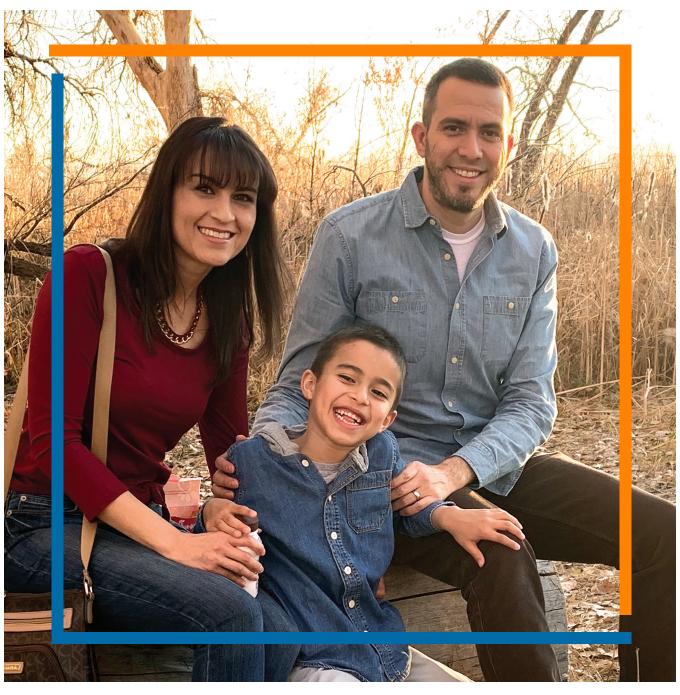


# Hope no matter how complex

# Hope no matter how complex



The TSC Alliance was founded on the core belief that community is a sustaining strength in the face of difficult challenges. In 1974 four mothers who shared the common bond of tuberous sclerosis complex (TSC) came together to provide fellowship, generate awareness, pursue more knowledge and offer hope to each other. That was the birth of the TSC Alliance, and the spirit and intention of those founders permeate everything we do to this day.

For most everyone as well as the TSC Alliance, 2020 started with so much hope and momentum. While those aspirations were soon eclipsed by an unforeseen pandemic, our partners, volunteers, donors and most importantly the TSC community at large worked in concert like never before to ensure the TSC Alliance was able to continue working toward a future where every person and family affected by TSC has what they need to live their fullest lives.

# The TSC Alliance's work wouldn't be possible without the commitment of our community.

Advancing research requires dedicated investigators, individuals with TSC, government and industry. Improving quality of and access to care demands healthcare professionals and dedicated volunteers. Raising awareness takes the work of families, individuals and volunteers.

Despite the challenges of COVID-19, the collaboration of individuals and families, along with the partnership of other organizations, fueled our efforts to ensure people navigating TSC always have support—and hope—every step of the way. Some 2020 highlights include:

- The 2020 March on Capitol Hill to advocate for TSC research led to 216 signatures in the House, 35 in the Senate and an \$8 million appropriation for TSC Research Program through the Congressionally Directed Medical Research Program at the Department of Defense.
- To address TSC-Associated Neuropsychiatric Disorders (TAND), the TSC Alliance developed a series of informational webinars featuring hands-on practical tips especially pertinent during the pandemic.
- The TSC Alliance offered more than 30 COVID-19 Webinars, Virtual Townhalls and Open Forums to address needs and answer questions of TSC families and individuals.
- During May, the TSC community raised unparalleled awareness by joining the #TSCstrong social media campaign and supporting the TSC Awareness Month of Caring fundraising effort.

- The 2020 TSC & LAM Virtual Conference Series was another huge success, featuring leading experts discussing cutting-edge research and clinical care for children and adults living with TSC and LAM.
- In our ongoing quest to better understand how TSC affects each person differently, the TSC community continued to advance TSC research by participating in clinical trials and the Natural History Database, including a pivotal COVID-19 study. The Biosample Repository also grew as we began to collect samples through mobile collection.
- The historic Step Forward to Cure TSC® National Virtual Walk-Run-Ride included a weekend of events, attracting more than 1,750 participants from all across the country who joined together to celebrate our community, raise crucially needed funds and spread awareness.

This **2020 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 connects 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 and 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.



# Fueling and funding collaborative TSC research

The TSC Alliance's 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 the disease. Our research program 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. Since 1984, the TSC Alliance has invested \$27.7 million into TSC research projects through our Research Grants program and contracts, including:

- \$18.5 million in researchgrants and postdoctoral fellowships,
- \$4.4 million into the Natural History Database and Biosample Repository, and
- \$4.1 million into the Preclinical Consortium and \$0.7 million into the Clinical Research Consortium.

For a complete list of currently funded projects and an archive of past awardees, visit tscalliance.org/grants.

The Natural History Database (NHD) captures clinical data to document the impact of the disease on people's health over their lifetime. As of December 2020, 2,268 people with TSC were enrolled in the project from among 18 U.S.-based sites and through the TSC Alliance. In 2020, the TSC Alliance added a sub-project to address detailed questions about COVID-19 infection in individuals with TSC.

The Biosample Repository collects high-quality biosamples—such as blood, DNA and tissues to understand why TSC is so different from person to person. By the end of 2020, the project housed 1,571 biosamples, including 421 blood, 358 buccal and 29 tissues samples from individuals with TSC enrolled in the NHD; 374 blood samples from the TSC Clinical Research Consortium collaborative projects; and 389 DNA



samples from the TSC Autism Center of Excellence Network Autism Biomarker study. The TSC Alliance also funded three seed grants totaling \$60,000 to labs who submitted meritorious and innovative ideas for research on them. The TSC Preclinical Consortium works to advance more drug candidates into clinical testing and provides the infrastructure to foster collaboration between academia and pharmaceutical industry researchers and for access to resources designed to help facilitate drug development in TSC. Since inception, the consortium has helped advance the evaluation of drugs for TSC by conducting 54 studies, evaluating 44 candidate drugs. In 2020, the Preclinical Consortium evaluated 13 candidate drugs in mouse models and screened an additional 10 compounds in cell-based models of TSC.

The TSC Alliance also stimulates collaboration and innovation through convening experts and stakeholders within and outside the TSC field. The first Innovation Workshop was held in 2020 and focused on newborn screening. This workshop's goals included: define the critical path of developing a screening assay to enable nomination of TSC to the Recommended Uniform Screening Panel; specify the immediate next steps needed along the critical path; recommend components of a funding opportunity announcement to elicit the best ideas and applicants to implement those next steps; and enable the TSC Alliance to fund the most meritorious applications.

# **Ensuring no one is alone for the TSC journey**

The TSC Alliance's Community Programs team 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 as well as manages the organization's volunteers and educational outreach efforts.

A wide array of TSC Connect volunteers including Adult Regional Coordinators, TSC Clinic Ambassadors, Dependent Adult Transition Resource Coordinators, Education Parent Mentors and Future Leaders worked in tandem to facilitate 28,447 support interactions in 2020. A network of 33 volunteer branches of the organization, called Community Alliances, provided local TSC education and personal support throughout the country to 4,988 families/individuals living with TSC.

To help our community navigate the challenges of COVID-19 throughout 2020, the TSC Alliance created tscalliance.org/COVID-19, dedicated to sharing important information about the pandemic specifically curated to meet the needs of those impacted by TSC. This web page gained 23,447 views on the COVID-19 landing page in 2020. The organization also launched a weekly educational series in March with programming lasting 11 weeks. This effort included five Virtual Town Halls, two World Forum



webinars with Tuberous Sclerosis Complex International, 15 webinars on topics of relevance to TSC individuals and families, and nine open forums for caregivers, teens, siblings and adults with TSC to openly discuss issues related to COVID-19 and TSC. In total, 9,151 people participated in or watched recordings of these webinars and Town Hall series.

The TSC Alliance also co-hosted a three-part virtual Conference Series with The LAM Foundation, attracting 818 registered attendees, 1,106 subsequent video views and 424 visits to the virtual exhibit halls.

# **Amplifying the voices of TSC**

The TSC Alliance's Communications Department heightens awareness of TSC by telling stories of the TSC community and creates awareness campaign and educational tools and resources. During 2020, the organization's website attracted an average of more than 22,300 unique visitors each month, working hand in hand with our social media channels to educate constituents and promote new resources and events. The private TSC Alliance TSC Facebook Discussion Group is the largest in the world with more than 10,000 members. Our Twitter and Instagram accounts both have 2,400-plus followers.

Eleven *TSC Now* podcasts were downloaded 1,906 times, while our bi-montly e-newsletter *TSC Matters* has 1,006 subscribers. In addition, the TSC Alliance's online educational platform, TSC Academy, introduced three new courses covering the topics of CBD, FDA Review Process and State and Local Advocacy.

To both reach the undiagnosed and educate the public about TSC, the TSC Alliance participated in the Sixth Annual TSC Global Awareness Day on May 15 as well as TSC Awareness Month throughout May and heavily promoted Infantile Spasms Awareness Week, December 1 to 7. This awareness campaign included social media outreach and targeted national print publications, medical trade magazines and podcasts, resulting in 10 major media placements, 31.7 million-plus impressions and 550-plus social engagements. Finally, the TSC Alliance's various news releases culminated in 694 million impressions throughout 2020.

# **Educating professionals about TSC**

Everyone should know about TSC, especially health-care professionals. Too many people go undiagnosed or misdiagnosed for years because of a lack of awareness, even though TSC is as prevalent as ALS, cystic fibrosis and Huntington's disease. Early diagnoses change lives because they enable early interventions, which may prevent symptoms like

developmental delays. In addition to offering and supporting Professional Education programs about TSC targeted toward healthcare providers and educators, TSC Alliance staff members participated in and presented at 22 professional meetings in 2020. The TSC Alliance also has formal partnerships with The Arc USA and Parent Training Information Centers around the United States to help parents and individuals navigate a myriad of educational issues and challenges.

# **Empowering the community through advocacy**

The TSC Alliance's grassroots-driven Government Advocacy program focuses on increasing federal and state appropriations for TSC research, increasing awareness among lawmakers and collaborating with government partners to drive TSC research forward as well as improve clinical care and treatment options for individuals with TSC. The TSC community's collective voice is a powerful force for accelerating discoveries.

On the state level, the TSC Alliance advocated for state funding for TSC Centers in Missouri and Maryland, resulting in at least \$500,000 in state appropriations.



The annual TSC Alliance March on Capitol Hill to advocate for federal TSC research funding was supported by more than 120 TSC community members who urged their Senators and Representatives to sign onto Dear Colleague letters in support of the Tuberous Sclerosis Complex Research Program (TSCRP) at the Congressionally Directed Medical Research Program.

The House Dear Colleague Letter, co-sponsored by Representatives Markwayne Mullin (R-OK) and Dave Loebsack (D-IA), closed with 216 signers, while the Senate Dear Colleague Letter, sponsored by Senators Kevin Cramer (R-ND) and Jon Tester (D-MT), closed with 35 signatures. For FY2021, the TSCRP received an \$8 million appropriation—a \$2 million increase over FY2020, bringing its cumulative funding to \$97 million since 2002.



# Making connections around the world

Our Global Outreach efforts work to address unmet needs of TSC communities around the world through our network of Global Alliances and as a member of Tuberous Sclerosis Complex International.

Dedicated volunteers work at every Global Alliance, and we partner with them to create and implement plans to help people navigating TSC outside of the United States. 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. In addition, the TSC Alliance recognizes 10 TSC Clinics in Global Alliance countries.



# Raising support to fuel our mission

The TSC Alliance's Development and Community Programs Departments work together, focused on raising funds to make sure no one is alone on their TSC journey. Special events, community fundraisers and personal donations, large and small, allow our organization to be a central hub for information about TSC care and treatment, offering resources and support for individuals, families, healthcare professionals and educators to ensure quality care from diagnosis onward.

In 2020, special events netted \$1,227,326, representing 24% of the organization's overall revenue.



# Step Forward to Cure TSC® National Virtual Walk-Run-Ride

The inaugural and historic Step Forward to Cure TSC® National Virtual Walk Run Ride took place August 22-23, 2020 and raised \$660,000.

The weekend kicked off Friday, August 21 and featured Kari Luther Rosbeck, President and CEO; Shelly Meitzler, Community Programs Manager, East; Dr. Peter Crino, Vice Chair of the TSC Alliance Board of Directors; Laura Wallker, Owner, Powerful Fitness; and quest speaker Bao Heffron, a young adult with TSC. Numerous virtual mixers held over the course of the weekend provided a platform for TSC community members to network, get live updates and watch interviews with TSC Champions Carly Kaye, Jill Hyman, Katie Martin and Amy Hightower. The wrap-up rally was co-hosted by long-time celebrity spokesperson Jim O'Heir, who announced our top prize winners with host Kari Luther Rosbeck, with closing remarks from Chris Russell, Chair of the TSC Alliance Board of Directors, and Philip Tallman, a TSC adult and parent.

The event also featured a Facebook Live challenge, called "Getting Saucy with Parker B for TSC," hosted by Ryan and Andrea Beebe with Kari Luther Rosbeck and Chief Scientific Officer Steve Roberds, PhD, that raised \$6,305. In addition, the first annual Step Forward to Cure TSC Virtual Auction raised more than \$28,000.

The TSC Alliance thanks our National 2020 Step Forward to Cure TSC Walk-Run-Ride sponsors, outstanding planning committee, donors and the 1,758 participants who all made our first virtual major event one to remember.

# National Step Forward to Cure TSC Walk-Run-Ride Sponsors

Greenwich, Mallinckrodt, Novartis, UCB, Upsher-Smith Laboratories LLC, LivaNova, MassMutual SpecialCare and Neurelis

# **Local Step Forward to Cure TSC Walk-Run-Ride Sponsors**

Stanford Children's Health, *Variety*, Streamwood Fire Fighters, Cavarocchi Ruscio Dennis Associates, Fifth Third Bank, Level Up Drywall, Soboba Foundation and Seizure Tracker

#### **Grand Prize Winner**

Mike Gryo, Little D's Heroes

## **Highest Fundraisers**

1st Place: Amy Hightower, #teamarthur—\$36,174 2nd Place: Kalyan O'hara, Bodies Buddies—\$28,918 3rd Place: Jill Hyman and Katie Martin, Skyblue

Crew—\$22,128

#### **Largest Teams**

Corporate: Greewich Bioscience (238 participants) Non-Corporate: #teamarthur / Amy Hightower (125 participants)

TSC Clinic: Robert & Ann E. Lurie Children's Hospital (10 participants)

#### **Most Spirited Team**

Brynleigh's Believers: Lauren Shillinger, Captain

#### **TSC Miles**

Most Miles Walked: Kelly Simontacchi, Team Greenwich (21 miles)

Most Miles Biked: Kelly Andreas, Snoopy's Friends (73 miles) and Jack Lyons, Lyon's Pride (81 miles) Most Miles Run: Kate Critchfield, Team Topher (15 miles) Most Miles Completed by a Team: Kirsten Swain, Team Topher (95 miles)



# 19th Annual Comedy for a Cure®

In July and October, the TSC Alliance successfully hosted two virtual evenings of Comedy for a Cure. As one of our most celebrated events, we expanded what is usually one night of comedic performances and honors into Summer and Fall Editions, which together raised \$179,000.

We are extremely thankful to Comedy for a Cure's 2020 sponsors: Greenwich Biosciences, Novartis, Mallinckrodt, Variety, CVS Health, Horizon Therapeutics, the Maginn Family, Neurelis, Saks Foundation, the Szilagyi Family, UCB, WNC & the Cooper Family, Upsher-Smith Laboratories LLC, Tim and Kathi Dills, the Keith A. Hall Family, Lauren and Richard Packard, Susie and Nolan Spencer, and Ted and Peggy Mastroianni.

During the Summer Edition, we were so grateful for our hilarious emcees—Jim O'Heir, Alex Skuby and Craig Shoemaker; our comedians—Ahmed Ahmed, Bruce Jingles, Sarah Halstead, and Ryan Niemiller; and our esteemed TSC Champion, Dr. Shafali Jeste, for her groundbreaking research in autism and TSC and setting the stage for preventative interventions.

The Fall Edition featured the same amazing emcees—Jim O'Heir, Alex Skuby and Craig Shoemaker—who were joined by auctioneer extraordinaire, Damon Casitico, and an incredible group of comedians—Ben Gleib, Adam Ray, Kira Soltanovich and headliner Jay Mohr. We presented the much-deserved Courage in Leadership Award to the Carroll Family for their unwavering generosity and dedicated service to the TSC community through their advocacy for Federal TSC research funding. We also paid tribute to TSC Champion Edina Kiss for her compassionate partnership over the past decade via cause-related marketing and in-kind support of Comedy for a Cure and other nationwide TSC Alliance events.

# **Virtual 4th Annual Sound Bites**

On November 20, Melissa Peterman and Chris Hawkey co-hosted the TSC Alliance's 4th Annual Virtual Sound Bites, which raised \$71,500. The event gave us the opportunity to present the Courage in Leadership Award to the Wiltscheck Family for their exceptional community support and to honor Kat Perkins with the TSC Champion Award for her partnership and years of spectacular music supporting the TSC Alliance. Backed by Eric Warner on guitar, Kat's beautiful voice kicked off the music for the evening, followed by the Erin and Jay Cabaret with Chris Hawkey bringing it home musically with his sincere passion for our cause.

We are extremely grateful for the support of our TSC community in Minnesota and sincerely thankful to the event's sponsor: Dr. Michael and Janie Frost, Greenwich Biosciences, the Maginn Family, Minnesota Epilepsy Group, Novartis, Upsher-Smith Laboratories LLC, Goodin Co., RW Baird, Ray Chan, WPT Industrial and Fairchild's FosterCare.

# Other community campaigns

The TSC Alliance kicked off 2020 with two successful community events held in January with others planned throughout the year. However, everything changed in the wake of the COVID-19 pandemic. Despite challenges and cancellations of all in-person events planned after the first week in March, the TSC community and other supporters rallied around the TSC Alliance and created some unique virtual events to maintain the mission and strength of the organization.



# **3rd Annual Brewing for a Cure**

January 18,2020 Host: Heather Harden Raised: \$27,637

#### **Krewe for a Cure**

January 25, 2020 Host: Margaret Cox Raised: \$10,775

# **TSC Global Month of Caring**

May 2020 Raised: \$178.858

## **Getting Saucy with Parker B**

May 2020

Host: Ryan and Andrea Beebe

Raised: \$73,875

# **Step Forward to Cure TSC National Virtual Walk-Run-Ride**

T-shirt Campaign Host: Carly Kaye Raised: \$13,000

Team TSC Raised: \$17,491

## 2020 TCS New York City Marathon—Canceled

The 2020 New York City Marathon on November 1, 2020 was canceled due to coronavirus-related health and safety concerns. Race managers provided charity partners with an option for 2020 registered participants to defer their entries to 2021, 2022 or 2023. At the time of this determination, the TSC Alliance had eight of our ten entries registered. Of the eight contacted, six runners have elected to defer their entries to a later date. Special thanks to our official deferred 2020 team members: Amanda Alberts, Shalonda Alexander, Bridget Faria, Bridget Lucas, Shelly Meitzler and Sarah Skelton.

# The TSC Alliance President's Council

Founded in 2016, the TSC Alliance President's Council is comprised of members of families impacted by TSC who work with the President & CEO and Board of Directors to ensure TSC researchers have the data and funds they need to deliver breakthroughs. President's Council members give or get a minimum gift of \$100,000 per year to fund research. President's Council Members since its inception include:

- David Coit
- Cowlin Family
- Tim and Kathi Dills
- · Christopher and Joy Dinsdale
- Engles Family Foundation on behalf of Engles Collaborative Research Fund
- Jim and Andrea Maginn, through the creation of the Abigail and Amelia Clinical Accelerator
- Jonathan Rothberg and Bonnie Gould Rothberg, Rothberg Family Charitable Foundation for Children's Disease
- Brittany Smith and John Gottschall
- William Watts
- Lorne Waxlax, through the creation of the Waxlax Biosample Collection Initiative



# Annual Fund – Major Donors and Contract Revenue

# Fiscal Year 2020: January 1 to December 31

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

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Loren Backe Photography Patrick and Lisa Mills

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Vanessa Vazquez and Max Bertolotti

Eric Warner David Webb Gayle Wilson

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.

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)

Andrea Hall and the late Keith Hall Robert and Joan Appleby Foundation

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

Michael and Milly Augustine Paul and Pam Waxlax

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

Farrar Family Charitable Fund Jason and Brandi Lowe Network for Good Laura Wilson-Brown

# **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 join the Eternal Flame Society. If you or a loved one has designated the TSC Alliance through a planned gift and are currently not listed in the Eternal Flame Society, please let us know so we can add you. We are pleased to honor the following distinguished Eternal Flame Society members:

Harry Alcorn\* Anonymous David Armijo Michael and Millicent Augustine Harold and Barnice\* Belfer Jeffery and Gloria\* Benham Matt Bolger Treasa Bolger-Dunlap Alice Brossart Anthony Brunno\* Scott and Jan Burton Marguerite Cleveland John and Katherine Conrad Kay and Will 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 Jave Isham Ken\* and Shonnie Johnson Arnold and Carol Kamm Steve and Laura Kozisek David and Cathy Krinsky Mark Leal Phyllis Leist Craig T. Lewis\* Doug and Linda Loftus Magdalena Lutskey James Lynch Glennwood Dale Maier\* Robert McBride\* Donna McGaha David and Jan Mintz William Morris\* Maria Sharon Munoz-Chargoy Ottilitt Nadel\* Jean Panther\* David and Penney Parkes Jeffrey and Bonnie Rickert 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 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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# **Adult Regional Coordinators**

Region 1: Washington, Oregon, Idaho, Montana, Wyoming, Alaska Rob and Shannon Grandia supported by 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

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Region 7: Connecticut, Vermont, Maine, Rhode Island, New Hampshire, New York, New Jersey, Massachusetts Phillip Tallman

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.



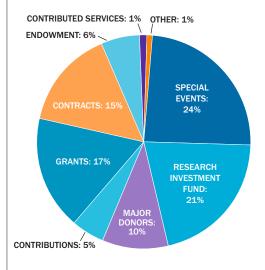
# National Tuberous Sclerosis Association & Affiliate

## **Consolidated Statements of Financial Position**

As of December 31,	2020	2019
Assets		
Cash and cash equivalents	\$ 2,370,947	\$ 2,093,560
Investments	5,913,426	5,941,995
Accounts receivable	113,491	10,243
Promises to give	1,578,285	2,033,626
Prepaid expenses and other assets	403,498	262,620
Operating lease right of use asset, net	833,830	-
Property and equipment	510,367	80,221
Total assets	\$ 11,723,844	\$ 10,422,265
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued expenses	\$ 181,331	\$ 333,196
Accrued compensation	254,553	200,306
Deferred revenue	422,226	54,700
Operating lease liability, net	1,336,433	7,176
Gift annuity obligations	66,740	70,300
Total liabilities	2,261,283	665,678
Net assets		
Without donor restrictions		
Undesignated	189,609	(214,362)
Board-designated	5,764,868	5,936,709
Total without donor restrictions	5,954,477	5,722,347
With donor restrictions	3,508,084	4,034,240
Total net assets	9,462,561	9,756,587
Total liabilities and net assets	\$ 11,723,844	\$ 10,422,265

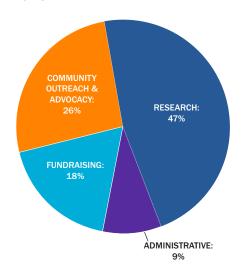
The TSC Alliance annually engages a certified public accounting firm to conduct an independent audit of its operations. The auditors issued an unmodified opinion on the organization's 2020 and 2019 financial statements to the TSC Alliance Board of Directors. The complete audited financials are on file 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 2020 and 2019 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 negative (\$271,742) and a positive \$355,028 for 2020 and 2019, respectively.

# TSC Alliance Revenue Sources 2020



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

# TSC Alliance Expenses 2020



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

# National Tuberous Sclerosis Association & Affiliate

# **Consolidated Statement of Activities**

Cost of direct benefits to donors         (59,986)         (28)           Special events, net         1,100,439         126,886         1,227,325         2,42           Contributions         1,353,452         1,422,050         2,775,502         3,02           Contracts         791,210         791,210         24           Conferences         1,475         1,475         17           Interest and dividends         113,341         17,838         131,179         19           Memorials and honoraria         107,148         2,949         110,097         100           Federated funding         38,743         38,743         38,743         45           Other income         -         -         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         6,20           Net assets released from restrictions         2,139,948         (2,139,948)         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         5,07           Expenses         Program services         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582 <th></th> <th>Without Donor Restrictions</th> <th>With Donor Restrictions</th> <th>2020 Total</th> <th>2019 Total</th>		Without Donor Restrictions	With Donor Restrictions	2020 Total	2019 Total
Cost of direct benefits to donors         (59,986)         (28           Special events, net         1,100,439         126,886         1,227,325         2,42           Contributions         1,353,452         1,422,050         2,775,502         3,02           Contracts         791,210         791,210         24           Conferences         1,475         1,475         17           Interest and dividends         113,341         17,838         131,179         19           Memorials and honoraria         107,148         2,949         110,097         100           Federated funding         38,743         38,743         38,743         45           Other income         -         -         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         6,20           Net assets released from restrictions         2,139,948         (2,139,948)         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         5,07           Expenses         Program services         Research         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582	Revenue and Support				
Special events, net         1,100,439         126,886         1,227,325         2,42           Contributions         1,353,452         1,422,050         2,775,502         3,02           Contracts         791,210         24           Conferences         1,475         1,475         1,475           Interest and dividends         113,341         17,838         131,179         19           Memorials and honoraria         107,148         2,949         110,097         10           Federated funding         38,743         38,743         45           Other income         -         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         6,20           Expenses         Program services         Research         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582	Special Events	\$ 1,160,425	\$ 126,886	\$ 1,287,311	\$ 2,706,594
Contributions         1,353,452         1,422,050         2,775,502         3,02           Contracts         791,210         791,210         24           Conferences         1,475         1,475         17           Interest and dividends         113,341         17,838         131,179         19           Memorials and honoraria         107,148         2,949         110,097         100           Federated funding         38,743         38,743         45           Other income         -         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         6,20           Net assets released from restrictions         2,139,948         (2,139,948)         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         5,07           Expenses         Program services         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,5	Cost of direct benefits to donors	(59,986)		(59,986)	(285,156)
Contracts         791,210         791,210         24.2           Conferences         1,475         1,475         17.5           Interest and dividends         113,341         17,838         131,179         19           Memorials and honoraria         107,148         2,949         110,097         107.7           Federated funding         38,743         38,743         45           Other income         -         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         6,20           Net assets released from restrictions         2,139,948         (2,139,948)         -         -           Total revenue and support         5,645,756         (570,225)         5,075,531         5,07           Expenses         Program services         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582	Special events, net	1,100,439	126,886	1,227,325	2,421,438
Conferences         1,475         1,475         17.           Interest and dividends         113,341         17,838         131,179         19           Memorials and honoraria         107,148         2,949         110,097         100           Federated funding         38,743         38,743         45           Other income         -         -         -           Net assets released from restrictions         2,139,948         (2,139,948)         -           Total revenue and support         5,645,756         (570,225)         5,075,531         5,07           Expenses           Program services         8         2,591,582         2,591,582         2,591,582         2,590           Family services         765,051         765,051         925         925         925           Family services         765,051         765,051         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925         925	Contributions	1,353,452	1,422,050	2,775,502	3,021,932
Interest and dividends	Contracts	791,210		791,210	247,384
Memorials and honoraria         107,148         2,949         110,097         107,148           Federated funding         38,743         38,743         45           Other income         -         -         -           Net assets released from restrictions         2,139,948         (2,139,948)         -           Total revenue and support         5,645,756         (570,225)         5,075,531         5,07           Expenses         765,051         5,075,531         5,07         5,07           Research         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582         2,591,582	Conferences	1,475		1,475	174,381
Federated funding Other income         38,743 Other income         38,743 Other income         38,743 Other income         45,000           Net assets released from restrictions         2,139,948 (2,139,948)         -         -           Total revenue and support         5,645,756 (570,225)         5,075,531         5,07           Expenses         Program services         8         2,591,582         2,591,582         2,591,582         2,590,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591         929,591 <td>Interest and dividends</td> <td>113,341</td> <td>17,838</td> <td>131,179</td> <td>191,528</td>	Interest and dividends	113,341	17,838	131,179	191,528
Other income         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         -         - <t< td=""><td>Memorials and honoraria</td><td>107,148</td><td>2,949</td><td>110,097</td><td>102,250</td></t<>	Memorials and honoraria	107,148	2,949	110,097	102,250
Net assets released from restrictions   2,139,948   (2,139,948)   -	Federated funding	38,743		38,743	45,664
Net assets released from restrictions         2,139,948         (2,139,948)         -           Total revenue and support         5,645,756         (570,225)         5,075,531         5,07           Expenses         Program services           Research         2,591,582         2,591,582         2,591,582         2,590,501           Family services         765,051         765,051         925           Public health education         503,125         503,125         435           Government relations         149,610         149,610         165           Professional education         24,320         24,320         9           Total program services         4,033,688         -         4,033,688         4,213           Supporting services         1,085,941         1,085,941         1,135           Management and general         517,311         517,311         54           Total supporting services         1,603,252         -         1,603,252         1,674           Total expenses         5,636,940         -         5,636,940         5,636,940         5,636,940         5,636,940         5,636,940         5,636,940         5,636,940         5,636,940         5,636,940         5,636,940         5,636,940         5,636,9	Other income	-		-	714
Total revenue and support         5,645,756         (570,225)         5,075,531         5,07           Expenses         Program services           Research         2,591,582         2,591,582         2,590           Family services         765,051         765,051         925           Public health education         503,125         503,125         435           Government relations         149,610         149,610         149,610         165           Professional education         24,320         24,320         92           Total program services         4,033,688         -         4,033,688         4,217           Supporting services         1,085,941         1,085,941         1,135           Management and general         517,311         517,311         54           Total supporting services         1,603,252         -         1,603,252         1,674           Total expenses         5,636,940         -         5,636,940         5,895           Change in net assets from operations         8,816         (570,225)         (561,409)         305           Net investment income (loss)         223,314         44,069         267,383         765           Change in net assets         232,130		3,505,808	1,569,723	5,075,531	6,205,291
Expenses         Program services       Research       2,591,582       2,591,582       2,591,582       2,591,582       2,590,591         Family services       765,051       765,051       925         Public health education       503,125       503,125       435         Government relations       149,610       149,610       149,610       160         Professional education       24,320       24,320       92         Total program services       4,033,688       -       4,033,688       4,217         Supporting services       517,311       517,311       517,311       54         Management and general       517,311       517,311       54         Total supporting services       1,603,252       -       1,603,252       1,674         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       76         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587	Net assets released from restrictions	2,139,948	(2,139,948)	-	-
Program services       Research       2,591,582       2,591,582       2,591,582       2,591,582       2,590,551       925         Family services       765,051       765,051       925         Public health education       503,125       503,125       435         Government relations       149,610       149,610       165         Professional education       24,320       24,320       92         Total program services       4,033,688       -       4,033,688       4,217         Supporting services       Fundraising       1,085,941       1,085,941       1,135         Management and general       517,311       547       547       547         Total supporting services       1,603,252       -       1,603,252       1,674         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       76         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Total revenue and support	5,645,756	(570,225)	5,075,531	5,075,531
Research       2,591,582       2,591,582       2,591,582       2,590,591         Family services       765,051       765,051       925         Public health education       503,125       503,125       438         Government relations       149,610       149,610       165         Professional education       24,320       24,320       92         Total program services       4,033,688       -       4,033,688       4,217         Supporting services       50,032,688       -       4,033,688       4,217         Management and general       1,085,941       1,085,941       1,135         Management and general       517,311       517,311       547         Total supporting services       1,603,252       -       1,603,252       1,674         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       76         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587	Expenses				
Family services       765,051       925         Public health education       503,125       503,125       435         Government relations       149,610       149,610       165         Professional education       24,320       24,320       92         Total program services       4,033,688       -       4,033,688       4,217         Supporting services       5upporting services       1,085,941       1,085,941       1,135         Management and general       517,311       517,311       54         Total supporting services       1,603,252       -       1,603,252       1,674         Total expenses       5,636,940       -       5,636,940       5,835         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       765         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Program services				
Family services       765,051       925         Public health education       503,125       503,125       435         Government relations       149,610       149,610       165         Professional education       24,320       24,320       92         Total program services       4,033,688       -       4,033,688       4,217         Supporting services       5upporting services       1,085,941       1,085,941       1,135         Management and general       517,311       517,311       54         Total supporting services       1,603,252       -       1,603,252       1,674         Total expenses       5,636,940       -       5,636,940       5,835         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       765         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Research	2,591,582		2,591,582	2,590,463
Government relations       149,610       149,610       169         Professional education       24,320       24,320       92         Total program services       4,033,688       -       4,033,688       4,217         Supporting services       5undraising       1,085,941       1,085,941       1,135         Management and general       517,311       517,311       547         Total supporting services       1,603,252       -       1,603,252       1,674         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       76         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Family services	765,051		765,051	929,277
Professional education         24,320         24,320         92           Total program services         4,033,688         -         4,033,688         4,217           Supporting services         5upporting services         1,085,941         1,085,941         1,135           Management and general         517,311         517,311         54           Total supporting services         1,603,252         -         1,603,252         1,676           Total expenses         5,636,940         -         5,636,940         5,895           Change in net assets from operations         8,816         (570,225)         (561,409)         305           Net investment income (loss)         223,314         44,069         267,383         767           Change in net assets         232,130         (526,156)         (294,026)         1,076           Net assets, Beginning of Year         5,722,347         4,034,240         9,756,587         8,679	Public health education	503,125		503,125	439,992
Total program services       4,033,688       -       4,033,688       4,217         Supporting services       1,085,941       1,085,941       1,135         Management and general       517,311       517,311       54         Total supporting services       1,603,252       -       1,603,252       1,676         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       767         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Government relations	149,610		149,610	165,225
Supporting services       Fundraising       1,085,941       1,085,941       1,135         Management and general       517,311       517,311       547         Total supporting services       1,603,252       -       1,603,252       1,676         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       767         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Professional education	24,320		24,320	92,979
Fundraising       1,085,941       1,085,941       1,135         Management and general       517,311       517,311       54         Total supporting services       1,603,252       -       1,603,252       1,676         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       765         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Total program services	4,033,688	-	4,033,688	4,217,936
Management and general       517,311       547         Total supporting services       1,603,252       -       1,603,252       1,676         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       767         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Supporting services				
Total supporting services       1,603,252       -       1,603,252       1,676         Total expenses       5,636,940       -       5,636,940       5,895         Change in net assets from operations Net investment income (loss)       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       767         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Fundraising	1,085,941		1,085,941	1,135,609
Total expenses         5,636,940         -         5,636,940         5,895           Change in net assets from operations Net investment income (loss)         8,816         (570,225)         (561,409)         305           Net investment income (loss)         223,314         44,069         267,383         767           Change in net assets         232,130         (526,156)         (294,026)         1,076           Net assets, Beginning of Year         5,722,347         4,034,240         9,756,587         8,679	Management and general	517,311		517,311	542,410
Change in net assets from operations       8,816       (570,225)       (561,409)       305         Net investment income (loss)       223,314       44,069       267,383       767         Change in net assets       232,130       (526,156)       (294,026)       1,076         Net assets, Beginning of Year       5,722,347       4,034,240       9,756,587       8,679	Total supporting services	1,603,252	-	1,603,252	1,678,019
Net investment income (loss)         223,314         44,069         267,383         767           Change in net assets         232,130         (526,156)         (294,026)         1,076           Net assets, Beginning of Year         5,722,347         4,034,240         9,756,587         8,679	Total expenses	5,636,940	-	5,636,940	5,895,955
Net investment income (loss)         223,314         44,069         267,383         767           Change in net assets         232,130         (526,156)         (294,026)         1,076           Net assets, Beginning of Year         5,722,347         4,034,240         9,756,587         8,679	Change in net assets from operations		(570,225)	(561,409)	309,336
Net assets, Beginning of Year 5,722,347 4,034,240 <b>9,756,587</b> 8,679					767,563
	Change in net assets	232,130	(526,156)	(294,026)	1,076,899
Net assets, End of Year \$ 5,954,477 \$ 3,508,084 <b>\$ \$9,462,561</b> \$ 9.756	Net assets, Beginning of Year	5,722,347	4,034,240	9,756,587	8,679,688
	Net assets, End of Year	\$ 5,954,477	\$ 3,508,084	\$ \$9,462,561	\$ 9,756,587





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