ANNUAL REPORT | 2024

H CARE
N DATA
SCIENCE
HOPE
FRIENDS

50 Years of Progress and Promise

TSC Alliance

TSC Alliance
1974
2024
FORWARD

50 YEARS OF
Progress and Promise

In 1974, four moms in Southern California—refusing to accept the status quo for their children—formed this organization and in doing so started a community.

For the next 50 years the TSC Alliance and the TSC community have forever changed what we know about tuberous sclerosis complex (TSC) and what living with this disease looks like.

2024 marked the 50th anniversary of the TSC Alliance® with the theme "50 Forward," and throughout the year we honored those who helped shape this organization and remembered the moments when their courage and leadership paved the way for breakthroughs in research, clinical care and community support services. This celebration culminated with our 50th Anniversary Gala on October 25, 2024, which ended up being the single biggest fundraiser in our history.

But as the theme implies, last year was not just about remembering where we've come from but also looking forward to a more hopeful future for those living with TSC and building a foundation today for the next generation of advances that will make that future a reality.

Within this report you will read about how we worked with the same interminable spirit of our founding moms over the last year to ensure access to lifelong care, further TSC research and expand our efforts into new areas, including reproductive and perinatal health. You'll also learn about how we continued to expand clinical and community support and raise funds to support our critical mission, including by launching the 50 Forward Fund, our largest research initiative in our 50-year history. The 50 Forward Fund bolsters the momentum we've built since our founding while ambitiously looking forward to a future where everyone affected by TSC can live their fullest lives.

> " I was looking for someone, anyone who'd heard of it. My doctor told me Stacia was the only one in the country. I got 15 letters back in a week. Three were from Southern California. I remember thinking, if we can get together, maybe we can do something.

SUSAN MCBRINE,
TSC ALLIANCE FOUNDING MOM, ON THE CREATION OF THE TSC ALLIANCE

1974
2024
MILESTONES

First NTSA Conference held.

1975

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 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, including 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 improves quality of life for everyone affected by TSC by catalyzing new treatments, driving research toward a cure and expanding access to lifelong support. As an internationally recognized nonprofit, we are a source of hope and connection for all affected by TSC. 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. With the power of families and support of donors, volunteers, researchers, educators, industry partners and more, we can create a future where everyone with TSC can realize their full potential—no matter how complex their journeys are to get there.

Research

Since 1984, the TSC Alliance has invested more than $39 million into TSC research projects through grants and contracts: $20.9 million in research grants and postdoctoral fellowships, $5.5 million into the Natural History Database and Biosample Repository, $11.6 million into the Preclinical Consortium, and $1.8 million into the Clinical Research Consortium.

In 2024, the TSC Alliance awarded grants to the following researchers, each of whom is an early career researcher as defined by the NIH.

- Wong Family Foundation Research Award: **Weibo Niu, PhD**: "Understanding the pathological roles of microglia in TSC" (Emory University)
- Keith Hall Award: Postdoctoral Fellow **Flaviane Silva, PhD**: "Regulation of kidney cystogenesis by a non-canonical Rag-GTPase mechanism" (University of Massachusetts)
- Research Grant: **Jeffrey Calhoun, PhD**: "Scalable assays to resolve variants of uncertain significance in TSC2" (Northwestern University)

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 2024, the Natural History Database contained 2,780 participants 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. To date, there have been 21 studies published from NHD data.

> "In the next five to 10 years we really do have to embrace some of the amazing advances happening in molecular and cellular biology. I think the concept of gene therapy in TSC five years ago was science fiction, but it's actually on the table now, which I think is remarkable.

> PETER CRINO, MD, PHD, ON THE FUTURE POTENTIAL OF TSC RESEARCH

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 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 2024, 83 individuals had completed the TAND-SQ through the self-report portal.

The TSC Biosample Repository collects high-quality biosamples such as blood, DNA, and tissues critical for researchers to understand why TSC is so different from person to person. Samples in the repository are linked to detailed clinical data in our existing TSC Natural History Database and are available to qualified researchers worldwide. Samples are housed at and distributed from the Van Andel Institute in Grand Rapids, MI, under control of the TSC Alliance. As of December 2024, the Biosample Repository has acquired 2,917 blood, buccal (cheek) swab, or tissue samples. 3,370 portions of samples have been distributed to 50 distinct researchers for 59 distinct projects.

Since the inception of our mobile phlebotomy initiative, generously supported by Lorne Waxlax, we have acquired 557 blood samples via mobile phlebotomy. To encourage and enable more researchers to utilize biosamples, the TSC Alliance awarded three seed grants in 2024, totaling $43,625, to labs that submitted meritorious and innovative ideas for research on TSC biosamples. These projects include looking at subependymal giant cell astrocytoma (SEGA) tumors (David Feliciano, PhD, Clemson University), looking at TAND biomarkers (Andy Liu, MD, MS, Duke University), and looking at aquaporins as a biomarker in TSC (Philip Kitchen, PhD, Aston University).

The TSC Alliance's **whole-genome sequencing (WGS) initiative** using DNA from blood samples in our biosample repository sequenced an additional 131 samples in 2024, totaling 242 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. The goal of this project is to spur further research in genetics, basic science, and biomarkers to accelerate clinical trials, identify individuals who could benefit from preventative interventions, and, eventually, enable personalized medicine. The WGS initiative began in 2021 as a small feasibility study generously supported by Julian and Janice Gangolli. The Gangolli family continues to support the WGS initiative and has been joined by the Watts family, Dr. Michael and Janie Frost, and Thomas and Stephanie McCann.

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. Since 2016, donors such as Drs. Bonnie and Jonathan Rothberg & Family and the Gerry and Bill Cowlin Foundation have helped establish and grow the consortium diversity and capacity for drug testing. Collaborating with the TSC community, the Consortium has identified and implemented robust and reproducible cell and animal models for TSC manifestations including tumors, epilepsy, TAND and LAM. The Preclinical Consortium ended 2024 with 10 active industry partners, increasing the total number to 24 industry partners since 2016. The consortium tested nine unique compounds in 2024, raising the total tested to 91 since 2016.

The TSC Clinical Research Consortium Core Team honored at the 50th Anniversary Gala.

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 (FDA) through competitive grant processes. The TSC Alliance also provides supplemental financial support to accelerate or expand NIH-funded studies.

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. In 2024, the TSC Alliance awarded an additional 12 months of funding, $163,737 in total, to support collection of additional data and biosamples from August 2024 through July 2025.

In 2025, we are initiating a **Clinical Research Network** with the TSC Alliance serving as a central hub for patient-focused clinical research. Benefits of doing so include participation by a broader group of recognized TSC Clinics, clinicians and researchers; inclusion of the diversity of TSC manifestations impacting multiple organ systems throughout a lifetime; and improved awareness and access of individuals with TSC to clinical studies by collaborating with additional sites across the country and working with global partners.

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. The TSC Alliance hosted an Innovation Workshop in April 2023, which focused on identifying biomarkers and predictors of specific aspects of TAND through collaborative and inclusive analysis of existing biosamples and data via metabolomic, genetic (RNA-seq), or other methods. After this innovative workshop, we began plotting a course to identify fluid-based biomarkers to improve clinical trials and clinical care associated with TAND. In 2024, we completed analysis of 84 samples from the DSC project utilizing protein analysis using an 11K protein assay at SomaLogic and whole genome sequencing. Additional support for TAND research was provided in partnership with The Gottschall Family, Kay and Will Cooper, and Heidi and Jerrill Sprinkle. We are also happy to announce that 2025 will begin the Anya's Accelerator Patient-Reported Outcome Measure (PROM) Project, led in collaboration with Agnies van Eeghen, MD, PhD, of UMC Amsterdam. Her project will focus on the harmonization of PRO measures used both in standard of care and clinical trials to standardize the assessment of symptoms under the TAND umbrella. With the guidance of the Anya's Accelerator PRO Steering Committee, this three-year project will also lead to the first TSC-PROM validated in adults and children.

In March 2024, the TSC Alliance hosted a **Reproductive and Perinatal Health (RPH) Workshop** in Memphis, Tennessee. The workshop gathered more than 25 TSC and LAM experts and community stakeholders to discuss present and future clinical recommendations for women with TSC and/or LAM who become pregnant. The RPH initiative is made possible thanks to generous support from the the Samuels Family Foundation and the Samuels Family.

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 2024, the TSC Alliance fully 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 and organized them into 14 Community Regions, led by more than **138 dedicated leaders** throughout the United States.

> I had never met any individuals with TSC or parents until I joined the board. I quickly realized the organization needed to expand to also serve teenagers and adults with the disease as well as help guide families. It's so important for families and individuals with TSC to know they don't have to face all challenges alone!

CAROL HERSCOT, FORMER BOARD MEMBER, ON THE EARLY NEED TO BUILD SUPPORT SYSTEMS FOR FAMILIES AND INDIVIDUALS AFFECTED

The Community Programs Team invested more than **997 training hours** to our leaders to ensure they were well-equipped to support and empower the TSC community. As a result, we provided 3,473 peer-to-peer support engagements and facilitated 88 school meetings, which involved TSC 101 training and IEP consultations. In addition, five "Ask an Advocate" webinars attracted 609 registrants.

The Community Programs team collaborated with key staff to host two research and corporate partner webinars. These webinars attracted 142 live attendees and garnered 267 recorded views as of December 31, 2024. The TSC Alliance hosted two **Regional TSC Conferences** held in Chapel Hill, NC and Palo Alto, CA and two Transition Workshops in Memphis, TN and Salt Lake City, UT. These conferences attracted 245 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 2024, as part of the TSC Alliance's website redesign, TSC Navigator was expanded across more pages on the website. TSC Navigator content had 72,249 page views in 2024 from 37,869 users. Support Navigators assisted 290 families including 23 one-hour long support navigator calls. Nine individuals or families were also supported for medication access issues via our TSC Navigator program during 2024, up from 5 in 2023, consistent with the goal of proactively helping people avoid medication access issues.

MILESTONES

Ann Landers features a column about TSC, which triggers 1,500 phone calls and 650 letters to NTSA.

1983

Awareness and education

Everyone should know about tuberous sclerosis complex, so our Communication 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 2024, the TSC Alliance produced two issues of its national magazine, *Perspective*, which is mailed to approximately 19,000 constituents as well as posted on the website. The TSC Alliance's podcast series, called TSC Now, produced three episodes with 1,391 total listens. Six issues of the electronic TSC Matters newsletter were distributed to 16,838 recipients. In January 2024, the TSC debuted a redesigned website featuring streamlined navigation. The TSC Alliance's website increases awareness and provides extensive education through a monthly average of 22,641 page views.

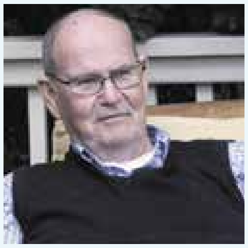
The TSC Alliance also relies heavily on social media to educate constituents and promote new resources and events. Its private Facebook TSC Discussion Group boasts more than 11,172 members from around the world, while its X account has 2,659 followers, LinkedIn has 2,453 followers and Instagram has 3,921 followers.

To increase public awareness, the TSC Alliance participated in the 12th 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 1.1 billion cumulative impressions and engagements.

> “We're never going to be big enough to do it ourselves. We need an alliance: parents, doctors, scientists, people researching other diseases, other drugs, all working together.

DAVID PARKES, FORMER BOARD MEMBER, ON CHANGING THE NAME OF THE ORGANIZATION TO TS ALLIANCE IN 2000

> “That was the first time they had a large group of medical people from around the world meeting with family members. The interchange was outstanding.



THE LATE KEN JOHNSON, FORMER BOARD MEMBER, REFLECTING ON THE FIRST INTERNATIONAL TSC CONSENSUS CONFERENCE IN 1997

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 (AES) annual meeting. Staff members and a volunteer shared educational materials with attendees who visited the booth, and staff presented data at a poster session, attended scientific sessions, and held many meetings with academic and industry partners. Staff also participated in the TSC Special Interest Group session, and the TSC Alliance hosted more than 100 people at a reception in partnership with Talk About It! Company and actor Greg Grunberg at his studio in Los Angeles. The evening included a video presentation of how people's lives have been impacted by TSC, how research has made tremendous impact, and how much is left to be done to cure, or fully treat, TSC.

The TSC Alliance participated in or presented at 24 professional meetings in 2024 including Research America Annual Advocacy Awards, Amgen Advisory Board meeting, ATS Corporate Advisory Board Meeting, Boston Children's Hospital Translational Research Symposium, Epilepsy Action Network (EAN) Congressional Briefing, Interagency Collaborative to Advance Research in Epilepsy (ICARE), Health Research Alliance: Convening on Bullying and Harassment Forum, Infantile Spasms Action Network annual meeting, BridgeBio Town Hall, TANDem Mini Symposium, Mallinckrodt Advisory Board meetings, NINDS Nonprofit Forum, Rare Disease Diversity Coalition, TSCi Workshop, TANDem Consortium, TSC Reproductive & Perinatal Health Task Force Workshop, CPATH Global Impact Conference, Global Genes Rare Summit, PCORI Annual Meeting, RDCRN Fall Meeting, AES, and the Milken Institute Future of Health Summit.

> “Volunteers still go up to Capitol Hill every year to advocate for continued funding. It’s wonderful to bring those families to the Hill, to tell their stories and to tell Congress what a difference that money makes.

> VICKY WHITTEMORE, PHD, FORMER TS ALLIANCE SCIENCE DIRECTOR, ON THE IMPACT OF GOVERNMENT ADVOCACY SINCE 2001

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, Missouri, and Maryland, resulting in at least **$1.275 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 on February 28, 2024, with Congressional meetings taking place through mid-March. More than 130 advocates met with over 367 Congressional offices in-person and virtually. Our House Dear Colleague Letter for FY25 was co-sponsored by Representatives Fitzpatrick (R-PA) and Raskin (D-MD) and closed with 185 signers. The Senate Dear Colleague Letter was co-sponsored by Senators Cramer (R-ND) and Heinrich (D-NM) and closed with 41 signers. Ultimately, cuts to the CDMRP in 2025 resulted in no funding allocated to the TSCRP for FY25, however, with the support of our champions in the House and the Senate, tuberous sclerosis complex was added as one of the 56 qualifying topic areas under the Peer Reviewed Medical Research Program (PRMRP). Our community continues their advocacy to restore funding for FY26.

50 TSC Alliance 1974 2024 MILESTONES

NTSA and New York Academy of Sciences present International Symposium on TSC.

1990

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.

The **Global Outreach** program provides the opportunity for the TSC Alliance to share experiences and assist in the start-up 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 **five global partnerships**, including TSC Alliance of Israel, TS Canada ST, TSC Alliance of Mexico, Hungarian Foundation for Tuberous Sclerosis, and TSC Alliance of India. The TSC Alliance recognizes 14 TSC Clinics in Global Alliance countries.

> “By becoming a Global Alliance of the US-based TSC Alliance, we will be able to collaborate on educational resources, research and care for individuals with TSC. We are proud to become an official partner of this global program. Together we will work to raise awareness about TSC, in Mexico and around the world.

> ARY AGAMI, PRESIDENT OF THE TSC ALLIANCE OF MEXICO, ON THE FORMATION OF THE GLOBAL ALLIANCE IN MEXICO IN 2017

Fund development

As we proudly celebrate 50 years of progress, resilience, and community, the TSC Alliance embarks on the next chapter of its journey—charting a course for the next 50 years with renewed purpose and unwavering commitment. With the steadfast support of thousands around the world, our dedicated Development and Community Programs teams continue to navigate new horizons. Fueled by the strength of our community, we raise critical funds for groundbreaking research and essential support services. Every contribution, no matter the size, helps propel us forward. Together, we are forging a future filled with hope, innovation, and impact.

With the continued dedication of all involved, we remain steadfast in our mission—improving 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.

50th Anniversary Gala

On October 25, 2024, the TSC Alliance hosted its 50th Anniversary Gala: *An Evening of Progress and Promise*, presented by Drs. Bonnie and Jonathan Rothberg & Family, at Cipriani 42nd Street in New York City, raising over $1.52 million to advance TSC research and support programs. The celebration honored the organization's five-decade legacy, highlighted community milestones, and looked ahead to a brighter future.

The event featured a lively live auction led by auctioneer Harry Santa-Olalla, a performance by acclaimed blues artist Mike Zito, and the announcement of the public phase of the 50 Forward Fund, a $40 million initiative for TSC research. A record-breaking $730,000 was raised through the Fund a Cure segment alone, including $123,000 for the Bcureful Travel Fund.

The evening also recognized five honorees for their exceptional contributions to the TSC community:

- David and Penney Parkes received the Courage in Leadership Award for their three decades of unwavering service to the TSC community, including providing leadership on the TSC Alliance Board of Directors, offering peer support, guiding strategic planning and marketing initiatives, volunteering for every major NYC event and ensuring everyone affected by TSC has access to care and treatment.
- The Ramesh and Kalpana Bhatia Family Foundation earned the TSC Champion Award for their leadership in the area of TSC-Associated Neuropsychiatric Disorders (TAND), an unmet need within the TSC community. The Bhatia Family Foundation launched Anya's Accelerator, aimed at catalyzing the development of biomarkers to inform clinical care and development of interventions for autism and other impactful aspects of TAND.
- Nobelpharma America was honored with a TSC Champion Award for their efforts in developing the first FDA-approved topical treatment for facial angiofibroma.
- The PREVeNT Trial Core Team (Drs. Martina Bebin, Jurriaan Peters, Brenda Porter, Darcy Krueger, Sarah O'Kelley, Hope Northrup, Mustafa Sahin and Gary Cutter) received the Progress in Research Award for their advancement in clinical research by implementing the first preventative clinical trial for epilepsy in the United States aimed to prevent or delay seizures in infants with TSC.
- Derek Bauer, MD, was awarded the Promise in Research Award to recognize his work as an adult neurologist specializing in TSC care, and his experience as an adult living with TSC to enhance the TSC Alliance's outreach and educational efforts focused on the adult population.

The gala was made possible through the hard work of the planning committee, led by co-chairs Jonathan Goldstein and Laura Marks, as well as from the support of 81 generous event sponsors.

You can learn more about the gala and read important moments throughout the TSC Alliance's history in the 50th Anniversary Commemorative Program Book at tscalliance.org/50program.

NTSA holds first National Family Conference in Washington, DC.

1999

Comedy for a Cure®

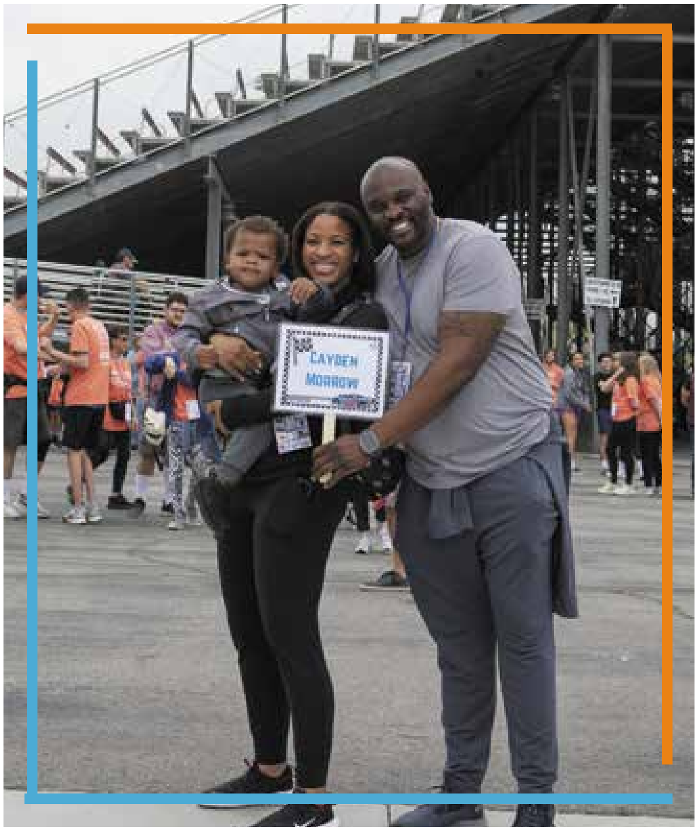
On April 14, the TSC Alliance hosted an incredible night of charity and comedy at the 23rd Annual Comedy for a Cure®, with Jazz Pharmaceuticals as Headline Sponsor, raising almost $449,000 at Vibiana in Los Angeles.

It was our honor to present the Courage in Leadership Award to The Hyman Family for their fierce advocacy, fundraising, and leadership on behalf of their daughter Skylar. We were also thrilled to honor Craig Shoemaker with the TSC Champion Award for his support of this event since 2015 and collaborative efforts as a founding member of Comedy for a Cure's Comedian Committee.

This exciting evening was led by Chair Anita Bhatia and emceed by two talented entertainers from our Comedian Committee, Jim O'Heir and Alex Skuby. We were thrilled to feature the extraordinary talent of comedian Jack Shaw and Headliner Billy Gardell after our auctioneer extraordinaire, Damon Casatico, orchestrated a Fund a Cure and Live Auction that raised more than $139,000.

We were thankful to have Jazz Pharmaceuticals as our Headline Sponsor and the Jim and Andrea Maginn Memorial Trust and Gottschall family as our Standing Ovation Sponsors for this special evening.

Additional sponsors included the Ramesh and Kalpana Bhatia Family Foundation, Marinus Pharmaceuticals, Skechers, the Szilagyi Family, Upsher-Smith Laboratories, LLC, WNC & The Cooper Family, Amgen, BridgeBio, CVS Health, Kathi and Tim Dills, the Holmes Family, the Hyman Family, Knobbe Martens, Nobelpharma America, LLC, Barry and Sharon Carpenter, MassMutual *SpecialCare*, The Schweitzer Family, Ray Chan, Christy Hobart and Henry Shapiro, Peggy and Ted Mastroianni, OpenNode, UCB, Edina Kiss and Tom Bercu Presents.



Step Forward to Cure TSC®

The 2024 Step Forward to Cure TSC walk series kicked off April 13 and culminated over the weekend of May 18-19. This year, an impressive 3,188 participants came together to raise a remarkable $784,071, of which $31,322 was generated through the dedicated fundraising efforts of 10 TSC Clinics and Centers of Excellence.

Thirteen walk locations provided a vital platform for families, friends and supporters to connect and share their TSC journeys, fostering a strong sense of community and reminding everyone they are not alone. Each year, the dedication of our hosts and the collective support of the TSC community play a crucial role in creating these meaningful experiences.

The triumph of the event owes much to the tireless work of our National Planning Committee: Andrea Beebe, Elizabeth Brown, Jocelyn Cenna, Michal Cepler, Joseph Cervantez and family, Alexandra Ewing, Cristina Fitzgerald, Christine Gomes, Shannon Grandia, Jackie Grenia, Heather Harden, Frances Harper, Jenelle Hitchcock, Lisa Huddleston, Cassie Jimenez, Karen Whittington Johnston, Mary Ann Lamb, Heather Lens, Bridget Lucas, Aida Lucero, Jack Lyons, Kristen Moore, Jo Anne Nakagawa, Kelly Nelson, Noor Panjwani, Zohra Panjwani, Lauren Perry, Brittani Rich, Lauren Shores Shillinger, Cassie Souder, Kirsten Swain, Jackie Tallman, Tammy Thorne, Gloria Triebenbach, Lee Triebenbach, Stephanie Venbeekum, Adrienne Wasserman, and Krystal Watts.

TS Alliance announces partnership with the Rothberg Institute for Childhood diseases to advance drug discovery efforts specific to TSC.

2002

We are also immensely grateful for the support of our National Sponsors: Title Sponsor Nobelpharma America, LLC, Premier Sponsor Marinus Pharmaceuticals, Jazz Pharmaceuticals, LivaNova, Neurelis, UCB, Upsher-Smith, MassMutual *SpecialCare*, and BridgeBio Gene Therapy. Additionally, we extend our appreciation to our Regional Sponsors: All Rise Foundation, MN Epilepsy Group, Stanford Medicine Children's Health, Wall Development Group, SOBOBA Foundation, Charles Town Moose Lodge #948, Kendamil, Level Up Drywall, North-West Roofing, Rawr Organics, TJM, Waste Connections, Cunningham Construction, and Erin Catron & Company.

A heartfelt thank you goes out to our national and regional sponsors, the dedicated members of our planning committee, our inspiring walk leads and the countless volunteers and staff who made this year's walk a success. Your unwavering support has been the driving force behind our mission. Together, we are part of a larger movement, advancing research and fostering meaningful connections as we strive for a cure. Here's to many more years of collaboration and progress as we work together to transform lives and bring hope to those affected by TSC!

> "Right after Dan was born there were problems... So I did what every red-blooded American girl does whenever she doesn't know what to do, I call my mom. My mom found out there was an organization. And I launched into action...I knew this guy named Frankie, a stand-up comic. He said, 'You know, I've done these comedy nights for benefits.' And I was like, 'Can you get your comics together?'... He hooks us up with this guy at a night club. We got food. We got booze. I figured if people drank, they would bid higher.

> LIZ BUCHSBAUM, ON ORGANIZING THE FIRST FUNDRAISING EVENT IN NEW YORK CITY WITH HER MOM FRANCINE THAT WOULD LATER EVOLVE INTO COMEDY FOR A CURE®

Team TSC

The TSC Alliance is proud to be an official charity partner of the TCS New York City Marathon. This partnership is vital in raising awareness and funds for TSC research, support, and advocacy. In 2024, Team TSC raised $51,217, directly supporting initiatives for those affected by TSC.

In 2024, we participated in our first-ever half marathon on March 17, followed by participation in the full marathon on November 3.

We are deeply grateful to the dedicated runners who made up Team TSC. The half marathon team included: **Ashleigh Daweritz, Margaret Gabriel, Kimberly Moran Puerta, Kristi Lengyel, and Taylor Ryan**. The full marathon team included: **Joshua Cohen, Jason Lavallee, Jurriaan Peters, Lauren Perry, Jeffrey Perry, Shannon Suarez**, and others.

These runners showed incredible dedication and passion, raising awareness and funds for TSC. Their efforts truly embody the spirit of Team TSC and its mission.

Other events raising more than $10,000

- Pours for Parker B.: $23,493
- Facebook Donations/Birthday Fundraisers: $21,359

Annual Fund: major donors and contract revenue

Fiscal Year 2024: January 1 to December 31

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

Anonymous
Anonymous
Ramesh and Kalpana Bhatia Family Foundation
BridgeBio Pharma, Inc.
Gerry & Bill Cowlin Foundation
Chris and Joy Dinsdale
Foglia Family Foundation
Dawn B. Girard Revocable Trust
Brittany and John Gottschall
Jazz Pharmaceuticals
Marinus Pharmaceuticals, Inc.
Stephanie and Thomas McCann
Candace and Michael McCaw
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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.

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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.

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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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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.

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TSC Natural History Database reaches enrollment of 1,300 participants.

2013

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Thank you to the TSC Alliance's 2024 volunteer leaders.

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includes: Washington, Oregon, Idaho, Montana

Leslie Fox, WA
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Daniel Price, WA
Emily Racenet, AK
Rebecca Racenet, AK
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Lee Triebenbach, WA
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TSC Alliance: Pacific West Community Region

includes: California, Hawaii, and Nevada

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Anna Galvin, CA
Robert Grandia, CA
Bailey Green, CA
Shannon Hanks-Grandia, CA
Viviana Hernandez-Ferrer, CA
Maxx Kau, HI
Kaycee Kincade, CA
Kathleen Kingston, NV
Megan Newton, CA
Norma Vasquez Phan, CA
Tara Palage Spahr, CA

TSC Alliance: Rocky Mountain Community Region

includes: Arizona, Colorado, New Mexico, Utah, and Wyoming

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Brittani Rich, UT
Holden Rich, UT
Kayley Thurston, UT
Deanna Wall, UT

TSC Alliance: Upper Midwest Community Region

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Alanna Spotts, MN
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TSC Alliance adopts new Vision and Mission Statements to help launch the organization into its next chapter.

2024

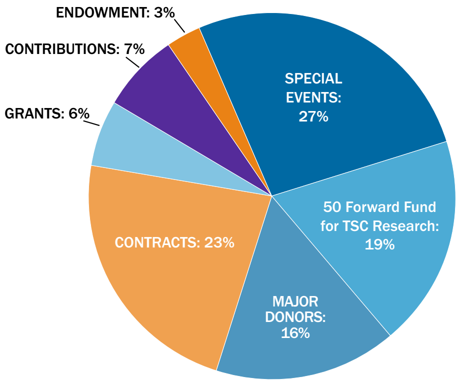
National Tuberous Sclerosis Association & Affiliate

Consolidated Statements of Financial Position

As of December 31,	**2024**	2023
Assets		
Cash and cash equivalents	**$ 4,746,313**	$ 2,305,166
Investments	**8,164,816**	7,898,056
Accounts receivable	**119,421**	350,534
Promises to give	**2,754,156**	4,306,013
Prepaid expenses and other assets	**337,110**	283,821
Operating lease right of use asset, net	**584,651**	654,282
Property and equipment	**634,558**	393,961
Total assets	**$ 17,341,025**	$ 16,191,833
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued expenses	**$ 372,308**	$ 519,162
Accrued compensation	**359,359**	310,445
Deferred revenue	**194,359**	189,493
Operating lease liability, net	**970,571**	1,084,988
Gift annuity obligations	**78,315**	90,397
Total liabilities	**1,974,912**	2,194,485
Net assets		
Without donor restrictions		
Undesignated	**2,215,476**	779,859
Board-designated	**6,212,579**	5,593,099
Total without donor restrictions	**8,428,055**	6,372,958
With donor restrictions	**6,938,058**	7,624,390
Total net assets	**15,366,113**	13,997,348
Total liabilities and net assets	**$ 17,341,025**	$ 16,191,833

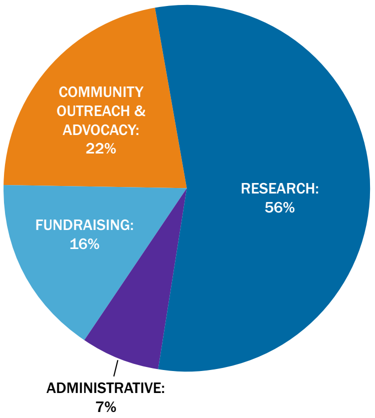
The TSC Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization's 2024 and 2023 financial statements to the TSC Alliance Board of Directors. The complete audited financials are on file 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 2024 and 2023 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 $430,082 and $1,221,702 for 2024 and 2023, respectively.

Revenue Sources FY2024
Total Revenue: $9,081,267



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

Functional Expenses FY2024
Total Expenses: $8,683,560



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

National Tuberous Sclerosis Association & Affiliate

Consolidated Statement of Activities

	Without Donor Restrictions	With Donor Restrictions	2024 Total	2023 Total
Revenue and Support				
Special Events	$ 2,108,901	$ 816,459	**$ 2,925,360**	$ 1,438,140
Cost of direct benefits to donors	(529,326)	-	**(529,326)**	(164,132)
Special events, net	1,579,575	816,459	**2,396,034**	1,274,008
Contributions	2,186,493	2,184,344	**4,370,837**	4,979,316
Contributed nonfinancial assets	360,043	-	**360,043**	36,799
Contracts	2,098,994	-	**2,098,994**	2,548,976
Conferences	6,035	-	**6,035**	266,377
Interest and dividends	200,133	28,487	**228,620**	206,108
Memorials and honoraria	72,628	2,800	**75,428**	87,622
Federated funding	35,677	-	**35,677**	48,667
Other income	5,482	-	**5,482**	**995**
	6,545,060	3,032,090	**9,577,150**	9,448,868
Net assets released from restrictions	3,756,519	(3,756,519)	**-**	-
Total revenue and support	10,301,579	(724,429)	**9,577,150**	9,448,868
Expenses				
Program services				
Research	4,820,601	-	**4,820,601**	5,022,281
Family services	1,034,068	-	**1,034,068**	895,227
Public health education	478,028	-	**478,028**	554,030
Government relations	245,579	-	**245,579**	188,742
Professional education	159,970	-	**159,970**	100,161
Total program services	6,738,246	-	**6,738,246**	6,760,441
Supporting services				
Fundraising	1,379,903	-	**1,379,903**	1,202,389
Management and general	614,027	-	**614,027**	580,436
Total supporting services	1,993,930	-	**1,993,930**	1,782,825
Total expenses	8,732,176	-	**8,732,176**	8,543,266
Change in net assets from operations	1,569,403	(724,429)	**844,974**	905,602
Net investment income (loss)	485,694	38,097	**523,791**	636,900
Change in net assets	2,055,097	(686,332)	**1,368,765**	1,542,502
Net assets, beginning of year	6,372,958	7,624,390	**13,997,348**	12,454,846
Net assets, end of year	$ 8,428,055	$ 6,938,058	**$ 15,366,113**	$ 13,997,348

Charity Navigator
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