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

TSC Alliance® charts new courses for the organization's future

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.

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.

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, increase 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.

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.



Thanks to a gift from the Ramesh and Kalpana Bhatia Family Foundation, the TSC Alliance created **Anya's Accelerator** 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.



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.



TSC Alliance **research grants** support focused projects enabling early-career investigators to test innovative ideas and produce data to help them obtain funding from larger organizations such as the NIH and TSCRP. In 2023, the TSC

Alliance awarded grants to 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 Joochan 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)

Additionally, in 2023 the TSC Alliance continued supporting the following researchers:

- Research Grant: Uchenna Unachukwu, PhD: "Defining the pathogenic role of neural crest cells in tuberous sclerosis complex" (Columbia University Medical Center)
- Postdoctoral Fellowship: Annelot Clementine Mathilda von Esbroeck, PhD: "Investigating ASO therapy for TSC-associated neuropathophysiology" (Erasmus MC)



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.



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.



The Community Programs team collaborated with key staff to host seven research and corporate partner webinars.

These webinars attracted 312 live attendees and garnered 832 recorded views, with 801 landing page views as of December 31, 2023. The TSC Alliance also partnered with The LAM Foundation to co-host four **Regional TSC & LAM Conferences** held in Denver, CO; Birmingham, AL; Washington, DC and Seattle, WA. These conferences drew 350-plus participants.



The TSC Alliance's **TSC Navigator** is an easy-to-use, interactive online tool to help guide individuals and families through the complexities of TSC across the lifespan, proactively manage their care, and live their fullest lives. In 2023, the tool had 2,379 users. Eight individuals or families were also supported for medication access issues via our TSC Navigator program during 2023, down from 55 in 2022, consistent with the goal of proactively helping people avoid medication access issues.

Awareness and education

Everyone should know about tuberous sclerosis complex, so our Communications Department diligently works to increase 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.

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.

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.



“ 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.

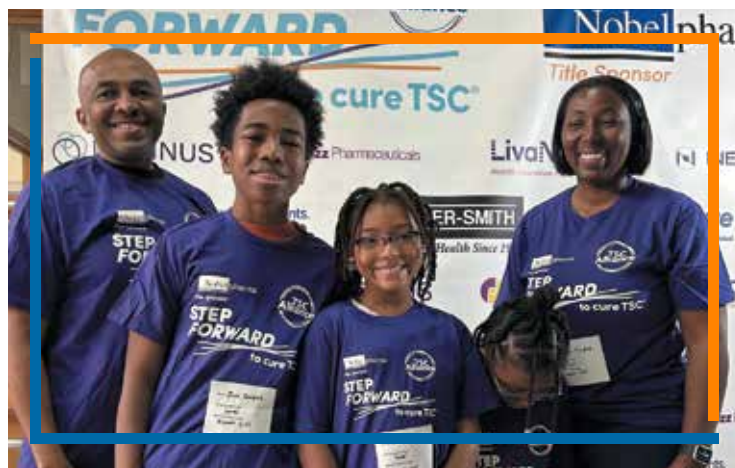
Comedy for a Cure®

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.

We were thankful to have Jazz Pharmaceuticals as our Headline Sponsor and The Ramesh and Kalpana Bhatia Family Foundation, Kay and Will Cooper, The Maginn Family, and Nobelpharma as our Standing Ovation Sponsors for this special evening. Additional sponsors included Marinus Pharmaceuticals, The Szilagyi Family, Ten Oaks, WNC Inc., BridgeBio, CVS Health, Tim and Kathi Dills, Horizon Therapeutics, MassMutual Special-Care, Neurelis, Skechers, Upsher-Smith Laboratories LLC, Longboard Pharmaceuticals, Mallinckrodt Pharmaceuticals, UCB Inc., Ray Chan, Christy Hobart and Henry Shapiro, Ted and Peggy Mastroianni, Richard and Lauren Packard, Edina Kiss, and Tom Bercu Presents.



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.





The triumph of the event owes much to the tireless work of our National Planning Committee: Andrea Beebe, Ali Bigger, Michal Cepler, Bridgett Claxton, Andrew Darvin, Alexandra Dahlgren, Alexandria Ewing, Cristina Fitzgerald, Jonathan Goldstein, Shannon and Rob Grandia, Jackie Grenia, Heather Harden, Frances Harper, Lesley Holmes, Karen Johnston, Jessica Krefting, Mary Ann Lamb, Heather Lens, Jack Lyons, Kristen Moore, Nathalie Mortine, Jo Anne Nakagawa, Noor Panjwani, Zohra Panjwani, Lauren Perry, Brittani Rich, Joan Ridler, Mary Roberds, Pat Schmutte, Lauren Shillinger, Cassie Souder, Jackie Tallman, Gloria and Lee Triebenbach, and Adrienne Wasserman.

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
- Luminare the Night: \$13,375
- Adolfo and Sabine Orive Wedding: \$12,626
- GivingTuesday: \$12,358



Annual Fund: major donors and contract revenue

Fiscal Year 2023: January 1 to December 31

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

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Ramesh and Kalpana Bhatia Family Foundation
BridgeBio Pharma, Inc.
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Marinus Pharmaceuticals, Inc.
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Drs. Bonnie and Jonathan Rothberg & Family
Samuels Family Foundation
TSC Alliance Endowment Fund
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Benefactor (\$50,000 - \$99,999)

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Kay and Will Cooper, Sr.
Janice and Julian Gangolli Family Fund
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Neurelis, Inc.
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OPL Charities
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UCB, Inc.
Upsher-Smith Laboratories, LLC
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The LAM Foundation
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WNC & Associates, Inc.

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Amazon Smile Foundation
Andreas Therapeutics
Anonymous
Jeffrey Avansino
Andrea and Ryan Beebe
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Michelle Benham
April and David Bennett

Eric Beresford
Sonu Bhatia
Biotechnology Innovation Organization
John Blake
Nick Boccella
Lauren R Boros
Monica and Bobby Boyd
Erin Bradley
Mary and Walter Bradley, Jr.
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Michael Brown
Maureen and Bob Bruncati
Keri Buchanan
Brandon Bunker
Pablo and Corina Burbridge
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Sara Campbell
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Ingrid and Daniel Carroll
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Sara Chieffo and David Skillman
Vincent Chieffo
Mardel Chinburg
Savannah and James Citron
Danielle Clark
Starr H. Clark Endowment Fund
Coca Cola Company
Wendy Cochran
Patricia Cochran
Connie and Richard Cockerham
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Kimberly and Mark Colby
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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.

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 Michael Zito



“ 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)**

Âme Salon Santa Monica
 BeautyMarcdd
 Bob Bendetson
 April and David Bennett
 Anita Bhatia
 Alonzo Bodden
 Shane Brady
 Amy and Matthew Bredeson
 Frances Briones
 Campiello Ristorante & Bar
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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

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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:

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Anonymous
David Armijo
Michael and Millicent Augustine
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Jeffery and Gloria* Benham
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Barbara Witten and William Bradley
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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:

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Augustine Family Fund
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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.



“ 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

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Thank you to the TSC Alliance's
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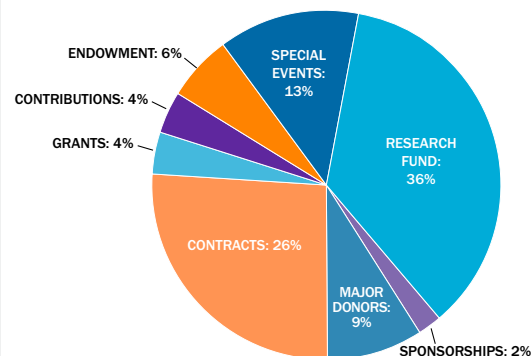
National Tuberosus Sclerosis Association & Affiliate

Consolidated Statements of Financial Position

As of December 31,	2023	2022
Assets		
Cash and cash equivalents	\$ 2,305,166	\$ 2,440,085
Investments	7,898,056	5,577,848
Accounts receivable	350,534	181,490
Promises to give	4,306,013	5,280,316
Prepaid expenses and other assets	283,821	279,571
Operating lease right of use asset, net	654,282	718,708
Property and equipment	393,961	463,272
Total assets	\$ \$16,191,833	\$ 14,941,290
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued expenses	\$ 519,162	\$ 599,548
Accrued compensation	310,445	298,339
Deferred revenue	189,493	285,264
Operating lease liability, net	1,084,988	1,189,842
Gift annuity obligations	90,397	113,451
Total liabilities	2,194,485	2,486,444
Net assets		
Without donor restrictions		
Undesignated	779,859	(158,002)
Board-designated	5,593,099	5,309,341
Total without donor restrictions	6,372,958	5,151,339
With donor restrictions	7,624,390	7,303,507
Total net assets	13,997,348	12,454,846
Total liabilities and net assets	\$ 16,191,833	\$ 14,941,290

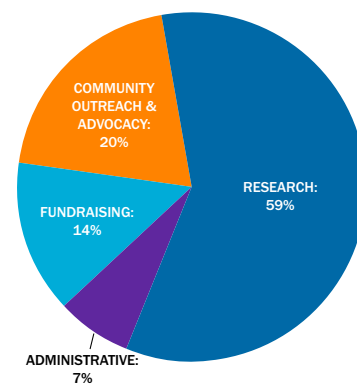
The TSC Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization's 2023 and 2022 financial statements to the TSC Alliance Board of Directors. The complete audited financials are on file with the TSC Alliance or available on its website. To obtain a copy, please call (800) 225-6872 or download at tsalliance.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.

TSC Alliance Revenue Sources 2023 Total Revenue: \$9,706,331



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

TSC Alliance Expenses 2023 Total Expenses: \$8,478,395

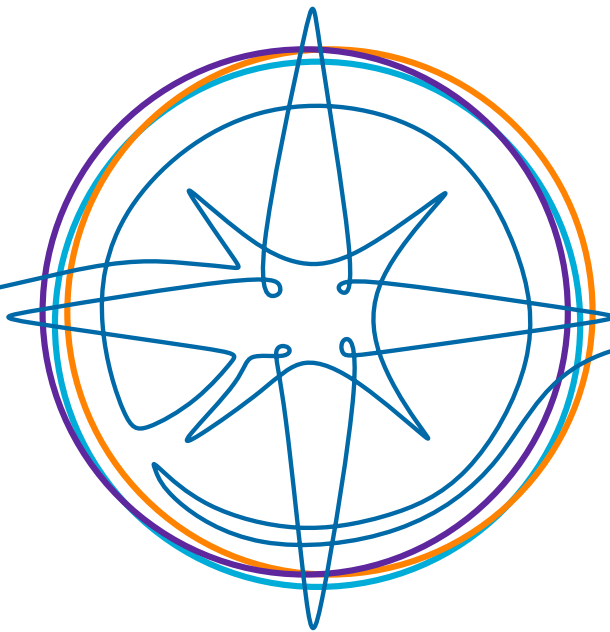


NOTE: These are the stand-alone expenses of the TSC Alliance.

National Tuberosus Sclerosis Association & Affiliate

Consolidated Statement of Activities

	Without Donor Restrictions	With Donor Restrictions	2023 Total	2022 Total
Revenue and Support				
Special Events	\$ 1,308,033	\$ 130,107	\$ 1,438,140	\$ 1,559,148
Cost of direct benefits to donors	(164,132)	-	(164,132)	(125,478)
Special events, net	1,143,901	130,107	1,274,008	1,433,670
Contributions	1,302,612	3,676,704	4,979,316	5,504,298
Contributed nonfinancial assets	36,799		36,799	33,843
Contracts	2,548,976		2,548,976	1,906,672
Conferences	266,377		266,377	813,645
Interest and dividends	180,486	25,622	206,108	164,568
Memorials and honoraria	85,722	1,900	87,622	117,466
Federated funding	48,667		48,667	52,175
Other income	995		995	15,492
	5,614,535	3,834,333	9,448,868	10,041,829
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				
Research	5,022,281	-	5,022,281	3,794,438
Family services	895,227	-	895,227	1,701,754
Public health education	554,030	-	554,030	520,210
Government relations	188,742	-	188,742	162,771
Professional education	100,161	-	100,161	105,471
Total program services	6,760,441	-	6,760,441	6,284,644
Supporting services				
Fundraising	1,202,389	-	1,202,389	1,178,795
Management and general	580,436	-	580,436	672,392
Total supporting services	1,782,825	-	1,782,825	1,851,187
Total expenses	8,543,266	-	8,543,266	8,135,831
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	320,883	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



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Hope no matter how complex™

