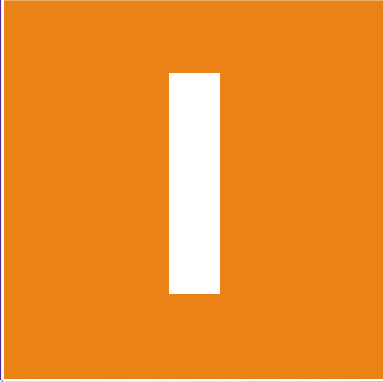


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RESILIENCE IS BASED
ON COMPASSION FOR
OURSELVES AND OTHERS.

SHARON SALZBERG

Throughout 2025, the TSC Alliance and tuberous sclerosis complex (TSC) community faced unpredictability at every turn. Natural disasters, such as the California wildfires in January, the economic roller coaster and cuts to federally funded TSC research created unforeseen obstacles. As an organization, we had to find ways to stay nimble; monitor changes to public policy and appropriations; maximize fundraising opportunities and be creative; and aggressively pursue advances in drug development, all while ensuring we continued to be a lifeline for those living with TSC every day. And, through all of it, the staff, volunteers, and wider community demonstrated remarkable resilience in the face of ongoing challenges.

Resiliency defines who we are—it's woven into our organizational DNA. You find it in our founding mothers who refused to accept the status quo for their children and formed a community when they could not find one. You find it in the researchers who have dedicated their careers to unraveling the mysteries of this disease. You find it in the advocates who fought for the approval of treatments and who continue to push for funding for TSC research year after year. And you find it in the volunteers who work tirelessly to ensure no one faces this diagnosis alone. No matter the challenges we've faced, we keep showing up for one another.

Throughout this report you will read the words of individuals and families impacted by TSC who have shown strength, adaptability, and determination—despite the uncertainty that comes with a TSC diagnosis. Their resilience was forged not just by the positive impact research has already had on their lives, but from the unwavering hope that more breakthroughs are possible. We share their stories as part of our 50 Forward Fund campaign, our effort to raise \$40 million to change the course of TSC for all. They serve as our north star, keeping us singularly focused on our mission **to improve 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**. United by shared purpose and hope, the TSC Alliance and TSC community transformed obstacles into momentum, reinforcing that resilience is not just enduring hardship, but advancing together toward a better future.

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. 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

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 live their fullest lives—no matter how complex their journeys are to get there.

*Resiliency defines who we are—
it's woven into our organizational DNA.*

Research

The Science and Medical Department empowers researchers with the data and funding needed to drive breakthroughs in TSC. In partnership with the TSC community, researchers, and industry collaborators, we accelerate the development of new treatments by investing in shared resources and fostering collaboration across key stages of the drug discovery pipeline.

“Our hope for research is that we can continue to make life easier for those who are severely affected, for those who are minimally impacted like Bear, but at the end of the day, it’s driving towards a cure so that no child has to have this disease and so that when parents hear that diagnosis, they know that there’s hope.”



CHIP BURKHALTER ON HIS HOPE FOR TSC RESEARCH FOR HIS SON BEAR AND ALL AFFECTED

[Learn more about their story.](#)



Since 1984, the TSC Alliance has invested more than \$44 million into TSC research projects through grants and contracts: \$21.6 million in research grants and postdoctoral fellowships, \$6.2 million into the Natural History Database and Biosample Repository, \$14.3 million into the Preclinical Consortium, and \$2.3 million into the Clinical Research Consortium and Clinical Research Network.



In 2025, 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: Postdoctoral Fellow **Taesun Yoo, PhD**: “The role of astrocytes in TSC2-induced epilepsy using cortical organoids” (University of California, Berkeley)
- Research Grant: **Aynara Wulsin, MD, PhD**: “Somatic mosaicism and mTOR hyperactivation as mechanisms of epileptogenesis” (Cincinnati Children’s Hospital)
- Research Grant: **Alexander Cohen, MD, PhD**: “Predicting neurologic outcomes in TSC from tuber location and connectivity” (Boston Children’s Hospital)



The **TSC Natural History Database (NHD)** captures clinical data to document the impact of the disease on a person’s health over their 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 2025, the Natural History Database had 2,932 participants enrolled in the project from among 24 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 22 studies published using NHD data.



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 complements medical data in the Natural History Database.

The purpose of this initiative is to help 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 2025, 114 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 linked to detailed clinical data in the TSC Natural History Database. This connection is critical for researchers to understand why TSC is so different from person to person. Samples 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 2025, the Biosample Repository has acquired 3,117 blood, buccal (cheek) swab, or tissue samples. Since inception, 4,036 portions of samples have been distributed to 57 distinct researchers for 63 distinct projects.

Since the inception of our **mobile phlebotomy initiative**, generously supported by Lorne Waxlax, we have acquired 635 blood samples via mobile phlebotomy. To encourage and enable more researchers to utilize biosamples, the TSC Alliance awarded three seed grants in 2025, totaling \$57,952.64, to labs that submitted meritorious and innovative ideas for research on TSC biosamples.

- **Kimberly Raab-Graham, PhD:** “Utilizing patient data to facilitate discoveries in preclinical models of Tuberous Sclerosis Complex” (Wake Forest University)
- **Joseph Bateman, BSc, PhD:** “Mis-regulation of RNA splicing as a major potential driver of pathology in SEGAs” (King’s College London)
- **Peter Scheiffele, PhD:** “Molecular analysis of PBMC and brain samples from TSC patients” (University of Basel)

The TSC Alliance’s **whole genome sequencing (WGS)** initiative using DNA from blood samples in our biosample repository has sequenced 290 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 help them better understand their unique TSC diagnosis and provide valuable information for future decision making such as family planning. This initiative has been generously supported by Dr. Michael and Janie Frost, Thomas and Stephanie McCann, Janice and Julian Gangolli Family Fund and William Watts.

Our collaboration with the TSC Preclinical Consortium was instrumental in identifying and advancing AV078. The Consortium’s rigorous and disease-relevant models allowed us to rapidly evaluate selectivity, CNS penetration, and efficacy, giving us the confidence to move AV078 into clinical development.

ALLISON J. HULME, PH.D. PRESIDENT & CEO, AEOVIAN PHARMACEUTICALS



The **TSC Preclinical Consortium** helps advance more drug candidates into clinical testing by providing the infrastructure and resources to foster collaboration between academia and pharmaceutical industry researchers to facilitate drug development. 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 lymphangioleiomyomatosis (LAM). The Preclinical Consortium ended 2025 with 12 active industry partners, increasing the total number to 31 industry partners since 2016. The consortium tested 17 unique compounds in 2025, raising the total tested to 108 since 2016. Many compounds will enter preclinical testing, though only some will advance to clinical testing due to lack of efficacy and safety.



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.



In 2025, the TSC Alliance launched the **TSC Clinical Research Network (CRN)** with the TSC Alliance serving as the central hub for patient-focused clinical research. The mission of the CRN is to lead and facilitate the development of new diagnostics, therapies, interventions, processes, and other research advances to improve the quality of life of individuals with TSC. The network consists of 75 TSC Alliance-recognized clinics throughout the US. The TSC Alliance also launched a new Clinical Trial Finder on our website to enable members of our community to identify clinical research opportunities which interest them.

In 2020, the TSC Alliance provided \$200,000 supplemental funding for TSC-STEPPS (Stopping TSC Onset and Progression 2B: Sirolimus TSC Epilepsy Prevention Study), which is ongoing. The TSC Alliance continues to educate the community about this pivotal trial. Fifty infants have been enrolled to date and 31 biospecimens have been collected. 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, PTEN Hamartoma Syndrome, and SYNGAP1-related disorders. Researchers in this study are trying to find earlier signs of autism spectrum disorder (ASD) and intellectual disability (ID) to enable effective treatments and interventions. The DSC was renewed in 2025 for a third and final 5-year funding period. 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, the TSC Alliance provided one-time bridge funding to Petrus J. de Vries, MBChB, FRCPsych, PhD, and Anna Jansen, MD, PhD, for their work on “Maintaining momentum to close the intervention gap for TAND” (University of Cape Town and Vrije Universiteit Brussel) to ensure continuity in their research after an Executive Order stopped all federal funding to South Africa.



Thanks to a gift from the Ramesh and Kalpana Bhatia Family Foundation in 2022, the TSC Alliance created **Anya's Accelerator** to focus on furthering translational research on TAND. In January 2025, we launched the Anya's Accelerator Patient-Reported Outcome Measure (PROM) Project, led in collaboration with Agnies van Eeghen, MD, PhD of UMC Amsterdam. The project will focus on the harmonization of core outcome measures used both in standard of care and clinical trials to standardize the assessment of symptoms under the TAND umbrella.



2025 TSC INTERNATIONAL RESEARCH CONFERENCE
BETHESDA, MD • JUNE 26-28, 2025
Presented by Drs. Bonnie and Jonathan Rothberg & Family

The TSC Alliance hosted the **2025 TSC International Research Conference: Engage, Accelerate, Transform**, presented by Drs. Bonnie and Jonathan Rothberg & Family, which was held at the Bethesda

North Marriott Hotel & Conference Center in North Bethesda, MD, June 26-28, 2025. The conference welcomed 255 attendees from 25 different countries and featured 29 main-session oral presentations, 56 poster presentations, an Early Career Researcher Symposium, and 3 focused mini symposia. This conference brought together the research community at a very uncertain time and provided them refuge to focus on their work—to advance TSC breakthroughs.

We are at a very challenging time right now in healthcare and science. This meeting happened at a very important time to remind all of us that there is incredible work being done, that there's hope for progress, and that we have to keep at it.

SHAFALI JESTE, MD, TSC INTERNATIONAL RESEARCH CONFERENCE CO-CHAIR

Research Conference Co-Chairs Shafali Jeste, MD (left) and Carmen Priolo, MD, PhD (right) with Kari Luther Rosbeck



In 2025, members of the **Reproductive and Perinatal Health (RPH) initiative** began a systematic review of the literature and collection of real-world data through the natural history database and the development of a series of short surveys to the

TSC community to gather community perspectives on pregnancy and TSC. The RPH initiative is made possible thanks to generous support from the Samuels Family Foundation and the Samuels Family.

"Outside of my personal health issues, my husband and I decided not to have any children given the 50/50 chance of me passing it along... and that has been a very difficult thing to deal with as an adult with TSC."



DANIELLE CLARK ON HOW HER TSC DIAGNOSIS CHANGED HER PLANS FOR THE FUTURE

[Learn more about her story.](#)



Community support and resources

In partnership with volunteers across the country, the TSC Alliance's Community Programs team is committed to ensuring that no one walks their TSC journey alone. By providing outreach, support services, improved access to medical care, and educational resources, they help those impacted by TSC overcome obstacles and thrive throughout their lives.

In 2025, the TSC Alliance continued to advance its community support model through the **Community Leadership Hub**, a platform to connect, manage, and recognize its 149 active volunteers. Across 14 Community Regions, these volunteers sustain a coordinated network that strengthens support for individuals and families affected by TSC.



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 89,932 page views in 2025 from 55,274 users. Support Navigators assisted 317 families including 17 one-hour long support navigator calls. Three individuals or families were also supported for medication access issues via our TSC Navigator program during 2025, down from nine in 2024, consistent with the goal of proactively helping people avoid medication access issues.



Participants at the TSC Regional Conference in Iowa City

The **Community Programs Team** devoted more than **2,036 training hours** for our leaders, to ensure they were well equipped to support and empower the TSC community. As a result, those volunteers provided 6,613 peer-to-peer support engagements and facilitated 102 school meetings, which involved TSC 101 training and IEP consultations. In addition, six “Ask an Advocate” webinars attracted 490 registrants.

The Community Programs team collaborated with key staff to host the **2025 Transition Webinar Series** with 268 attendees and recorded videos garnered 267 views as of December 31, 2025. The TSC Alliance also hosted three educational **TSC Regional Conferences** in Waltham, MA; Iowa City, IA (with the opportunity to participate virtually); and Los Angeles, CA with a combined total of 210 in person attendees and 40 virtual participants (Iowa).

“When Amaan was born, we were told he wouldn’t walk, he may not talk. And two years ago, he not only walked, he walked across the stage.”



NOOR PANJWANI ON HIS SON, AMAAN, GRADUATING FROM HIGH SCHOOL

[Learn more about their story.](#)



“She was diagnosed with TSC at 32 weeks pregnant in utero. They found the two rhabdomyomas in her heart and that’s what began our journey... And a week later, I found out that I have TSC as well.”



BAILEY GREEN ON HOW HER DAUGHTER KINSELY’S DIAGNOSIS LED TO HER OWN

[Learn more about their story.](#)



Awareness and education

Everyone should know about tuberous sclerosis complex, so our Communication Department works to raise public awareness of TSC to broaden the scope of support and understanding beyond TSC individuals and their families. The goal is to help reach individuals who are newly diagnosed or undiagnosed, and connect them with the resources they need.

During 2025, the TSC Alliance produced two issues of its national magazine, *Perspective*, which is mailed to approximately 18,500 households as well as posted on the website. The TSC Alliance’s podcast series, called **TSC Now**, produced two episodes with 1,970 total listens. Six issues of the electronic **TSC Matters** newsletter were distributed to 16,227 recipients. The TSC Alliance’s website increases awareness and provides extensive education through a monthly average of 25,303 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 11,737 members from around the world, while its Facebook page has 12,128 followers, LinkedIn has 2,797 followers, Instagram has 4,436 followers, and its YouTube channel has 9,010 subscribers.

To increase public awareness, the TSC Alliance participated in the **13th 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, digital ads, and social media outreach efforts, resulted in more than 800 million cumulative impressions.

Professional education

Lack of awareness about TSC too often leads to delayed or incorrect diagnoses. Through targeted professional education for researchers, healthcare providers, medical students, genetic counselors, and educators, we work to reduce the harmful effects of misinformation and improve outcomes for individuals with TSC.

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 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 which featured a testimony by Wendi Scheck, a TSC Mom sharing how her family has been impacted by TSC. TSC Alliance staff also presented a scientific poster at the annual Society for Neuroscience meeting and attended the biennial LAMposium conference.



Wendi Scheck presenting at the TSC Alliance Reception

Additionally, the TSC Alliance participated in or presented at **24 professional meetings** in 2025, including Research!America Annual Advocacy Awards, Defense Health Research Consortium meeting, RAD workshop, Rare Disease Innovation and Partnering Summit, Mallinckrodt Advisory Council meeting, Interagency Collaborative to Advance Research in Epilepsy (ICARE), NORD, RDCRN meeting, CZI workshop, Angelman SFARI-FAST, TSCi Workshop, CB-PAG advisory board meeting, ISAN in person workshop, American Thoracic Society (ATS) International Conference, the ATS Board of Directors meeting, LAMposium, 2nd Canadian Symposium on Tuberous Sclerosis Complex, SFN, RDDC coalition meetings, ATS Public Advisory Roundtable (PAR) planning meeting, CDMRP senate meeting, and American Epilepsy Society annual meeting.



Participants at the in-person Infantile Spasms Action Network Workshop

Government advocacy

The Government Relations program champions state and federal funding for TSC research and clinical care—and empowers the TSC community to advocate alongside us. Together, and in collaboration with government partners, our collective voices drive innovation, expand research, and improve care and treatment options for people living with TSC.

On the state level, the TSC Alliance advocated for state funding for TSC Centers in Alabama, Missouri, and Maryland, resulting in more than \$1.275 million in state appropriations.

The 2025 **March on Capitol Hill** to advocate for federal funding for the Tuberous Sclerosis Complex Research Program (TSCRCP) at the Department of Defense's (DoD) Congressionally Directed Medical Research Program (CDMRP) took place on March 5 with Congressional meetings taking place through mid-March. More than 130 people participated in over 367 in-person and virtual meetings. Our House Dear Colleague Letter for FY26 was co-sponsored by Representatives Fitzpatrick (R-PA) and Raskin (D-MD) and closed with 163 signers. The Senate Dear Colleague Letter was co-sponsored by Senators Cramer (R-ND) and Heinrich (D-NM) and closed with 35 signers.

Congress passed a Continuing Resolution for FY25 that included a 57% cut to the CDMRP. This cut was not made uniformly across all CDMRPs and unfortunately resulted in no funding allocation to the TSCR in FY25 which ended September 30, 2025. However, TSC was added as one of the 56 qualifying topic areas under the Peer Reviewed Medical Research Program (PRMRP). \$150 million was appropriated to this program in FY25 and the inclusion of TSC enabled TSC researchers to apply.

Global outreach

Through our network of Global Alliances, we support TSC communities around the world and work closely with our partners to design and carry out initiatives that strengthen care, resources, and support for the global TSC community.

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 Global Outreach program provides the TSC Alliance the opportunity to share experiences and assist in starting TSC-related organizations in other countries.

The TSC Alliance has **five global partnerships**, including Hungarian Foundation for Tuberosus Sclerosis, TS Canada ST, TSC Alliance of India, TSC Alliance of Israel, and TSC Alliance of Mexico. The TSC Alliance recognizes 16 TSC Clinics in Global Alliance countries.

TSC International (TSCi) held its annual meeting on Thursday, June 26. This meeting brought together key stakeholders in the TSC space, including TSCi member organizations, clinicians, researchers, and industry partners to discuss global clinical trials in TSC and hear an update on the TANDem project. 35 representatives from 18 countries attended the meeting. It was sponsored by Aevion Pharmaceuticals, Biogen, Grin Therapeutics, Jazz Pharmaceuticals, and Lundbeck.



TSC Alliance advocates at the March on Capitol Hill

Because of the advocacy, support, and resiliency of our TSC community, the FY26 Defense bill reinstated funding for the TSCR and included a **\$2 million increase** going from \$8 million in FY24 to \$10 million. Total funding for the TSCR has been \$131 million since 2002. Additionally, FY26 also resulted in report language included in the Labor, Health, and Human Services appropriation for the National Institutes of Health (NIH) requiring no less than \$30 million be spent on TSC research across NIH Institutes, thanks to the support of Senator Eric Schmitt (R-MO). In 2024, TSC categorial spending at NIH was \$21 million (a \$9 million increase).



TSCi members at the 2025 TSC International Research Conference

Fund development

Supported by our community, the Development and Community Programs teams generate critical funding for groundbreaking research and vital support services. Each contribution—large or small—helps accelerate progress and create lasting impact for the TSC community.

This year, the TSC community joined forces to drive remarkable progress. Together, they accelerated research, strengthened essential programs, and proved that when our community unites, we can move mountains.

50 Forward Fund

In 2024, during our 50th Anniversary Gala, the TSC Alliance kicked off the public phase of the 50 Forward Fund, the largest research initiative in our history, with the goal of raising \$40 million to change the course



of TSC and bring more hopeful futures to all affected. In 2025, we debuted and sent six issues of our research e-newsletter, **TSC Research Matters**, to 16,300 recipients. The e-newsletter featured lay summaries of published research articles,

features on TSC-funded scientists, donor profiles, and community stories about how TSC research changes lives. The TSC Alliance solicited donations for the 50 Forward Fund through a digital fundraising appeal in June featuring the Burkhalter family, through a mailed research appeal in September, through Fund A Cure during Comedy for a Cure, and through the campaign website at tscalliance.org/50ForwardFund. The TSC Alliance raised \$3,356,048 toward the 50 Forward Fund in 2025, bringing the total raised for the campaign to \$22,659,825. The TSC Alliance is grateful to Carol Herscot for her \$1 million gift to support TSC research in honor of her son Bradley Jay Herscot and in memory of her husband James S. Herscot.

“Carol Herscot has long been a champion for the TSC community. Her advocacy for adult care was a catalyst for so many of the changes we have seen today. This extraordinary donation will have similar impact on our ability to move the most promising research forward and to build a pipeline of potential new treatments for TSC.”

KARI LUTHER ROSBECK,
TSC ALLIANCE PRESIDENT & CEO



Lisa Huddleston and family accepting the Courage in Leadership Award

Comedy for a Cure®

On Sunday, April 6, the TSC Alliance hosted an incredible night of charity and comedy at the 24th Annual Comedy for a Cure® at Vibiana in Los Angeles. With Jazz Pharmaceuticals as headliner sponsor, the event raised almost \$372,000.

It was our honor to present the Courage in Leadership Award to the Huddleston Family for their fearless mission to raise awareness of TSC and funds to drive research through hosting events at their Irwindale Speedway, engaging the NASCAR and celebrity community and providing peer support to others living with TSC. Their support is inspired by their daughter, Hailey, who has TSC. We were also thrilled to honor Greg Grunberg and ‘Talk About It!’ with the TSC Champion Award for his support of Comedy for a Cure since 2008 and for raising unprecedented awareness of epilepsy. Greg co-founded the ‘Talk About It!’ Company, which activates celebrities, industry, and the general public with a goal to get everyone talking about key issues that need more public attention. ‘Talk About it!’ originally focused on epilepsy, as Greg’s oldest son lives with epilepsy.

This exciting evening was led by Chairs Anita Bhatia and Jill Hyman, and emceed by Gary Cannon, a comedian with more than 25 years of warm-up, stand-up, and corporate entertainment experience. We were thrilled to feature the extraordinary talent of comedian Ron Pearson and headliner Tom Papa after our auctioneer extraordinaire, Damon Casatico, orchestrated a Fund a Cure that raised more than \$87,000.

We were thankful to have Jazz Pharmaceuticals as our Headline Sponsor. Additional sponsors include: The Ramesh and Kalpana Bhatia Family Foundation, CVS Health, The Seraphina Holmes Charitable Fund, the Szilagyi/LaGraff Family, Upsher-Smith Laboratories, LLC, OpenNode, Tim and Kathi Dills, Amgen Rare Disease, Kam Babaoff, GondolaBio, The Hyman Family, Knobbe Martens, Jim and Andrea Maginn Memorial Trust, Mallinckrodt Pharmaceuticals, MassMutual SpecialCare, Skechers, UCB, Inc., Ray Chan, Keith Hall Family, Christy Hobart, Ted and Peggy Mastroianni, Edina Kiss, and Tom Bercu Presents.

Step Forward to Cure TSC®

The 2025 Step Forward to Cure TSC walk series took place from April 11 to June 7. This year, an impressive 3,242 participants came together to raise a remarkable \$799,683, of which \$26,564 was raised by the 15 TSC Clinics and Centers of Excellence.

Across 17 walk events, families, friends, volunteers, clinicians, and supporters came together to build connections, inspire hope, and advance the mission of the TSC Alliance. Each walk featured heartfelt stories, passionate teams, and a powerful reminder that no one faces TSC alone. For those unable to participate in person, the Virtual Walk provided an opportunity to engage from anywhere, contributing more than \$50,000 to the overall fundraising impact.

The success of the 2025 walk series was made possible through the dedication and leadership of our National Planning Committee: Stephanie Alcid, Ally Arcaro, Andrea Beebe, Dylan Brooks, Katrina Caban, Junior Carvajal, Michal Cepler, Joseph Cervantez, Brenda Christmas, Joanie Cueni, Michele Della Costa, Emily Dockett, Tiffany Donohue, Ashley Eason, Sandy Ewing, Cristina Fitzgerald, Kristin Frausto, Jenelle Hitchcock, Haley Hoffman, Emilie Hyde, Karen Johnston, Toni Kuzawski, Mary Ann Lamb, Heather Lens, Aida Lucero, Jack Lyons, Lauren Mercurio, Kristen Moore, Carrie Myatt, Raquel Nelson, Guinevere Pandolfi, Noor Panjwani, Abigail Passeri, Kelsey Perez, Lauren Perry, Daniel Price, Gwen Pryor, Brittani Rich, Megan Self, Cassie Shields, Lauren Shillinger, Blaire Simon, Jackie Tallman, Rebecca Thereault, Gloria Triebenbach, Lee Triebenbach, Grace Wall, Adrienne Wasserman, and Tabitha Wilbanks.

We are also deeply grateful for the generous support of our sponsors: **Title Sponsor:** Nobelpharma, **Premier Sponsor:** Upsher-Smith Laboratories, LLC, **National Sponsors:** Jazz Pharmaceuticals, LivaNova, Neurelis, UCB, and MassMutual SpecialCare. Additionally, we extend our appreciation to our **Regional Sponsors:** GondolaBio, Isabel & The Incredibles, Minnesota Epilepsy Group, Stanford Children's Health, Wall Development Group, CRD Associates, Redline, The Epilepsy Care Center, Your Bridge Wealth Management, Ascension, Allied HVACR Services, Inc., Waste Connections, Alta California Regional Center, CM Brown Nurseries, Inc., CEI Constructors, Dei Rossi Marketing, Level Up Drywall, Norbert E. Mitchell Company, Perry Service Learning, Roya Wellness (Bahareh Lazemizadeh), Savvy Socks, LLC, Sharon Oberlander, and UC Davis Medical Health Center.

A heartfelt thank you to our sponsors, donors, planning committee members, walk leads, volunteers, participants, and staff whose dedication and passion made this year's walk series such a meaningful success. Your unwavering support continues to drive progress toward a future where everyone affected by TSC can live their fullest lives.



Participants at the Westchester, PA, Step Forward to Cure TSC® event

Team TSC

The TSC Alliance is proud to serve as an official charity partner of the **United Airlines NYC Half Marathon** and the **TCS New York City Marathon**. These partnerships play a vital role in raising awareness and critical funds to support TSC research, education, advocacy, and support programs. In 2025, Team TSC raised an impressive **\$58,286** to help advance the mission of the TSC Alliance.

We are deeply grateful to the dedicated runners who represented Team TSC throughout the year. The United Airlines NYC Half team included Tatiana Cuellar-Gaviria, Eddie Freedman, Jackie Grenia, Matthew Schleich, and Kasey Walther. The TCS New York City Marathon team included Gadi Glogowski, Jennifer Hand, Diana Keller, Emily Michaels, and Margaret Tanner.

Through their determination, training, and fundraising efforts, these runners helped raise awareness and inspire hope for individuals and families affected by TSC. Their commitment and passion truly embody the spirit of Team TSC and the strength of our community.

Other events raising more than \$10,000

- Pours for Parker (\$23,768)
- Scotty Fitness (\$21,266)
- Facebook Donations/Birthday Fundraisers: \$18,656

Annual Fund: Major Donors and Contract Revenue

Fiscal Year 2025: January 1 to December 31

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

Anonymous
Cassava Sciences, Inc.
Chris and Joy Dinsdale
Foglia Family Foundation
Gerry & Bill Cowlin Foundation
Carol Herscot
Jazz Pharmaceuticals
Diane McSwain
Drs. Bonnie and Jonathan Rothberg
& Family
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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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"It can be very isolating having a child with TSC, especially if you don't know anybody else who has it. And so having that community and just knowing that these people really get it is really wonderful."

BLAIR SIMON (MOTHER TO JACOB WITH TSC) ON THE IMPORTANCE OF COMMUNITY FOR SUPPORT

[Learn more about their story.](#)



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"We were given a drug called vigabatrin. She was on that for several years and then eventually became seizure-free. That drug was available due to research and the efforts of the TSC Alliance."



FRANCES BRIONES ON HOW RESEARCH IMPACTED HER DAUGHTER ROSY

[Learn more about their story.](#)



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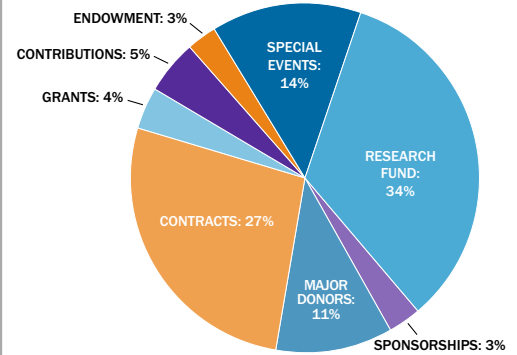
National Tuberosus Sclerosis Association & Affiliate

Consolidated Statements of Financial Position

As of December 31,	2025	2024
Assets		
Cash and cash equivalents	\$ 4,638,059	\$ 4,746,313
Investments	9,439,624	8,164,816
Accounts receivable	136,853	119,421
Promises to give	2,511,408	2,754,156
Prepaid expenses and other assets	609,612	337,110
Operating lease right of use asset, net	509,349	584,651
Property and equipment	263,658	634,558
Total assets	\$ 18,108,563	\$ 17,341,025
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued expenses	\$ 438,877	\$ 372,308
Accrued compensation	338,406	359,359
Deferred revenue	362,695	194,359
Operating lease liability, net	846,003	970,571
Gift annuity obligations	74,176	78,315
Total liabilities	2,060,157	1,974,912
Net assets		
Without donor restrictions		
Undesignated	2,114,039	2,215,476
Board-designated	7,290,693	6,212,579
Total without donor restrictions	9,404,732	8,428,055
With donor restrictions	6,643,674	6,938,058
Total net assets	16,048,406	15,366,113
Total liabilities and net assets	\$ 18,108,563	\$ 17,341,025

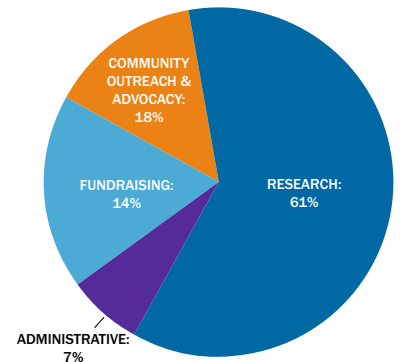
The TSC Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization's 2025 and 2024 financial statements to the TSC Alliance Board of Directors. The complete audited financials are on file 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 2025 and 2024 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 negative \$410,591 and a positive \$430,082 for 2025 and 2024, respectively.

Revenue Sources FY2025 Total Revenue: \$8,807,012



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

Functional Expenses FY2025 Total Expenses: \$9,143,804



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	2025 Total	2024 Total
Revenue and Support				
Special Events	\$ 1,253,584	\$ 90,064	\$ 1,343,648	\$ 2,925,360
Cost of direct benefits to donors	(161,477)	-	(161,477)	(529,326)
Special events, net	1,092,107	90,064	1,182,171	2,396,034
Contributions	1,533,183	3,337,061	4,870,244	4,370,837
Contributed nonfinancial assets	69,896	-	69,896	360,043
Contracts	2,344,367	-	2,344,367	2,098,994
Conferences	308,731	-	308,731	6,035
Interest and dividends	285,300	20,387	305,687	228,620
Memorials and honoraria	67,104	1,355	68,459	75,428
Federated funding	31,527	-	31,527	35,677
Other income	-	-	-	5,482
	5,732,215	3,448,867	9,181,082	9,577,150
Net assets released from restrictions	3,823,088	(3,823,088)	-	-
Total revenue and support	9,555,303	(374,221)	9,181,082	9,577,150
Expenses				
Program services				
Research	5,592,767	-	5,592,767	4,820,601
Family services	941,019	-	941,019	1,034,068
Public health education	418,184	-	418,184	478,028
Government relations	206,522	-	206,522	245,579
Professional education	119,190	-	119,190	159,970
Total program services	7,277,682	-	7,277,682	6,738,246
Supporting services				
Fundraising	1,268,528	-	1,268,528	1,379,903
Management and general	658,777	-	658,777	614,027
Total supporting services	1,927,305	-	1,927,305	1,993,930
Total expenses	9,204,987	-	9,204,987	8,732,176
Change in net assets from operations	350,316	(374,221)	(23,905)	844,974
Net investment income (loss)	626,361	79,837	706,198	523,791
Change in net assets	976,677	(294,384)	682,293	1,368,765
Net assets, beginning of year	8,428,055	6,938,058	15,366,113	13,997,348
Net assets, end of year	\$ 9,404,732	\$ 6,643,674	\$ 16,048,406	\$ 15,366,113





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Hope no matter how complex™