



A transformative year of generosity



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2021 marked the most successful year in the 47-year history of our organization. It was a year of transformative, foundational change, epitomized in the evolution of our name to the TSC Alliance® and reflected in every facet of what we do. Here are just a few examples of how this change manifested across our organization:

- **We reimagined how we accelerate research** by investing more in researchers than ever before, testing more potential treatments to lay the foundation for future clinical trials and incorporating cutting-edge science to help us better understand the variability and progression of tuberous sclerosis complex (TSC).
- **We reshaped how we educate and mobilize our constituents** to meet people where they are, empowering more community members to advocate for federally funded TSC research, connect and learn from leading TSC researchers and clinicians and participate virtually in TSC Alliance events from anywhere in the world.
- **We redefined how we provide support** through updating guidelines and standards to ensure the highest quality of care for those affected, developing new tools to provide resources for every stage of life and recommitting to reaching more people with TSC, including those from underrepresented groups.

What makes these feats even more impressive is the backdrop in which they took place. Facing another year impacted by the COVID-19 pandemic, we built upon lessons learned from the year before and continued to find new ways to innovate, collaborate and inspire. And at every turn **our success was spurred by the overwhelming support of our community** of volunteers, researchers, clinicians, donors and partners.

Our challenge now is to not rest on the laurels of our success, but to carry this momentum forward and continue to innovate and transform to meet the changing needs of our community, so we can realize our vision of a world where everyone affected by TSC can live their fullest lives.

This 2021 Annual Report provides additional information about these and other accomplishments, overviews of our programs and services, fundraising successes, donor acknowledgements and much more.



About tuberous sclerosis complex

Tuberous sclerosis complex (TSC) is a rare genetic disease that affects people at all stages of life. TSC causes tumors to grow in different organs and can impair their function, primarily the brain, heart, kidneys, skin, eyes and lungs. 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. Every individual's experience with TSC is different—many live independently while others require complex care.

Too often, TSC goes undiagnosed. But we know at least two babies born each day in the United States will have it. Nearly one million people worldwide are estimated to be living with TSC, with approximately 50,000 in the United States. The TSC Alliance helps connect them.

About the TSC Alliance

The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with TSC. We drive research, improve quality care, increase access and advocate for all affected by the disease. 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. **Join us at tscalliance.org or contact us at info@tscalliance.org.**

Research

The TSC Alliance ensures TSC researchers have the data and funds they need to discover breakthroughs.

Our Science and Medical Department stimulates and supports basic, translational and clinical research on the various manifestations of tuberous sclerosis complex to further the development of clinical therapies and, ultimately, a cure for TSC. The department builds and fosters collaborations between basic and clinical researchers by collecting and distributing TSC natural history data and biosamples, through collaborative preclinical and clinical research programs and by hosting biennial International TSC Research Conferences.

In 2021, the TSC Alliance invested more in TSC research than ever before: \$3.9 million. Since 1984, the TSC Alliance has spent \$31 million on innovative TSC research through our grants and contracts funding mechanisms.

“ I sincerely thank the TSC Alliance for supporting and trusting my TSC research project as it’s not easy to describe how important this funding has been for my professional path. Thanks to you I became aware of the importance of TSC pathology, and this really pushed me to give my best for this important research.

Ilaria Barone, PhD, Postdoctoral Research Fellow, Boston Children’s Hospital



Implemented in 2006, the TSC **Natural History Database** captures clinical data to document the impact of the disease on a person’s health over his or her lifetime. As of December 2021, 2,357 people with TSC were enrolled in the project from among 18 U.S.-based sites and through the TSC Alliance.



Building upon the Natural History Database, the TSC **Biosample Repository** will impact research over the next 10 years or more. High-quality biosamples—such as blood, DNA and tissues linked to detailed clinical data—are critical for researchers

to understand why TSC is so different from person to person. As of December 31, 2021, the TSC Biosample Repository has acquired 2,000 biosamples. The organization continues to grow the Biosample Repository by collecting blood samples annually from participants who volunteer to do so, enabling researchers to study changes in proteins and other molecules in the blood over time; adding additional TSC Clinics as participating Biosample Repository collection sites; and collecting blood using mobile

phlebotomy, enabling people to donate samples regardless of where they live in the United States and whether they are seen at a TSC Clinic. In 2021, portions of 456 of these samples were shared with 13 distinct researchers and since inception, 1,290 samples have been distributed to 34 different researchers for 39 distinct projects to further scientific advances.

In 2021, the TSC Alliance also completed a **Whole-Genome Sequencing (WGS)** pilot study using DNA from blood samples in our Biosample Repository to demonstrate the feasibility of this approach. The TSC Alliance submitted 20 DNA samples that had not been previously analyzed to the Translational Genomics Research Institute for WGS. Results confirmed disease-causing variants in 13 of 20 samples while 6 were newly discovered as likely disease-causing variants and demonstrated feasibility of WGS to deliver valuable information to both patients and researchers.



In December 2021, the TSC Alliance added the **TSC Self-Report Portal** to the TSC Natural History Database. This new portal will permit the collection of patient-reported outcomes on how TSC affects individuals and families, which will complement medical data in the Natural

History Database. 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). The TSC Alliance is helping the TANDem project team validate the utility of the TAND-SQ for future use in a mobile application.



The TSC Alliance launched the TSC **Preclinical Consortium** in 2015 to help advance more drug candidates into clinical 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 and TAND. As of December 2021, 10 companies were active members of the consortium. Since inception, the consortium has helped advance the evaluation of drugs for TSC by conducting 90 studies, evaluating 57 candidate drugs.



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, consortium investigators have been

awarded more than \$39 million by the National Institutes of Health (NIH) and Food and Drug Administration (FDA) through competitive grant processes. TSC Alliance personnel serve on the leadership team for the consortium, actively track enrollment and raise community awareness to help identify potential participants for clinical studies. TSC Alliance also provides supplemental financial support to accelerate or expand NIH-funded studies.



The TSC Alliance stimulates collaboration and innovation through convening experts and stakeholders within and outside the TSC field. The first **Innovation Workshop** topic was newborn screening, held in late 2020 and culminating in a Zoom meeting

on January 29, 2021. Following peer-review by experts in TSC and screening research, the TSC Alliance fully funded two proposals totaling \$164,856 for hypothesis-driven research in assay development for early detection of TSC.



The **2021 Virtual International TSC & LAM Research Conference: Driving Discoveries Beyond Boundaries**, presented by Greenwich Biosciences and The

Rothberg Institute for Childhood Diseases, held October 28-30, 2021, welcomed 179 people from 18 countries. Co-sponsored by the TSC Alliance and The LAM Foundation, the conference featured three plenary sessions with 17 oral presentations and two poster sessions with 14 posters.

Support services

No one is alone on their TSC journey with the TSC Alliance. Our Community Programs Department develops programs and services that provide individuals with TSC direct access to information, resources and specialists experienced in the diagnosis, treatment and management of TSC.

In 2021 the TSC Alliance facilitated 8,742 **peer-to-peer supports** from Adult Regional Coordinators (12 volunteers in 8 regions nationwide), Clinic Ambassadors (16 volunteers in 19 TSC Clinics and TSC Centers of Excellence nationwide), Dependent Adult Transition Resource Coordinators (31 volunteers in 26 states and Puerto Rico), Education Parent Mentors (29 volunteers in 21 states) and Community

Alliance Leaders (47 volunteers in 33 regions across the United States) with active Future Leaders (8 Volunteers) and Past Future Leaders (6 volunteers) who have agreed to remain as leaders for other young adults with TSC.

“Until I became involved in the TSC Alliance peer-to-peer support programs as an Adult Regional Coordinator, I had never met anyone else with TSC. Being able to connect with other adults with TSC has provided me with a sense of community and helped me realize I am not alone, which has been invaluable to me, especially during the pandemic when it has been easy to feel isolated.”

Iris Mustich, MPH, Volunteer

The TSC Alliance works to ensure school systems understand and adapt to the learning needs of students with TSC. **Education Parent Mentors** attended 55 school meetings (IEPs, Evaluation Team Meetings, 504 Plan Meetings, Resolution Meetings and Mediations) in person, through SKYPE/Zoom and via conference calls to support families in attaining educational services for their children throughout the country. Several school systems also requested “TSC 101” in an effort to help them understand the complexities of TSC and learning issues for children with TSC.

Our nationwide network of **Community Alliances** supports individuals and families affected by TSC at the local level. Every branch is run by caring and welcoming volunteers—parents, grandparents, adults and friends—who host educational meetings, raise awareness and fundraise, foster local connections and serve as a resource in their communities.

To ensure the TSC community continues to receive updated information about TSC, TSC-Associated Neuropsychiatric Disorders (TAND), transition and research, the TSC Alliance developed an **e-Webinar series**. In 2021, we hosted 27 e-Webinars with 1,219 cumulative live attendees, 5,567 cumulative recording views and 3,123 cumulative landing pages visits. Additionally, we held the following webinars: April COVID Vaccine Town Hall – 66 live attendees, 304 video views; ABC to SAP Webinar – 50 live attendees, 458 video views; August COVID Update Town Hall – 307 live attendees, 463 video views. Adding in live attendees with additional webinars total live audience for webinars is 1,642, total cumulative recording views is 6,636 and 3,123 cumulative landing page visits.



In 2021, the TSC Alliance launched **TSC Navigator**, 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. Users can access information based on the age of one's diagnosis, such as prenatal, childhood or adult, to help determine which steps will help empower them throughout their individual journeys, regardless of age. The TSC Navigator launched October 14 and received more than 2,700 visits by year end. In addition, 587 individuals and families were assisted directly by the Director of Medical Affairs and team members acting as Support Navigators. Of the assistance provided, 78 were medication-related, 60 were TAND-related, 88 were new diagnosis and 252 were for assistance with access to care with 46 COVID-19 related. The remainder served a variety of other needs.

Our hope is for the TSC Navigator to serve as a central guide for newly-diagnosed families and individuals, as well as those encountering new areas of concern along the TSC journey. Having a wealth of information, resources and support all in one place is invaluable for our community.

Lesley Holmes, Parent



Awareness and education

The more people know about TSC, the faster it can be diagnosed and treated. The TSC Alliance's Communications Department heightens awareness of TSC throughout the general public to broaden the scope of support and understanding beyond TSC individuals and their families.

One major project in 2021 was **changing the organization's name to TSC Alliance**. The change was formally announced Sunday, May 16, after almost two years of planning by staff and members of the TSC community.

During 2021, the TSC Alliance also produced two issues of its national magazine, **Perspective**, which is mailed to approximately 17,900 constituents as well as posted on the website. The TSC Alliance's podcast series, called **TSC Now**, produced 12 episodes with 2,186 downloads. Six issues of the electronic **TSC Matters** newsletter were distributed to 1,340 subscribers. The TSC Alliance's **website** increases awareness and provides extensive education through an average of more than 24,000 unique visitors each month.

The TSC Alliance also relies heavily on **social media** to educate constituents, provide online support and promote new resources and events. Our private Facebook TSC Discussion Group boasts more than 10,000 members, while our Twitter account has 2,579 followers and Instagram has 2,762 followers.

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





Advocacy

We advocate for state and federal funding of TSC research and clinical care—and give the TSC community the tools to do the same. Our Government Relations efforts focus on increasing government appropriations for TSC research, raising awareness and collaborating with partners to drive TSC research.

On the state level, the TSC Alliance advocated for **state funding** for TSC Centers in Missouri and Maryland, resulting in at least \$750,000 in state appropriations. The annual TSC Alliance March on Capitol Hill to advocate for **federal funding** for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense's (DoD) Congressionally Directed Medical Research Program (CDMRP) took place in early March 2021.

“TSC research funding at the state and federal levels is very important to my brother Frank and our family! State funding enabled the setup of the first adult TSC Clinic in Maryland. Federal funding enabled research in treatments, including an FDA-approved facial cream for all TSC patients. Using cutting-edge research, we want to one day find a cure for this rare disease.”

Jocelyn Cenna, Sibling

More than 135 advocates made virtual appointments with 75 Senate and 280 House offices to advocate for a continuation of **\$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 202 signers. The Senate letter sponsored by Senators Cramer (R-ND) and Heinrich (D-NM) closed with 34 signers. Total funding for the TSCRP has been \$105 million since 2002. Research performed through the TSCP has led to multiple clinical trials. The TSCRP also funded research to develop animal models of TSC that have seizures, enabling a better understanding of the etiology of TSC.

Global outreach

The TSC Alliance works to address unmet needs within the global TSC community. Our **Global Alliance** program provides the opportunity for the TSC Alliance to share experiences and assist in the start-up of support of TSC-related organizations in other countries.

“TSC Alliance India is grateful to the Global Alliance program for jumpstarting our organization with a good governance plan, devising a strategy and mentoring our activities. We are indebted to the TSC Alliance for helping us achieve much progress in a short time.”

Rahul Vipparthi, President, TSC Alliance of India

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 10 TSC Clinics in Global Alliance countries.

The TSC Alliance is also active in **Tuberous Sclerosis Complex International** (TSCi), a consortium of TSC organizations around the world. TSCi provides a forum to share information, exchange ideas and methods, co-fund research projects and promote increased international awareness of TSC. In 2021, TSCi wrote a paper entitled, “Beyond the Guidelines: How We Can Improve Healthcare for People with TSC Around the World,” which examines the state of TSC care around the world, identifies gaps in TSC care and makes recommendations for how TSC organizations and key stakeholders can work together to overcome barriers in TSC care.

Professional education

Everyone should know about TSC, especially healthcare professionals. Our Professional Education activities expand programs to 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 August, **two new publications** were accepted by *Pediatric Neurology*, “Updated International TSC Diagnostic Criteria and Surveillance and Management Recommendations” and “Beyond the Guidelines: How We Can Improve Healthcare for People with TSC Around the World.” The new papers provide the first significant updates to the international guidelines since 2013 because of new medications and advances in treatments. To address the changes, a working group led by Darcy A. Krueger, MD, PhD, Cincinnati Children’s Hospital Medical Center, and Hope Northrup, MD, McGovern Medical School, University of Texas Health Science Center at Houston, included 80 participants from 16 countries.

The TSC Alliance participated in or presented at **37 professional meetings** in 2021 including Curing the Epilepsies 2020: Setting Research Priorities, NIMH 2021 Virtual Workshop: Gene-based therapeutics for rare neurodevelopmental psychiatric disorders, TSC Alliance: Newborn Screening Workshop, ATS Board of Directors Meeting, Rare Disease Day at NIH, ISAN Membership Meeting, Inaugural O’Donnell Brain Institute Symposium on Autism Spectrum Disorders, Overcoming Barriers to Diversifying Clinical Trials (RDCRN), ELHS Spring Learning Session, Health Research Alliance Cultural Competency Workshop with BME, Research!America Annual Meeting of the Members, Medicaid and Chip Payment and Access Commission (MACPAC) Webinar, ICARE Meeting, Trans-NIH Meeting, ATS PAR Meet-the-Experts Patient/Family Forum, ATS Scientific Symposium, USF Diversity, Equity, and Inclusion in the Workplace Series, ISAN Membership Meeting–Summer, Global Genes RARE Drug Development Symposium: Preclinical Modeling–What Advocates Need to Know about Animal & Cell Models, International TSC Research Conference–UK, Rare Disease Patient-Focused Drug Development (PFDD) Guidance Compendium, Global Genes ACCESS Working Group Lunch Briefing: Medicaid Coverage for Genomic Sequencing, NINDS Nonprofit Forum Advisory Board Meeting–Industry Partner, LGS Foundation Meeting of the Minds, EveryLife Virtual Newborn Screening Bootcamp, CNF Symposium (within CNS), RDCRN Fall Meeting, NIAMS, BIO, Virtual International TSC & LAM Research Conference, ATS PAR Annual Planning Meeting, TSCi Virtual Workshop, TSCR Programmatic Review & Vision Setting, American Epilepsy Society Annual Meeting and and Infantile Spasms Action Network Member Meeting.

Fund development

Thousands of supporters, TSC community members and other partners work together to help fuel the TSC Alliance’s mission. Our Development and Community Programs Departments focus on raising funds for research, programs and support for individuals, families, healthcare professionals and educators. Special events, community fundraisers and personal donations—large and small—help underwrite these initiatives and allow the TSC Alliance to work hand-in-hand with the TSC community to ensure people navigating TSC have hope and support every step of the way.

“One of the things that impresses me about the TSC Alliance is their ability to identify research needs and collaborate effectively with researchers. Donating to this organization means they can get results faster.”

Lorne Waxlax

Second Annual Step Forward to Cure® TSC Global Virtual Walk-Run-Ride

The TSC Alliance hosted its second annual Step Forward to Cure TSC Global Virtual Walk-Run-Ride on May 15-16, **raising more than \$805,000!** We also hosted our second annual Step Forward to Cure TSC Virtual Auction.

This year’s event schedule started on May 10 and featured Kari Luther Rosbeck, TSC Alliance President and CEO, and Lisa Moss, Vice President, Donor Relations, hosting Facebook Live lunch-and-learn interviews with national sponsors and members of the TSC community members. The Facebook Live Kick-Off Ceremony was held May 15 with Kari Luther Rosbeck; Dr. Peter Crino, Chair, TSC Alliance Board of Directors; and special guest, Althea Grace, *American Idol* Season 19 contestant and TSC mom.

The Wrap-Up Rally was hosted by Jim O’Heir, TSC Alliance Champion and celebrity spokesperson, and Kari Luther Rosbeck, TSC Alliance President & CEO, who announced our top prize winners. The opening remarks were presented by Bill Joseph, Vice Chair of the TSC Alliance Board of Directors. Bill graciously acknowledged the strength and support of the TSC community and thanked this year’s planning committee members and TSC Alliance staff for all of their work behind the scenes and throughout the event weekend. We were thrilled to end our Wrap-Up Rally with the official launch of the new TSC Alliance name, logo and tagline.

Again, we want to thank our National 2021 Step Forward to Cure TSC Global Virtual Walk-Run-Ride sponsors, our outstanding planning committee, donors and the 2,112 supporters and 202 teams who registered to make our second virtual walk a stellar event.

National Sponsors

Greenwich Biosciences; Marinus; Nobelpharma; Novartis, UCB, Inc.; Upsher-Smith Laboratories, LLC; MassMutual SpecialCare; LivaNova

Regional Sponsors

Accurate Healthcare, Hightower Dermatology, Hightower Veterinarian Services, Michael P. Wilson Inc., Real Estate Appraisers, Stanford Children's Health, Cavarocchi Ruscio Dennis Associates, SOBOBA Foundation, Fifth Third Bank, Level Up Drywall, Western & Southern Financial Fund, Klace & Company Real Estate, Carolina Tailwinds, Sharon Oberlander, Seizure Tracker

Participating TSC Clinics and Centers of Excellence

Atrium Health (NC), Beaumont Health (MI), Boston Children's Hospital, Boston Children's Hospital Physicians, Children's Hospital of Los Angeles, Children's National Medical Center, Cincinnati Children's Hospital, Cooke Children's Hospital, Dell Children's Hospital, Duke University, Herscot Center for TSC at Massachusetts General Hospital, Institute of Neurology at St. Barnaba, Le Bonheur Children's, Lurie Children's Hospital, MN Epilepsy Group, Seattle Children's Hospital, Stanford Children's Health, Texas Children's Hospital, Texas Scottish Rite Hospital for Children, University of Alabama/Birmingham, UCLA, University of Iowa, University of Maryland Medical Center, Virginia Commonwealth University, Washington University/St. Louis

Top Fundraisers

1. Ryan and Andrea Beebe, Parker's Phantics: \$40,951
2. Jill Hyman and Kate Martin, Team SkyBlue Crew: \$40,793
3. Mary Ann Lamb, Team Jay: \$33,425

19.5 Comedy for a Cure®

The TSC Alliance hosted a wildly successful hybrid edition of Comedy for a Cure, which **raised \$143,000** on October 17. The show was live-streamed to online viewers from Feinstein's at Vitello's in Studio City, CA with a sold-out in-person audience.

We were thrilled to present the much-deserved Courage in Leadership Award to Althea Grace, a singer-songwriter who gained national attention as a top contestant on American Idol Season 19. We were also pleased to honor Wendy Liebman, who has been a significant behind-the-scenes contributor to Comedy for a Cure and the mission of the TSC Alliance for many years, with a TSC Champion Award. The magical night included musical entertainment by Althea Grace and a piano performance by Emily Phan, TSC Alliance Future Leader. The event featured an action-packed lineup of hilarious comedians: Jodi Miller, Marty Ross, Taylor Williamson and headliner Drew Lynch. We are thankful to our fabulous co-hosts Jim O'Heir and Wendy Liebman who, together with auctioneer extraordinaire Damon Casatico, hosted another stellar event.

Comedy for a Cure sponsors included Greenwich Biosciences; Horizon; The Maginn Family; Neurelis; The Szilagyi Family; WNC/Cooper Family; Upsher-Smith Laboratories, LLC; UCB, Inc.; Ray Chan; Tim and Kathi Dills; The Keith A. Hall Family; Ted and Peggy Mastroianni; and Regenxbio.

Other events raising more than \$10,000

- Facebook Donations/Birthday Fundraisers: \$97,775
- Getting Saucing with Parker B., hosted by Ryan and Andrea Beebe: \$24,464
- Bcureful Valentine's Day Campaign—Show Your Heart, Send a Heart: \$11,590

Team TSC

The TSC Alliance and Team TSC were proud to be an Official Charity Partner with the 50th TCS New York City Marathon, held Sunday, November 7, 2021. Team TSC **raised \$53,939** to fund the mission of the TSC Alliance. Congratulations and thanks to Team TSC runners: Raymond Capogna, Claire Blyth, Katherine Chapman, Maureen Elliott, Kristin Burkhalter, Chip Burkhalter, Ryan Kennedy and Amanda Alberts.

The President's Council

The TSC Alliance founded the President's Council in 2016, bringing together members of families impacted by TSC who work with the President & CEO and the Board of Directors to fund and fuel research. Members contribute a **minimum gift of \$100,000** per year to fund research. President's Council members since its inception include:

- David M. Coit
- Kay and Will Cooper, through the creation of the Kay and Will Cooper TSC Mental Health Fund
- Cowlin Family
- Tim 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
- Julian and Janice Gangolli
- Brittany and John Gottschall
- Jim and the late Andrea Maginn, through the creation of the Abigail and Amelia Clinical Accelerator
- Diane McSwain
- Jonathan and Bonnie Rothberg, Rothberg Charitable Foundation of Children's Disease
- William Watts
- Lorne Waxlax, through the creation of the Waxlax Biosample Collection Initiative
- Wong Family Foundation

Annual Fund – major donors and contract revenue

Fiscal Year 2021: January 1 to December 31

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

Anonymous
Anonymous
BridgeBio Pharma, Inc.
David M. Coit
Kay and Will Cooper Sr., WNC & Associates
Facebook Community Donations
Foglia Family Foundation
Gerry and Bill Cowlin Foundation
Janice and Julian Gangolli Family Fund
Jazz Pharmaceuticals
Jim and Andrea Maginn Memorial Trust
Diane McSwain
Ovid Therapeutics
Small Business Administration, Paycheck Protection Program
TSC Alliance Endowment Fund
UCB, Inc.
Lorne Waxlax
Wong Family Foundation

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

Anonymous
Brittany and John Gottschall
Novartis Pharmaceuticals Corporation
Emma J. Rocco Living Trust
Jonathan Rothberg and Bonnie Gould Rothberg, Rothberg Institute for Childhood Diseases
Upsher-Smith Laboratories, LLC
William Watts

Sponsor (\$20,000 - \$49,999)

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Edward and Kristin Burkhalter
Child Neurology Foundation
Haag Family Foundation
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Mallinckrodt Pharmaceuticals
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MassMutual SpecialCare
Neurelis, Inc.
Nobelpharma
Allan and Carla Price
Irene Rothberg

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

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Karen White and Julie Geissman
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PeerView Institute for Medical Partnership
Rebecca Anhang Price and Matthew Price
Leslie and Chris Russell
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Lacinda and Douglas Scott
Heidi and Jerrill Sprinkle
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Defender (\$5,000 - \$9,999)

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America's Charities
Anonymous
Jeffrey Avansino
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Biotechnology Innovation Organization
Linda Buchman
Cassandra and Bryce Carroll
Cliff and Deborah White, Cliff and Deborah White Family Foundation
Margaret and Jared Cox
Peter Crino
Cornelius and Linda DenHarder
Prachee Devadas
Tim and Kathi Dills
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Doe Family Foundation
Nick Giardina
Robert and Kathryn Groves
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The Hall Family
Lori and James Hartge
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Irene Marton
Stuart and Carina Marton
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Mischel Family Charitable Fund
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Noema Pharma AG
James Norman
Chris Parker
Jo Anne Nakagawa
Premier Research International, LLC
Mark Reich
Nancy Richards
Michele Smith
Michael Sorenson
Stanford Children's Hospital
The late Mary Lou Thurston-Smoot
TSC Alliance of Hungary
TSC Alliance of Israel
TSC Alliance of Mexico
Tuberous Sclerosis Canada Sclerose Tubereuse
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Adam Wayne
Sarah and Kevin Wright
Wurwand Foundation
Deborah and Joseph Yohn

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

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Connie and Richard Cockerham
Ned and Susan Coen
Saundra and Harvey Cohen
Kimberly and Mark Colby
Craig and Margie Colby
George and Susan Conlon
Kathleen and Steve Conrad

April and Alfred Cooper
Jennifer and Wilfred Cooper, Jr.
Jason and Michelle Cox
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Linda and Jody Gueningsman
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Mindy Hanks
Dan Hase
Hattie A. and Marie V. Fatz Foundation
Marcia Hecht
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Kathleen and Thomas Herndon
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Lisa Hidaybaca
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(\$500 - \$999)**

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Arul and Gowri Arulmoli
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Patricia and John Badorf
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Marissa Bedini
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Byron Elaine Bixiones
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Sherry Blyth
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The Chelsea Hutchison Foundation
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Danielle Clark
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 Cynthia Williams
 Scott Wilson
 Terence Wingert
 Rachel and Joshua Wojnilower
 Joel Wojnilower
 Stephanie Wright
 Joyce Wu
 Anna Wulick
 Bo Yang
 Marlin and Judy Yoder

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

Farzana Ali
 Anonymous
 Shane Brady
 Patricia Bronfman
 Damon Casatico
 Kristie Cline
 David Coit
 Mo Collins
 April and Alfred Cooper

Derma Medical Spa
 Tony Dunlap and Treasa Bolger-Dunlap
 Edina Kiss Jewelry
 Kate Flannery
 Tiffani Goff
 Althea Grace
 Shawn Briones and Frances Harper
 John Henson
 Dana and Bruce Holinka
 Alex and Lesley Holmes
 Jill and Jonathan Hyman
 Kaye Design Studios
 Kent and Yvonne Kahlen
 Wendy Liebman
 Doug P. Loftus, CFP, Wealth Dimensions
 Heather and Christopher Lens
 Drew Lynch
 Jim O'Heir
 Irfan Mamdani
 Jodi Miller
 Misson Bay Fly Fishing Co.
 Virginia Musselman
 Jeanine and Steven Page
 Amin Panjwani
 Melissa Peterman
 Kim and Lauren Phan
 Steve and Mary Roberds
 Christopher and Kari Luther Rosbeck
 Marty Ross
 Lauren and Sean Shillinger
 Craig Shoemaker
 Alex Skuby
 Cassie Souder
 Lisa and Robert Szilagyi
 Hal Tearse
 Supreme Wireless
 Taylor Williamson
 XIV Karats LTD

The TSC Alliance strives to correctly recognize all our donors. We apologize in advance for any errors, omissions or misspellings in this annual report. Please call our office at (800) 225-6872 with any corrections.

Endowment Fund

The TSC Alliance Endowment Fund is a separate fiduciary organization specifically chartered to receive gifts that will be invested to generate an income stream to help fulfill the mission of the TSC Alliance. The Endowment Fund ensures the TSC Alliance has an ongoing source of funding to better serve those touched by TSC through education, support services and research.

Founders Society (\$100,000 and above)

Michael and Milly Augustine

Advancement Society (\$25,000 - \$99,999)

Shonnie Johnson and the late Ken Johnson
Magdalena Lutsky
Philip and Marion Winsor

Century Society (10,000 - \$24,999)

Mark and Judy Fox
Andrea Hall and the late Keith Hall
Robert and Joan Appleby Foundation

Enrichment Society (\$5,000 - \$9,999)

Doug and Linda Loftus
James Norman
Paul and Pamela Waxlax

Investment Society (\$500 - \$4,999)

Jill and Randy Banks
Michael Durrant
Ever Loved, Inc.
Frank and Laura Gallagher
Fay and Carl Godman
Nancy and Robert Graham
Judy Graves
Phil and Karen Johnson
Arnold and Carol Kamm
Michael and Karen Loulakis
Network For Good
Kenneth and Julie Ostrowski
Parsons Corporation
Paypal Charitable Giving Fund
Richard Solomon
Louis and Joan Sudholz
Virginia and Robert Swain
Paul Xavier

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:

Harry Alcorn*
Anonymous
David Armijo
Michael and Millicent Augustine
Barbara Bartlett*
Harold and Bernice* Belfer
Jeffery and Gloria* Benham
Matt Bolger
Treaa Bolger-Dunlap
Alice Brossart
Anthony Bruno*
Scott and Jan Burton
Marguerite Cleveland
John and Katherine Conrad
Will and Kay Cooper
Richard and Reiko Donato
Cindy Fowler
Richard and Rosemarie Gammache*
Jeffrey Ross Goldstein
David and Laura Grimes
Robert W. and Kathryn A. Groves
Shannon Hackley
Keith Hall*
Jeffrey and Lisa Hargreaves
Clara Harwell
Anne Heilman*
James and Amy Hobbs
Jaye Isham
Ken* and Shonnie Johnson
Arnold and Carol Kamm
Steve and Laura Kozisek
David and Cathy Krinsky
Mark Leal
Phyllis Leist
Glenn Leiter*
Craig T. Lewis*
Doug and Linda Loftus
Magdalena Lutsky
James Lynch
Glennwood Dale Maier*
Robert McBride*
Donna McGaha
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William Morris*

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Ottillitt Nadel*
Jean Panther*
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Emma Rocco*
Pat and Jennifer Rolfes
Kari Luther Rosbeck
Dave and Nancy Scott
Robert and Mary Ellen Scott
Joan Smardan*
Fred and Ilse Smith
John and Janine Steenman
Mark Stromberger*
Rob Thurston
Kathy Trapp
Alma A. Tutrone*
Jim and Nancy Weir
Philip and Marion Winsor
Barbara Witten and William Bradley
Frieda Zimmerman*

*Deceased

Endowment Named Funds

On gifts of \$25,000 or more (with a pledge payable over five years), a donor has the opportunity to name a fund in honor of someone. We are deeply grateful for the following named funds:

Megan Augustine Fund
Augustine Family Fund
John A. Conrad Jr. Memorial Fund
Carrie Cooper Memorial Fund
Matthew J. Fox Fund
Ken Johnson Memorial Fund
Lauren E. Krinsky Fund
The Lawler Fund
Cade Scott Fund
Jeb Ward Legacy Fund

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



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Landon Cox
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Science Project Manager

Emebet G/Micheal
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Communications

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Kelsey Hudson, Chair

TSC Alliance of Wisconsin
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Daniel Price

Region 2: California, Arizona, Nevada, New
Mexico, Utah
Rob and Shannon Grandia, supported by
Daniel Price

Region 3: Colorado, Nebraska, South
Dakota, North Dakota, Iowa, Minnesota,
Wisconsin
Danielle Clark, supported by Melyssa
McDonough

Region 4: Texas, Oklahoma, Kansas,
Missouri, Arkansas, Louisiana
Jake Irby, supported by Emilie Peters and
Foster Hyde

Region 5: Illinois, Michigan, Indiana, Ohio,
Pennsylvania
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Region 6: Tennessee, Kentucky, Georgia,
Alabama, Mississippi, Florida
Kate Crossett

Region 7: Connecticut, Vermont, Maine,
Rhode Island, New Hampshire, New York,
New Jersey, Massachusetts
Iris Mustich, MPH

Region 8: Delaware, Virginia, West Virginia,
Maryland, North Carolina, South Carolina,
Washington DC
Kathy Henkel

Social Media: Danielle Clark

*View members of the TSC Alliance's
Professional and International Scientific
Advisory Boards at tscalliance.org.*

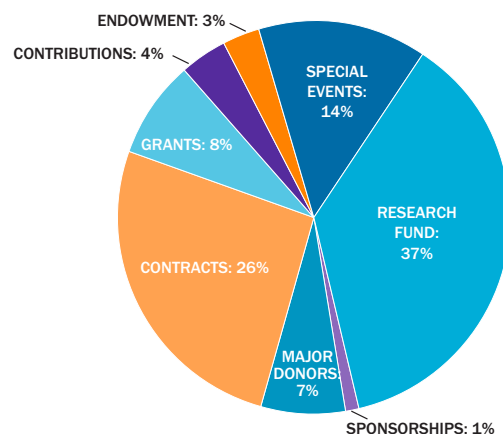
National Tuberosus Sclerosis Association & Affiliate

Consolidated Statements of Financial Position

As of December 31,	2021	2020
Assets		
Cash and cash equivalents	\$ 2,843,269	\$ 2,370,947
Investments	6,691,013	5,913,426
Accounts receivable	99,173	113,491
Promises to give	2,698,495	1,578,285
Prepaid expenses and other assets	620,148	403,498
Operating lease right of use asset, net	778,371	833,830
Property and equipment	437,169	510,367
Total assets	\$ 14,167,638	\$ 11,723,844
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued expenses	\$ 186,010	\$ 181,331
Accrued compensation	290,487	254,553
Deferred revenue	676,798	422,226
Operating lease liability, net	1,285,691	1,336,433
Gift annuity obligations	119,665	66,740
Total liabilities	2,558,651	2,261,283
Net assets		
Without donor restrictions		
Undesignated	(20,618)	189,609
Board-designated	6,601,224	5,764,868
Total without donor restrictions	6,580,606	5,954,477
With donor restrictions	5,028,381	3,508,084
Total net assets	11,608,987	9,462,561
Total liabilities and net assets	\$ 14,167,638	\$ 11,723,844

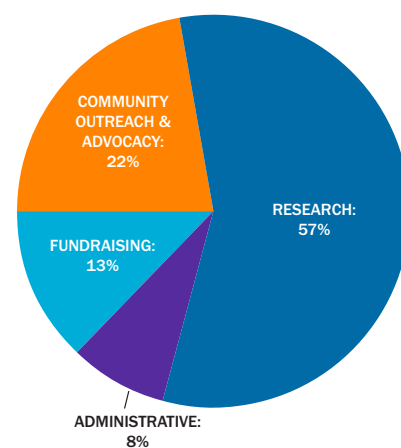
The TSC Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization's 2021 and 2020 financial statements to the TSC Alliance Board of Directors. The complete audited financials are on file 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 2021 and 2020 there were net gains, contributing to the total change in net assets on a consolidated basis for the year. On a stand-alone basis, excluding investment gains from the TSC Alliance Endowment Fund, the change in net assets of the TSC Alliance was a positive \$1,328,199 and a negative (\$271,742) for 2021 and 2020, respectively.

TSC Alliance Revenue Sources 2021 Total Revenue: \$8,229,936



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

TSC Alliance Expenses 2021 Total Expenses: \$6,903,591



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	2021 Total	2020 Total
Revenue and Support				
Special Events	\$ 1,169,138	\$ 55,434	\$ 1,224,572	\$ 1,287,311
Cost of direct benefits to donors	(46,439)		(46,439)	(59,986)
Special events, net	1,122,699	55,434	1,178,133	1,227,325
Contributions	1,198,857	3,330,407	4,529,264	2,775,502
Contracts	2,120,485		2,120,485	791,210
Conferences	113,777		113,777	1,475
Interest and dividends	108,717	18,843	127,560	131,179
Memorials and honoraria	135,221	1,018	136,239	110,097
Federated funding	54,696		54,696	38,743
	4,854,452	3,405,702	8,260,154	5,075,531
Net assets released from restrictions	2,026,987	(2,026,987)	-	-
Total revenue and support	6,881,439	1,378,715	8,260,154	5,075,531
Expenses				
Program services				
Research	3,939,924		3,939,924	2,591,582
Family services	726,768		726,768	765,051
Public health education	524,284		524,284	503,125
Government relations	154,139		154,139	149,610
Professional education	122,600		122,600	24,320
Total program services	5,467,715	-	5,467,715	4,033,688
Supporting services				
Fundraising	990,443		990,443	1,085,941
Management and general	549,013		549,013	517,311
Total supporting services	1,539,456	-	1,539,456	1,603,252
Total expenses	7,007,171	-	7,007,171	5,636,940
Change in net assets from operations	(125,732)	1,378,715	1,252,983	(561,409)
Net investment income (loss)	751,861	141,582	893,443	267,383
Change in net assets	626,129	1,520,297	2,146,426	(294,026)
Net assets, beginning of year	5,954,477	3,508,084	9,462,561	9,756,587
Net assets, end of year	\$ 6,580,606	\$ 5,028,381	\$ 11,608,987	\$ 9,462,561



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