



hopeful

relentless

strong

Annual Report 2022

TOGETHER



hopeful | relentless | strong | together



## 2022 saw the TSC Alliance® reach new peaks in our organization's history.

The organization and those we serve grew even more **hopeful** following the trials and challenges of the pandemic, experienced the tuberous sclerosis complex (TSC) community's ongoing **relentless** dedication to our cause and finished the year in a **strong** financial position by reaching a record-breaking \$10 million in revenue for the first time.

All these accomplishments resulted from our entire community and other supporters and partners working **together** on a common goal to ensure every person with TSC can realize their fullest potential, no matter how complex the journey is to get there.

Isaac Newton famously said, "If I have seen further, it is by standing on the shoulders of giants." And this same sentiment applies to the TSC community as well. The progress the TSC Alliance continues to make is only possible because of the giant steps we take together. Our challenge now is to reach new heights until we achieve our goal of providing everyone affected by TSC with the tools they need to live their fullest lives.

In the following pages, you learn much more about the TSC Alliance's vast 2022 research, clinical and community programs accomplishments; fundraising victories; major donors; and our audited financials.

## About tuberous sclerosis complex

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 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

**Simply stated: successful TSC research improves lives. Our Science & Medical Department funds investigators, ensures TSC researchers have the data and connections they need to make progress, fuels collaborative research and streamlines the clinical trial process to bring more treatments to market.**

Since 1984, the TSC Alliance has invested more than \$34 million into TSC research projects through grants and contracts: \$20.1 million in research grants and postdoctoral fellowships, \$4.8 million into the Natural History Database and Biosample Repository, \$7.9 million into the Preclinical Consortium and \$1.3 million into the Clinical Research Consortium.



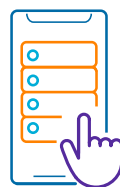
The **TSC Natural History Database (NHD)** captures clinical data to document the impact of the disease on a person's health over his/her lifetime. The database serves as a resource of information that helps TSC researchers better understand the progression of the disease, design hypothesis-driven questions to hasten the discovery of new treatments and identify persons with TSC who are eligible to participate in research studies. As of December 2022, 2,546 people with TSC were enrolled in the project from among 21 TSC Clinic sites and the TSC Alliance throughout the United States and in Canada. 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.



Initiated in 2014, 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, 2022, the TSC Biosample Repository has acquired 2,327 biosamples: 834 blood samples from individuals with TSC enrolled in the NHD, 395 buccal samples from individuals with TSC enrolled in the NHD, 174 tissue samples from individuals with TSC enrolled in the NHD, 525 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 so people can donate samples regardless of where they live, the TSC Alliance has acquired an additional 364 blood samples to bolster the Biosample Repository. To encourage and enable more researchers to utilize biosamples, the TSC Alliance awarded four seed grants in 2022 totaling \$59,324 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 the Biosample Repository sequenced an additional 48 samples in 2022, totaling 68 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 Natural History Database. This portal permits the collection of patient-reported outcomes on how TSC affects individuals and families to complement medical data in the NHD 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 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 2022, 69 individuals were enrolled through the Self-Report Portal.



The TSC Alliance's **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. In 2022,

two new industry members joined the Preclinical Consortium with a total of 10 active industry members at the end of the year. The consortium tested seven unique compounds in 2022, raising the total tested to 63 since 2016.



In 2022, the TSC Alliance also entered into a **partnership with The LAM Foundation** to add lymphangioleiomyomatosis (LAM) mouse models to the Preclinical Consortium. The TSC

Alliance has licenses to use specific TSC mouse models for experiments carried out by the Preclinical Consortium, and all mouse license agreements include the rights for the TSC Alliance to perform experiments under contract for commercial entities. Experiments are executed at partnering contract research institutions to ensure consistency in testing, data acquisition and interpretation.



In 2012, the TSC Alliance provided seed funding to help initiate 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—is the first preventative trial in the United States for any form of epilepsy and has completed enrollment of 86 participants with final results expected in early 2023. This trial will determine whether treatment with vigabatrin prior to the onset of clinical seizures in TSC is beneficial to children’s developmental and neurologic outcomes.

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.

## Community support and resources

**The TSC Alliance’s Community Programs team exists to uplift everyone living with TSC by developing programs and services that provide individuals with TSC direct access to information, resources and support in every way we can.**

Community Programs connects and educates individuals, families, friends, co-workers and others to support people with TSC at every step of their journeys. In 2022 the TSC Alliance facilitated 5,164 peer-to-peer supports from **Adult Regional Coordinators** (12 volunteers in 8 regions nationwide), **Clinic Ambassadors** (14 volunteers in 15 TSC Clinics and TSC Centers of Excellence nationwide), **Dependent Adult Transition Resource Coordinators** (28 volunteers in 23 states and Puerto Rico), **Education Parent Mentors** (28 volunteers in 19 states) and **Community Alliance Leaders** (41 volunteers in 36 regions across the United States) with active **Future Leaders** (eight volunteers).

The Community Programs team supports a network of 36 volunteer branches of the organization, called **Community Alliances**, that provide support and community education in all 50 states. Community Programs also joined together with the Science & Medical Department to offer five **research educational webinars** with 268 live attendees and 915 recording views by the end of 2022.



The TSC Alliance’s **TSC Navigator**—our easy-to-use, interactive online tool to help guide individuals and families through the complexities of TSC across the lifespan—had 3,071 users in 2022. Fifty-five individuals

or families were also supported for medication access issues via our TSC Navigator program during 2022, consistent with the goal of proactively helping people avoid medication access issues.

The reality of living with a rare disease means high-quality care can be very difficult to access. Through the **Bcureful Travel Fund** administered by the National Organization for Rare Disorders (NORD), we were able to ensure TSC individuals were able to receive care at TSC Clinics and TSC Centers of Excellence across the United States, as well as participate in clinical trials. In 2022, the Bcureful Travel Fund supported 106 families with \$129,795.80—78 of them were assisted with travel to a TSC Clinic or TSC Center of Excellence and 28 were assisted with travel to a clinical trial. This help is imperative to families seeking the best medical care for their loved ones with TSC.





TITLE SPONSOR  Jazz Pharmaceuticals

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**2022 World TSC Conference**  
JULY 28–31, 2022 • DALLAS, TEXAS

PRESENTING SPONSOR  Nobelpharma



**TSC** Tuberous Sclerosis Complex International

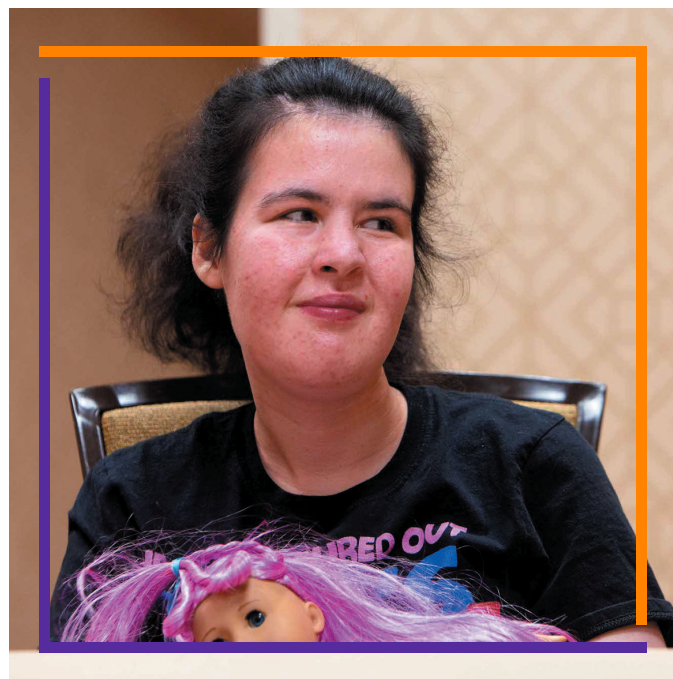
The TSC Alliance's **2022 World TSC Conference**, co-hosted by TSC International, was another resounding success for the world-wide TSC community with nearly 850 participants from across the globe gathering in Dallas, TX from July 28-31. More than 140 also participated virtually via livestreaming.

In-person attendees from 23 countries and 44 states enjoyed a wide variety of educational sessions, social gatherings, a robust exhibit hall, day camps for children and dependent adults, plenty of time for on-site relaxation activities and bonding opportunities. As always, the inspiring sessions and activities gave hope to all participants who were able to learn about the latest TSC diagnostic, treatment and management and a better understanding of the impact on the progress of TSC research.



Everyone left Dallas with a profound appreciation of new tools, coping skills and relationships to take back to TSC communities across the globe and feeling empowered by the knowledge and information shared. But most of all, the feeling of unconditional love and support felt throughout the event was a true inspiration.

Our sincere gratitude goes to the event's Title Sponsor Jazz Pharmaceuticals and Presenting Sponsor Nobelpharma as well as the other 54 sponsors who made the conference possible.



## Awareness and education

**Everyone should know about tuberous sclerosis complex, so our Communication Department diligently works to increase awareness among the general public, effectively reach the undiagnosed and newly diagnosed and provide a wide range of educational tools and materials for our community.**

To inform our constituents and other supporters throughout 2022, the TSC Alliance produced two issues of its national magazine, **Perspective**, which is mailed to approximately 18,000 constituents as well as posted on the website. Ten **TSC Now** podcast episodes attracted 2,248 total listens. Six issues of the electronic **TSC Matters** newsletter were distributed to 17,173 recipients. The **TSC Alliance website** increases understanding and provides extensive education through an average of more than 23,000 unique visitors each month.

The TSC Alliance also relies heavily on **social media** to educate constituents and promote new resources and events. Our private Facebook TSC Discussion Group boasts more than 10,500 members from around the world, while our Twitter account had 2,650 followers and Instagram had 3,070 followers by year's end.

To bolster public awareness, the TSC Alliance participated in the Tenth Annual **TSC Global Awareness Day** on May 15 as well as **TSC Awareness Month** throughout May. The TSC Alliance also heavily promoted the second annual **Seizure Action Plan Awareness Week** (February 8-14) and **Infantile Spasms Awareness Week** (December 1 to 7). These awareness campaigns along with the organization's various news releases culminated in more than 2.7 billion cumulative impressions.

## Professional education

Too many people go undiagnosed or misdiagnosed for years because of a lack of TSC awareness, which is why our Professional Education efforts strive to reach researchers, primary and specialty healthcare providers, medical students and genetic counselors in several ways, including publishing peer-reviewed articles and attending professional meetings and conferences.

In December, *Therapeutic Advances in Rare Disease* published “Racial differences in the dermatological manifestations of tuberous sclerosis complex and the potential effects on diagnosis and care.” The TSC Alliance’s Director of Medical Affairs Ashley Pounders, MSN, FNP-C, and Director of Research Gabrielle Rushing, PhD collaborated with Tanjala Gipson, MD (Le Bonheur Children’s Hospital) to write the article to highlight differences in skin manifestations between races in individuals with TSC and the potential effects of these differences on diagnosis and care.



The TSC Alliance participated in or presented at 28 professional meetings in 2022 including TANDem Consortium Meeting, Nobelpharma Town Hall, Mallinckrodt Ad Board, National Association of Pediatric Nurse Practitioners, American College of Medical Genetics, TAND Mini-Symposium (TANDem), Muscular Dystrophy Coordinating Committee Spring 2022 Meeting, American Thoracic Society 2022 International Conference, Rare Diseases International: 75th World Health Assembly, Interagency Collaborative to Advance Research in Epilepsy (ICARE) Annual Meeting, National Institute of Neurological Disorders and Stroke Nonprofit Forum, 2022 World TSC Conference, LAMposium, Global Genes Rare Summit, Health Research Alliance Fall 2022 Member Meeting, Rare Diseases Clinical Research Network Fall Meeting, Minnesota Pharmacy Conference, American Society of Human Genetics, Global Genes Atlanta, Infantile Spasms Action Network Membership Meeting, EveryLife Newborn Screening Bootcamp, Tuberous Sclerosis Complex Research Program, American Epilepsy Society, American Thoracic Public Advisory Roundtable Planning Meeting, Advanced Research Projects Agency for Health Rare Disease Planning Meeting, TANDem South Africa, American Thoracic Public Advisory Roundtable Lung Week and Partners Against Mortality in Epilepsy.

## Government advocacy

To ensure both federal and state appropriations for TSC research and clinical care, our Government Relations program—powered by the TSC community—collaborates with government partners to drive TSC research forward and improve clinical care and treatment options for individuals with TSC.

Held virtually in early March 2022, the annual TSC Alliance **March on Capitol Hill** once again advocated for federal funding for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense’s Congressionally Directed Medical Research Program. More than 204 people from 42 states participated in virtual appointments to champion \$8 million in funding for the TSCRP. The House TSCRP Dear Colleague Letter sponsored by Representatives Mullin (R-OK) and Raskin (D-MD) closed with 205 signers. The Senate letter sponsored by Senators Cramer (R-ND) and Heinrich (D-NM) closed with 35 signers. Since 2002, \$113 million has been cumulatively appropriated for the TSCRP.

On the state level, the TSC Alliance advocated for **state funding** for TSC Centers in Missouri and Maryland, resulting in \$1.1 million in state appropriations. Additionally, the Alabama TSC community held its first advocacy proclamation day with their Governor.

## Global outreach

**The TSC Alliance is proud to be recognized as a global leader for our efforts to address unmet needs in the international TSC community.**

Our Global Outreach program shares the TSC Alliance’s experience and assists in the startup and 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.

In addition, the TSC Alliance’s Director, Government & Global Affairs plays a key role in co-chairing **Tuberous Sclerosis Complex International** (TSCi), a world-wide consortium of existing tuberous sclerosis complex associations and organizations.





## Fund development

**Each year, the mission of the TSC Alliance is furthered by thousands of committed community members and other generous supporters from all over the globe.**

Together, our Development and Community Programs teams work tirelessly to harness the strength of our community to raise funds for research and for a wide range of support services and resources for families and individuals with TSC, health care professionals, educators and others. Even the smallest personal donation can have an incredible impact, and when combined with our special events and community fundraisers, those drops of rain can form a powerful monsoon of progress.

### 20th Anniversary Comedy for a Cure®

In April 2022 the TSC Alliance hosted its flagship fundraising event, Comedy for a Cure, at the Avalon Hollywood. With our headline sponsor Jazz Pharmaceuticals, this event shattered previous records by raising \$587,800!

The Dinsdale Family received the Courage in Leadership Award for their dedicated support over their years on behalf of their son Alex. We also honored Jo Anne Nakagawa with the TSC Champion Award for her decades of dedication to the cause, serving both individuals at UCLA and her impactful career at the TSC Alliance.

The event was headlined by the spellbinding Caroline Rhea, and featured comedian Brian Kiley, along with our hilarious emcees Wendy Liebman and Jim O'Heir. The evening also featured the musical talents of *American Idol* season 19 alum and last year's Courage in Leadership recipient Althea Grace.

This special anniversary event was sponsored by Jazz Pharmaceuticals, Andrea Maginn Memorial Trust, CVS Health, Tim and Kathi Dills, Horizon Therapeutics, Marinus Pharmaceuticals, Nobelpharma, Szilagyi Family, UCB Inc., WNC & Cooper Family, BridgeBio, Upsher-Smith Laboratories LLC, Keith A. Hall Family, Hobart and Shapiro Family, and Ted and Peggy Mastroianni.







## 20th Anniversary Step Forward to Cure® TSC

The TSC Alliance held our 20th Anniversary Step Forward to Cure TSC Global Hybrid Walk-Run-Ride over the weekend of May 14-15. Step Forward to Cure TSC has cumulatively raised more than \$18.4 million over the last two decades. 2022 also featured a return to in-person events in Philadelphia, Dallas and Los Angeles.

The event's success was in large part due to our national planning committee, including Shalonda Alexander, Andrea Beebe, Mary Jo Cardona, Danielle Clark, Lori DiStefano, Preston Fitzgerald, Cindy Fowler, Jonathan Goldstein, Shannon Grandia, Frances Harper, Lesley Holmes, Jill Hyman, Karen Johnston, Jessica Krefting, Jenny Kuehn, Mary Ann Lamb, Heather Lens, Jack Lyons, Jessie Myers, Noor Panjwani, Lauren Perry, Mary Roberds, Lauren Shillinger, Alanna Spotts, Jackie Tallman and Carol Ann White.

### Top Fundraisers

1. Seraphina's Sweeties: \$137,000
2. Team Jay: \$32,000
3. Bodie's Buddies: \$26,000

### National Sponsors

Marinus Pharmaceuticals, Jazz Pharmaceuticals, Nobelpharma, Ovid Therapeutics, UCB Inc., Upsher-Smith Laboratories LLC, MassMutual SpecialCare and BridgeBio.

### Participating TSC Clinics and Centers of Excellence

Atrium Health (NC), Beaumont Health, Boston Children's Hospital, Boston Children's Hospital Physicians, Children's Hospital Los Angeles, Children's National Medical Center, Children's Hospital of Orange County, Cincinnati Children's Hospital, Cook Children's Hospital, Dell Children's Hospital, Duke University, Carol and James Herscot Center for TSC at Massachusetts General Hospital, LeBonheur Children's, Lurie Children's Hospital, Minnesota Epilepsy Group, Nemours/duPont Children's, Penn State Children's Hospital, Seattle Children's Hospital, Texas Children's Hospital, Texas Scottish Rite Hospital for Children, UCLA, University of Alabama Birmingham, University of Iowa, University of Maryland Medical Center, University of Texas Health Science Center Houston, University of Virginia, Vanderbilt University and Washington University St. Louis.

## Team TSC

The TSC Alliance's Team TSC is proud to be an Official Charity partner with the annual TCS New York City Marathon to fund the mission of the TSC Alliance, raising \$29,209 in 2022. Congratulations and a sincere thank you to the 2022 Team TSC runners: Chip Burkhalter, Dr. Peter Crino, Jenny Kuehn, Bridget Lucas and Bridget Faria.



## Other events raising more than \$10,000

- Antique Sale in Memory of Thorpe Richards: \$14,488
- Bcureful Holiday eCard Campaign: \$12,292
- Facebook Donations/Birthday Fundraisers: \$51,948
- Luminate the Night: \$12,373
- Pours 4 Parker Raffle: \$17,980

## The President's Council

The TSC Alliance founded the President's Council in 2016 to assemble a team to fund and fuel research efforts. Members work with the President & CEO and the Board of Directors and contribute a minimum gift of \$100,000. President's Council members include:

- Ramesh and Kalpana Bhatia Family Foundation through the creation of Anya's Accelerator
- David Coit
- Kay and Will Cooper, through the creation of the Kay and Will Cooper TSC Mental Health Fund
- Cowlin Family
- Timothy and Kathi Dills
- Christopher and Joy Dinsdale
- Engles Family Foundation on behalf of Engles Collaborative Research Fund
- Foglia Family Charitable Gift Fund, through the Bcureful Travel Fund
- Dr. Michael and Janie Frost
- Julian and Janice Gangolli
- Michael and Abby Gregory Foundation at the Dallas Foundation
- Brittany and John Gottschall
- Jim and the late Andrea Maginn, through the creation of the Abigail and Amelia Clinical Accelerator
- Diane McSwain
- Drs. Jonathan and Bonnie Rothberg & Family, Rothberg Charitable Foundation of Children's Diseases
- William Watts
- Lorne Waxlax, through the creation of the Waxlax Biosample Collection Initiative
- Wong Family Foundation, through the creation of the Wong Family Foundation Research Award

# Annual Fund: major donors and contract revenue

Fiscal Year 2022: January 1 to December 31

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

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at The Dallas Foundation  
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William Watts  
Lorne Waxlax  
Wong Family Foundation

## Benefactor (\$50,000 - \$99,999)

Kay and Will Cooper, Sr.  
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Tuberous Sclerosis Canada Sclerose  
Tubereuse

## Protector (\$10,000 - \$19,999)

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Arlene and Ralph Sondag  
The Sperling Family Charitable Foundation  
St. James Elementary School  
Sweet Home High School  
Lisa and Robert Szilagyi  
TacomaBeast  
Tricia and Patrick Youssi Fund  
Robert Trout and Janet Studley



TSC Alliance of India  
TSC Alliance of Israel  
TSC Alliance of Mexico  
John Waterbury  
Pamela and Paul Waxlax  
WNC & Associates  
Wurwand Foundation  
Deborah and Joseph Yohn

## Advocate

### (\$1,000 - \$4,999)

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Paul and Patricia Anderson  
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Apex Title & Closing Services, LLC  
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Stephen and Eileen Ashwal  
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Naida Bamford  
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Julie Blum and Greg Linsin  
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Vincent Chieffo  
Mardel Chinburg  
Chris Latvala Campaign  
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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)

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Shonnie Johnson and the late  
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## 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 we can add you.

We are pleased to honor the following distinguished members of the Eternal Flame Society:

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

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Auxiliary Adult Regional Coordinator:  
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Region 2: California, Arizona, Nevada, New Mexico, Utah, Hawaii  
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Region 3: Colorado, Nebraska, South Dakota, North Dakota, Iowa, Minnesota, Wisconsin  
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Region 4: Texas, Oklahoma, Kansas, Missouri, Arkansas, Louisiana  
Co-Adult Regional Coordinator: Emilie Hyde  
Co-Adult Regional Coordinator: Foster Hyde

Region 5: Illinois, Michigan, Indiana, Ohio, Pennsylvania  
Adult Regional Coordinator: Phil Tallman

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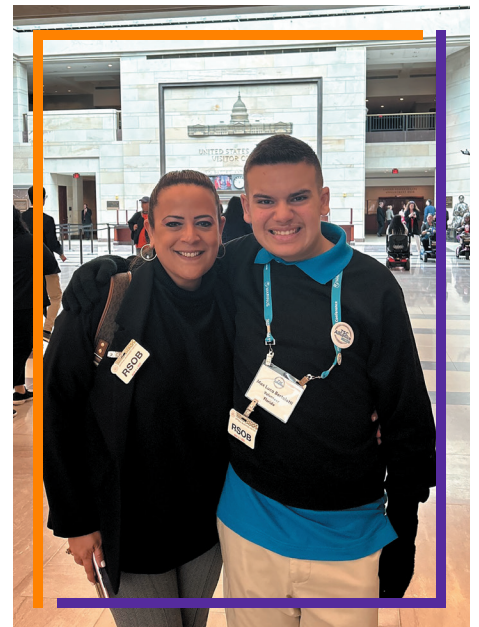
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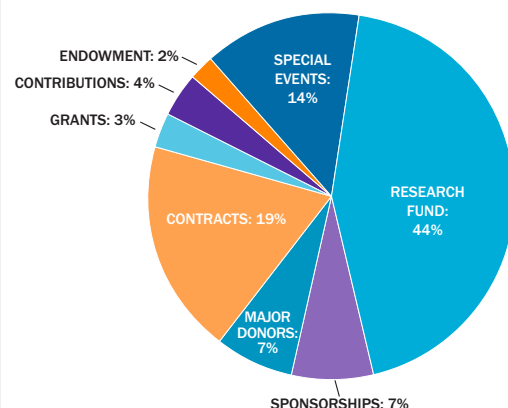
## National Tuberous Sclerosis Association & Affiliate

### Consolidated Statements of Financial Position

As of December 31,	2022	2021
<b>Assets</b>		
Cash and cash equivalents	\$ 2,440,085	\$ 2,843,269
Investments	5,577,848	6,691,013
Accounts receivable	181,490	99,173
Promises to give	5,280,316	2,698,495
Prepaid expenses and other assets	279,571	620,148
Operating lease right of use asset, net	718,708	778,371
Property and equipment	463,272	437,169
<b>Total assets</b>	<b>\$ 14,941,290</b>	<b>\$ 14,167,638</b>
<b>Liabilities and Net Assets</b>		
<b>Liabilities</b>		
Accounts payable and accrued expenses	\$ 599,548	\$ 186,010
Accrued compensation	298,339	290,487
Deferred revenue	285,264	676,798
Operating lease liability, net	1,189,842	1,285,691
Gift annuity obligations	113,451	119,665
<b>Total liabilities</b>	<b>2,486,444</b>	<b>2,558,651</b>
<b>Net assets</b>		
Without donor restrictions		
Undesignated	(158,002)	(20,618)
Board-designated	5,309,341	6,601,224
<b>Total without donor restrictions</b>	<b>5,151,339</b>	<b>6,580,606</b>
With donor restrictions	7,303,507	5,028,381
<b>Total net assets</b>	<b>12,454,846</b>	<b>11,608,987</b>
<b>Total liabilities and net assets</b>	<b>\$ 14,941,290</b>	<b>\$ 14,167,638</b>

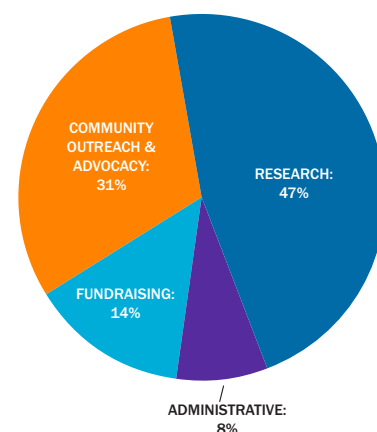
The TSC Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization's 2022 and 2021 financial statements to the TSC Alliance Board of Directors. The complete audited financials are on file with the TSC Alliance or available on its website. To obtain a copy, please call (800) 225-6872 or download at [tscalliance.org](https://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 2022 and 2021 there were net losses and gains, 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 \$2,057,220 and \$1,328,199 for 2022 and 2021, respectively.

### TSC Alliance Revenue Sources 2022 Total Revenue: \$10,130,649



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

### TSC Alliance Expenses 2022 Total Expenses: \$8,073,683



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	2022 Total	2021 Total
<b>Revenue and Support</b>				
Special Events	\$ 1,446,809	\$ 112,339	\$ 1,559,148	\$ 1,189,820
Cost of direct benefits to donors	(125,478)	-	(125,478)	(46,439)
Special events, net	1,321,331	112,339	1,433,670	1,143,381
Contributions	750,333	4,753,965	5,504,298	4,495,240
Contributed nonfinancial assets	33,843		33,843	68,776
Contracts	1,906,672		1,906,672	2,120,485
Conferences	813,645		813,645	113,777
Interest and dividends	140,009	24,559	164,568	127,560
Memorials and honoraria	105,306	12,160	117,466	136,239
Federated funding	52,175		52,175	54,696
Other income	15,492		15,492	-
	5,138,806	4,903,023	10,041,829	8,260,154
Net assets released from restrictions	2,473,109	(2,473,109)	-	-
Total revenue and support	7,611,915	2,429,914	10,041,829	8,260,154
<b>Expenses</b>				
Program services				
Research	3,794,438	-	3,794,438	3,939,924
Family services	1,701,754	-	1,701,754	726,768
Public health education	520,210	-	520,210	524,284
Government relations	162,771	-	162,771	154,139
Professional education	105,471	-	105,471	122,600
Total program services	6,284,644	-	6,284,644	5,467,715
Supporting services				
Fundraising	1,178,795	-	1,178,795	990,443
Management and general	672,392	-	672,392	549,013
Total supporting services	1,851,187	-	1,851,187	1,539,456
Total expenses	8,135,831	-	8,135,831	7,007,171
Change in net assets from operations	(523,916)	2,429,914	1,905,998	1,252,983
Net investment income (loss)	(905,351)	(154,788)	(1,060,139)	893,443
<b>Change in net assets</b>	(1,429,267)	2,275,126	845,859	2,146,426
Net assets, beginning of year	6,580,606	5,028,381	11,608,987	9,462,561
<b>Net assets, end of year</b>	\$ 5,151,339	\$ 7,303,507	\$ 12,454,846	\$ 11,608,987



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**Hope no matter how complex™**

