



FY 2023 Strategic Plan Progress Report

Objective: To find a cure for tuberous sclerosis complex (TSC), while improving the lives of those affected.

Goals

1. Accelerate Research

Measures	Results as of December 31, 2023	Results as of December 31, 2022	Results as of December 31, 2021	Results as of December 31, 2020	Results as of December 31, 2019
Invest \$17.8 million in research over the next five years to drive projects, workshops and collaborations	TSC Alliance invested \$5,019,778 into research in 2023. Overall, \$17,936,183 was invested over past five years. This includes preclinical contracts.	TSC Alliance invested \$3,794,438 into research in 2022.	TSC Alliance invested \$3,939,926 into research in 2021.	TSC Alliance invested \$2,591,578 into research in 2020.	Goal changed to \$40 million over seven years following a campaign study and on recommendation of our capital campaign consultants. TSC Alliance spent \$2,590,463 into research in 2019.
Maintain a minimum of \$8 million annually for TSCRCP	The TSCRCP is in the House Defense bill for \$10 million in FY23 after a \$2 million amendment was submitted by Reps. Raskin and Fitzpatrick. The Defense Bill is waiting for final approval by both the House and Senate.	Maintained \$8 million in FY22.	Increased to \$8 million in FY21	<ul style="list-style-type: none"> \$8 million was appropriated for the TSCRCP in FY21. The CSO chairs the Programmatic Panel of the Tuberous Sclerosis Complex Research Program administered by the DOD. 	\$6 million was appropriated for the TSCRCP for FY19 and FY20.

<p>Reach 75 IND-enabling studies executed by Preclinical Consortium with 21 cumulative company members</p>	<p>Reached 82 with 22 cumulative company members.</p>	<p>Reached 64 with 20 cumulative company members.</p>	<p>Reached 57 with 17 industry partners.</p>	<ul style="list-style-type: none"> • 44 compounds or combinations have been tested. • 7 companies remain active members at the end of 2020 – a total of 13 have been members since 2016. • Marinus launched a Phase 2 trial in epilepsy in TSC. COVID-19 delayed launch of the second clinical trial we had anticipated to begin in 2020. 	<ul style="list-style-type: none"> • 35 mechanisms or combinations have been tested. • 5 companies remain active members at the end of 2019. • 2 companies moving into clinical trials from resources utilized from Preclinical Consortium and Biosample Repository.
<p>Clinical Research Consortium receives \$30 million federal or industry funding for trials</p>	<p>Reached \$40.5 million.</p>	<p>Reached \$40.5 million.</p>	<p>Reached \$39 million awarded, including \$14 million awarded in 2019-2021.</p>	<ul style="list-style-type: none"> • The consortium did not receive new funding in 2020 but submitted an application to FDA to support the STOP-2 trial. • The CSO completed a four-year term on the Advisory Council for the National Institute of Neurological Disorders and Stroke. 	<p>\$7.5 million awarded to the Clinical Research Consortium for a 5-year renewal of the RDCRN grant from NIH.</p>
<p>Reach 2,500 biosamples with serial blood samples on 250 individuals, with each genetically tested and 12 use requests annually with clinical data captured in the Natural History Database</p>	<p>Reached 2,667 samples collected, serial blood samples from 250 individuals, 8 biosample use requests and 18 NHD data requests.</p>	<p>Reached 2,327 samples collected, serial blood samples from 199 individuals, 18 biosample use requests and 20 NHD data requests.</p>	<p>Reached 2000 samples collected at year end, serial blood samples from 142 individuals, and 18 biosample use requests in 2021 compared to 19 requests in 2020 and 5 in 2019.</p>	<ul style="list-style-type: none"> • 1,571 biosamples. • Serial blood samples on 75 individuals. • 19 tissues. • Received 8 NHD data requests plus 19 additional biosample requests. 	<ul style="list-style-type: none"> • 967 biosamples. • Serial blood samples on 36 individuals. • 10 tissues. • 12 NHD data requests, including 5 for biosamples + NHD data.

<p>\$450K paid annually on research grants to early-stage investigators</p>	<p>\$600,000 in research grants were <i>awarded</i> to early-stage investigators, and \$523,309 was <i>paid</i> toward research grants.</p>	<p>\$450,000 in research grants were <i>awarded</i> to early-stage investigators, and \$627,392 was <i>paid</i> toward research grants.</p>	<p>\$450,000 in research grants were <i>awarded</i> to early-stage investigators and \$672,343 was <i>paid</i> toward research grants, including one-time innovation awards.</p>	<ul style="list-style-type: none"> • \$408,212 paid on research grants, 57% to postdocs and 7% to early-stage investigators. This proportion will increase now that we limited grants to early-stage investigators in 2020 and 2021. • \$57,842 paid on biosample use seed grants. • \$50,000 paid on Clinical Research Consortium grant. • \$516,054 total. 	<ul style="list-style-type: none"> • \$314,914 paid on research grants, 2/3 of new grants awarded to postdocs. • \$40,000 paid on biosample use seed grants. • \$50,000 paid on Clinical Research Consortium grant. • \$404,914 total.
<p>Annual innovation workshop held with</p>	<p>An innovation workshop was held for Anya's Accelerator in April 2023. The workshop's main goal was to establish a plan to identify blood-based biomarkers associated with behavioral and cognitive aspects of TAND.</p>	<p>Removed for 2022.</p>	<p>The pandemic stretched the planned 2020 innovation workshop into a virtual effort concluding in 2021. A specific funding opportunity announcement led to funding two awards totaling \$164,856 for initiating development of TSC newborn screening assays.</p>	<p>Innovation Workshop on newborn screening held Nov 18 – Dec 11 using Zoom, recorded presentations, and Povernoodle. Wrap-up web meeting will be held January 29, 2021.</p>	<p>Biennial International TSC Research Conference held in 2019. Plan developed for first innovation workshop to be on newborn screening in June 2020.</p>

2. Improve Access and Quality of Care

Measures	Results as of December 31, 2023	Results as of December 31, 2022	Results as of December 31, 2021	Results as of December 31, 2020	Results as of December 31, 2019
Grow state initiatives to three states	Maintained successful state initiatives in Alabama, Maryland and Missouri, resulting in increased funding of \$1.25 million in state appropriations.	Grew state initiatives to three states – Alabama, Maryland and Missouri – and expanded funding for TSC Centers in Missouri and Maryland to \$1.1 million.	Maintained successful state initiatives in Missouri and Maryland where the TSC Centers received \$750,000 in continued funding.	State initiatives in Missouri and Maryland continued with \$250,000 in appropriations for Missouri and \$500,000 for Maryland.	Active state advocacy initiatives in 2 states with secured appropriations of \$250,000 in Missouri and \$500,000 in Maryland.
Increase partnerships with specialty pharmacies, payers, industry, private foundations and through TSC Navigator to decrease the number of individuals/ families in medication access crisis from 76 (2021 baseline) to 45 by 2023	8 individuals or families were helped with medication access issues in 2023.	55 individuals or families were helped with medication access issues in 2022.	76 individuals or families were helped with medication access issues in 2021.	<ul style="list-style-type: none"> 37 individuals/families received assistance in accessing FDA approved medications. Ongoing relationships with 19 industry partners and four specialty pharmacy partners. 	<ul style="list-style-type: none"> 20 individuals/families received assistance in accessing FDA approved medications. Added partnership with a major specialty pharmacy. Ongoing relationships with 12 industry partners and four specialty pharmacy partners.
Form task group of key stakeholders (medical professionals, patients/families) to critically evaluate current TSC Clinic designation standards and recommend new organizational structure and requirements to the TSC Alliance Board of	New guidelines were approved in 2020. In 2023, revisions and improvements continued to be made based on community feedback.	New guidelines were approved in 2020 to meet this goal. In 2022 we made revisions and improvements in the process based upon feedback from the community and Clinic Committee.	This goal was achieved in 2020. Implementation began in 2021 with collection of baseline metrics from 12 COEs and receipt of renewal applications from 61 clinics, and receipt of new applications from 6 clinics.	Board approved on Dec 14 new TSC Clinic Guidelines and Scope of Relationship Policy, Standards of Care Metrics, Structure and Expertise Requirements for Recognition/Designation, Clinic Committee Charter, and Patient and	TSC Focus Group established draft guidelines for the “standards of care” part of new clinic guidelines and will present full recommendations to the Board in 2020.

Directors for approval and implementation by 2020				Family Experience of Care Survey.	
Conduct 3 studies between 2021-2023 focused on advancing evidence-based standards of care for TSC and/or TSC patient/caregiver-reported outcomes, using a combination of patient survey, existing data review, and prospective study design	In 2023, PREVeNT concluded and offered preliminary results. TSC-STEPS is ongoing in collaboration and with financial support of the TSC Alliance. In 2023, the SUDEP-Quality Improvement project started, which aims to analyze data for proactive strategies and real-world solutions.	Two trials are running (PREVeNT, TSC-STEPS) in collaboration and with partial financial support of the TSC Alliance, which should result in evidence-based guidelines. TSC Alliance staff led publication of metrics from NHD related to diagnosis of TSC and skin manifestations in individuals with black or dark skin.	Two trials are running (PREVeNT, TSC-STEPS) in collaboration and with partial financial support of the TSC Alliance, which should result in evidence-based guidelines. PROs for TAND were added in 2021 to the NHD and should form the basis of future studies.	Gathering of baseline TSC Clinic and Center of Excellence standards of care metrics will occur in 2021.	TSC Focus Group standards of care will include measurements of outcomes, but this will begin in 2021.
Develop bi-annual curriculum (e.g., CME/CNE or TSC workshops at professional association meetings) that exposes TSC Clinic Directors and other health care providers to current evidence-based practices for TSC diagnosis, surveillance, and management <ul style="list-style-type: none"> • Participation goal of 1500 from online CME 	No new CMEs were offered in 2023.	Last CME was in 2021 so none was offered in 2022.	CME for updated clinical consensus guidelines launched in April 2021 in collaboration with PeerView Institute. By year end the activity had 2,151 learners with 613 completers. PeerView has no way to tell us who participated from TSC Clinics.	Obtained funding for and began development of CME for 2021 on clinical consensus guidelines.	200 child neurologists participated in the Harmful and Disruptive Behaviors CME Symposium at CNS, developed by the Child Neurology Foundation with the TSC Alliance as lead advocacy partner and assisting in curriculum development.
Identify TSC specialists to be resources for the 27 largely rural states participating in the	Peer-to-peer email listserv continues to grow as more healthcare	Peer-to-peer email list serve was established and enables health care professionals to share	No activity given that the pandemic revolutionized the practice of telehealth.	Not in 2020 goals. Impact of COVID-19 led to vastly increased telehealth, as	Not in 2019 goals.

<p>interstate medical licensure compact</p>	<p>professionals subscribe and share information.</p>	<p>and learn about specific cases and situations regardless of where the professionals are located.</p>		<p>demonstrated in a TSC Alliance survey:</p> <p>92% of 37 US TSC Clinics* are providing telehealth to existing patients in state/65% out-of-state.</p> <p>70% of 37 US TSC Clinics* are providing telehealth to new patients in state/49% out-of-state.</p> <p>* There are 65 US TSC Clinics. 37 TSC Clinics (57% response rate) completed the questionnaire by 2/16/2021.</p>	
<p>Increase TSC clinics providing services to children and adults, inpatient and outpatient services, to 65% by 2023</p>	<p>45% of recognized clinics see both pediatrics and adults, 50% see only pediatrics with the remaining 5% seeing only adults. In 2023, only one new clinic was added, which only sees pediatric patients as of right now but is actively working on growing to accommodate adult patients as well.</p>	<p>50% of clinics see both pediatrics and adults, 40% of clinics see only pediatrics, 10% of clinics see only adults. Five clinics were added in 2022, all of which see only pediatrics, which decreased the percentage seeing both.</p>	<p>60% as of December 31.</p>	<p>53.3% (40 of 75) TSC Clinics and COEs see individuals of all ages. The percentage is 76.9% (10 of 13) for COEs alone.</p>	<p>54.2% (39 of 72) TSC designated clinics see individuals of all ages.</p>

3. Support and Empower Constituents

Measures	Results as of December 31, 2023	Results as of December 31, 2022	Results as of December 31, 2021	Results as of December 31, 2020	Results as of December 31, 2019
<p>Grow peer to peer support to 10,578 by 2023</p> <ul style="list-style-type: none"> • Recruit 225 new volunteers into Support Services programs by 2023 • Provide 600 hours of volunteer training per year 	<p>4,278 peer-to-peer supports were provided in 2023.</p> <ul style="list-style-type: none"> • 904 training hours were completed. • 26 new volunteers added to leadership roles. • New volunteer leadership model had 103 active participants. 	<p>5,164 peer-to-peer supports were provided by our community leaders across the country.</p> <ul style="list-style-type: none"> • Volunteer recruitment was put on hold in 2022 with the creation of a new volunteer program which launches in 2023. • 13 new volunteers were added to the database. • 502 training hours were provided in 2022. 	<p>In 2021, Community Programs refined how they counted peer to peer supports and used the year as a new baseline. In total, there were 8,742 peer supports.</p> <ul style="list-style-type: none"> • 349 total volunteers recruited; 12 new community leaders were recruited • 511 training hours in 2021 	<p>28,447 peer-to-peer support contacts in 2020.</p> <ul style="list-style-type: none"> • 49 new volunteers added to Support Services program with 85 new volunteers overall. • 2,634 volunteer hours of training provided. 	<p>32,932 peer-to-peer support contacts in 2019.</p> <ul style="list-style-type: none"> • 60 new volunteers added to Support Services program and 117 new volunteers overall. • 1,429 volunteer hours of training provided.
<p>Increase the Education Parent Mentor program to support school meetings from 74 to 150 by 2023</p>	<p>50 school meetings held in 2023, and two (2) “Ask an Advocate” webinars had 94 registrants.</p>	<p>Held 29 school meetings in 2022.</p>	<p>Held 55 school meetings in 2021.</p>	<p>115 school meeting supports provided.</p>	<p>128 school meeting supports provided.</p>
<p>Build and maintain working partnerships with 15 national organizations/collaboratives (ARC, CNF, CTF, EF/REN, LAM Foundation, ATS-PAR, ELC, Global</p>	<p>Maintained 17 partnerships in 2023, including ATS-PAR, CNF, CTF, DEE-P, Dravet Syndrome Foundation, EF/REN, ELC, Epilepsy Action Network, Faster Cures, Global Genes, HRA,</p>	<p>Maintained 17 partnerships in 2022, including ATS-PAR, CNF, CTF, DEE-P, EF/REN, ELC, Epilepsy Action Network, Faster Cures, Global Genes, HRA, ISAN, NORD, The LAM Foundation, Rare As One,</p>	<p>Maintained 17 partnerships in 2021.</p>	<p>Built and maintained working partnerships with 17 national organizations/collaborations. 4 added in 2020 include: DEE-P, Faster Cures, Rare As One,</p>	<p>Built and maintained working partnership with 14 national organizations/collaborations</p> <ul style="list-style-type: none"> • TSC Alliance CEO serves as Chair of ATS-PAR.

<p>Genes, ISAN, NORD, RDCRN, TSCi)</p>	<p>ISAN, NORD, The LAM Foundation, LGS Foundation, RDCRN, and TSCi.</p>	<p>RDCRN, Seizure Action Plan and TSCi.</p>		<p>Seizure Action Plan Coalition.</p> <ul style="list-style-type: none"> • TSC Alliance CEO serves as Chair of ATS-PAR. • The Associate Director of Research serves on the Board of the Epilepsy Leadership Council. • TSC Alliance was a founding member of a new collaboration, the Seizure Action Plan (SAP) Coalition, promoting awareness of SAP and emergency plans. • TSC Alliance became members of the newly formed Governance Committee for the Infantile Spasms Action Network (ISAN). • Hosted virtual TSCi workshop in November 2020. • Co-hosted 3 progressive Virtual TSC and LAM Conferences in collaboration with The LAM Foundation. • The CSO served on the Scientific Committee for the Tuberous Sclerosis 	<ul style="list-style-type: none"> • The Improving Partnerships and Lives Grant was developed in 2019 to encourage working relationships with new 501c3 organizations. • Continued emphasis on ISAN and collaborating with multiple organizations to focus on the challenges of infantile spasms, including public awareness and access to care. • Participated in the Transition of Care Summit along with rare epilepsy partners to identify needs across the spectrum in partnership with CNF and Greenwich Biosciences. • Hosted TSCi meeting at International TSC Research Conference in Toronto. • Co-hosted 6 Regional TSC and LAM Conferences in collaboration with The LAM Foundation.
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<p>Establish relationships between all Community Alliances and local Arc Chapters where existing by 2023 utilizing Associate Partnership with The Arc US</p>	<p>Goal previously removed.</p>	<p>Removed for 2022.</p>	<p>Local ARC Chapters were greatly impacted by the pandemic; many closed and have not been responsive to partnerships on a local level.</p>	<p>21 referrals from our Community Alliances to local Arc Chapters to build new working relationships.</p>	<p>67 referrals from our Community Alliances to local Arc Chapters to build new working relationships.</p>
<p>Utilize technology or support services app to increase participation by 25% from 2,029 (Community Alliance meetings) attendees (2017) through live virtual meetings monthly in three major time zones, and create a podcast library by 2023</p>	<p>Seven (7) webinars held with 312 live attendees, 832 recorded views and 801 landing page views as of December 31, 2023.</p> <p>TSC Now podcast library resides on website under Resources.</p>	<p>Five (5) research webinars with 268 live attendees and 915 recorded views with 553 landing page views as of Dec 31, 2022.</p> <p>Three (3) Consenting Webinars lead by internal PhD were not recorded. Approximately 75-90 people attended.</p>	<p>440 attended peer support meetings. Additionally, we conducted 30 webinars for the community with total live audience of 1,642 and total cumulative recording views is 6,636. 9 community leadership webinars were also conducted.</p>	<p>64% (3,171 of the 4,988 attendees) of Community Alliance attendance at meetings was done virtually.</p>	<ul style="list-style-type: none"> 23% (430 of the 1,835 attendees) of Community Alliance attendance at meetings was done virtually. <i>TSC Now</i> podcast series launched in May; 8 monthly episodes were produced in 2019 with 1,426 total downloads/listens.

<p>Implement TSC Academy by 2020 with 75% of sponsored March on Capitol Hill advocates engaging with course content. 100% of new, sponsored advocate engagement 2021-2023. Increase # of courses available for learning by 100% and number of courses accessed by 50% between 2020-2023.</p>	<p>63% of new, sponsored advocates took the TSC Academy courses requested for MOTH participants. Seven courses are now available on the platform. A new course on Clinical Consensus Guidelines was also completed.</p>	<p>45 of 83 (54%) first-time participants took the TSC Academy courses required/requested for MOTH participants. We found this more challenging with virtual participation, especially for those who only attended one meeting.</p>	<p>135 participants attended the first Virtual March on Capitol Hill. 100% of new advocates took the TSC Academy courses required/requested for MOTH participants.</p>	<p>79% of sponsored attendees took TSC Academy in preparation for advocacy on Capitol Hill. Courses developed were a Primer on TSC 101, Introduction to Research and Funding, and The Advocate's Role.</p>	<p>TSC Academy launched on January 31, 2020, for the 2020 March on Capitol Hill.</p>
<p>Expand to 7 Global Alliances by 2023, growing each country's constituencies by 10%, increase global TSC Clinics to 15, and successfully launch NHD internationally</p>	<p>Maintained 6 Global Alliances and 13 global TSC Clinics. The recognition process for Global Alliance TSC Clinics was revised to allow for differences in health systems and country resources.</p>	<p>Maintained 6 Global Alliances. Exploratory conversations took place with members of the TSC communities in Singapore and South Africa. There are now 13 TSC Alliance globally recognized TSC Clinics. The NHD was launched in 2 sites in Canada, and the TSC Alliance of India is replicating its, version of our NHD that will be compatible.</p>	<p>Currently working with the Philippines to add them as a Global Alliance and implemented succession plan in Thailand to strengthen Southeast Asia outreach. Participated in Rare Disease International and the development of a Collaborative Global Network for Rare Diseases. Developed implementation plan for expanding NHD globally.</p>	<ul style="list-style-type: none"> Continued our 6 global partnerships Recognized 1 new global TSC Clinic, bringing the total number of internationally recognized clinics to 10 (3 in Israel, 4 in Canada, 2 in Mexico, and 1 in India). 	<ul style="list-style-type: none"> Maintained 6 global partnerships, including renewals of TSC Alliance of Israel and TS Canada ST. Recognized 1 new global TSC Clinic, bringing the total number of internationally recognized clinics to 9 (3 in Israel, 3 in Canada, 2 in Mexico, and 1 in India).

4. Educate and Mobilize to Increase Investment

Measures	Results as of December 31, 2023	Results as of December 31, 2022	Results as of December 31, 2021	Results as of December 31, 2020	Results as of December 31, 2019
Raise \$18.95 million for research over the next five years	\$16,871,412 raised through 2023.	\$12,860,591 raised through 2022.	\$8,212,256 raised through 2021.	\$4,107,146 has been raised for the Investment to Accelerate Research as of 12/31/20.	Goal changed to \$40 million over seven years following a campaign study and on recommendation of our capital campaign consultants. TSC Alliance raised \$2,650,212 in 2019.
Grow the Endowment Fund to \$10 million by 2023 and realize the maximum allowable annual contribution	\$5,921,817 in total net assets of the Endowment Fund and an annual contribution of \$238,000 was made to the TSC Alliance along with a one-time recognition of \$334,625 of funds approved but never transferred in prior years.	\$5,500,386 in total net assets of the Endowment Fund and an annual contribution of \$238,000 was made to the TSC Alliance.	\$6,711,748 in total net assets of the Endowment Fund and an annual contribution of \$226,000 was made to the TSC Alliance.	Total net assets for the TSC Alliance Endowment Fund are \$5,893,522 as of 12/31/20.	Total net assets for the TSC Alliance Endowment Fund are \$5,915,804 as of 12/31/19.
Mobilize grassroots community through budgeted special events to raise \$1.5 million average net annually over next 5 years	\$1,274,007 in net community fundraising events in 2023. \$1,502,017 average net over five years.	\$1,443,671 net in fundraising occurred in community events in 2022.	\$1,143,605 net in community fundraising events in 2021.	\$1,227,362 was raised through special events in 2020.	\$2,421,439 net was raised through special events in 2019.
Increase the number of people donating online to crowdfunded events from 1,257 (2017) to 2,514 (2023)	8,283 transactions, raised \$1,653,102.	6,404 transactions raising \$1,212,305.	7,519 transactions raising \$912,859.	4,815 individuals donated online to crowdfunded events through Classy with an additional 4,728	1,182 individuals donated online to crowdfunded events through Luminate and 4,016 donated through Facebook.

				individual donations made through Facebook in 2020.	
Secure at least 400 million impressions annually via multiple and varied outlets with minimum investment	Cumulative impressions in 2023 totaled 812 million.	Cumulative impressions in 2022 totaled more than 2.7 billion.	Cumulative impressions in 2021 totaled 809 million.	Nine news releases in 2020 led to 694 million impressions.	Four news releases in 2019 garnered 313 million impressions.
Achieve additional 100 million impressions through new awareness campaign and 3,500 contacts to the database per year of the campaign	Geben was not contracted in 2023 for additional TSC awareness or paid social media campaigns due to expense of website redesign project. 216 new TSC contacts were added to the database.	Geben's 2022 outreach efforts led to 7 media placements (1 podcast, 3 national outlets, 2 trade publications and 2 local outlets) garnering 75 million impressions; 2 paid social media campaigns created 3,738 engagements and 3,402 link clicks. 337 new contacts were added to the database.	The 2021 awareness campaign implemented by Geben Communication secured 24 media placements (6 podcasts, 4 national outlets, 9 trade publications and 5 local outlets) leading to 179.3 million impressions and 5,200+ social media engagements.	Marketing/communications presented findings/recommendations early 2020 and organization moved forward with planning and decisions for name change/rebranding in 2021, formally beginning May 15.	Marketing firm was contracted to conduct research on current messaging, branding and awareness with recommendations to be presented in 2020.

5. Build and Strengthen Organization

Measures	Results as of December 31, 2023	Results as of December 31, 2022	Results as of December 31, 2021	Results as of December 31, 2020	Results as of December 31, 2019
<p>Maintain a 4-star Charity Navigator rating and meet or exceed an 80/20 program/supporting expenses ratios by 2023 in accordance with the five-year Research Business Plan</p>	<p>The TSC Alliance currently has a 4-star rating on Charity Navigator and is a Platinum Charity by Candid (formerly Guidestar), 2023 Top-Rated Nonprofit by GreatNonprofits and an accredited charity by the Better Business Bureau Wise—Giving Program.</p> <p>Current program ratios are: 79.86% expenses going toward programs and 20.14% for supporting services for fundraising, management and admin.</p>	<p>The TSC Alliance currently has a 4-star rating on Charity Navigator and is currently rated as a Platinum Charity by Guidestar, 2022 Top-Nonprofit by GreatNonprofits, and an accredited charity by the Better Business Bureau Wise-Giving Program.</p> <p>Current program ratios are: 77.9% expenses going toward programs and 22.1% for supporting services for fundraising, management and admin.</p>	<p>TSC Alliance rated as 3-star charity for FY2020 and will qualify to return to a 4-star rating on Charity Navigator for FY2021. Currently rated as a Platinum Charity by Guidestar, 2021 Top-Nonprofit GreatNonprofits and an accredited charity by the Better Business Bureau Wise-Giving Program.</p> <p>Current program ratios are: 79.17% (\$5,465,789) of expenses going toward programs, and 20.83% for supporting services (\$919,902 for fundraising and \$517,901 for management and admin). The \$919,902 represents 11.18% of total revenues raised.</p>	<p>TSC Alliance received a 4-star Charity Navigator rating, Better Business Bureau Wise Giving accreditation, and Platinum Guidestar status in 2020.</p> <p>Expense ratios were 73.2% program/26.8% admin and fundraising for FY20.</p>	<p>TSC Alliance received a 4-star Charity Navigator rating, Better Business Bureau Wise Giving accreditation, and Platinum Guidestar status in 2019.</p> <p>Expense ratios were 72.9% program/27.1% admin and fundraising for FY19.</p>
<p>Implement in depth review to ensure integrity of constituent data with less than 1% duplicates by 2020 and maintain thereafter</p>	<p>The database's current constituent total is 162,245 with 1,407 suspected duplicate records, putting the total percentage of duplicate records at .87%.</p>	<p>The database's current constituent total is 158,174 with 1,228 suspected duplicate records, putting the total percentage of duplicate records at .77%.</p>	<p>The database's current constituent total is 154,259 with 321 suspected duplicate records, putting the total percentage of duplicate records well under 1%.</p>	<p>Maintaining the integrity of the database with 0.05% of duplicates noted on 12.31.20.</p>	<p>Constituent database was reviewed, and 1.2% dupes remain.</p>

<p>Participate/present at 25 professional/industry conferences per year</p>	<p>TSC Alliance staff attended and participated in 26 professional/industry conferences in 2023.</p>	<p>TSC Alliance staff attended and participated in 28 professional/industry conferences in 2022.</p>	<p>Participated in 37 professional/industry conferences in 2021.</p>	<p>TSC Alliance staff attended or participated in 22 professional/industry conferences.</p>	<p>TSC Alliance staff attended or participated in 40 professional/industry conferences.</p>
<p>Recruit 3-6 new Board members annually, reflecting the diversity of our constituency, with financial management, global relations, technology, scientific/medical expertise and ability to raise substantial unrestricted donations or for targeted initiatives including research or community initiatives</p>	<p>Added 3 new board members with expertise in finance and audit, government relations and outreach to under-represented communities.</p> <ul style="list-style-type: none"> • 1 woman and 2 men • 1 from diverse background • 1 from California, 1 from Minnesota, 1 from DC Area 	<p>Added 2 new board members with expertise in TAND and autism, ED&I and strategic planning.</p> <ul style="list-style-type: none"> • 1 woman and 1 man. • 1 from diverse background. • 1 from California and 1 from New York. • 1 physician and 1 adult with TSC. 	<p>Added 6 new board members with expertise in regulatory affairs, executive pharmaceutical leadership, commercial legal and litigation, government relations, global marketing and patient advocacy, and finance and audit.</p> <ul style="list-style-type: none"> • 4 are women and 2 are men. • 2 from diverse backgrounds. • Geographically: 2 from DC, 3 from CA, 1 from Chicago. <p>3 of 6 are parents of individuals with TSC. 3 are from corporate partners.</p>	<p>Added 4 new board members with expertise in science and medical, neurology, TAND, clinical care, nursing, government affairs, global relations.</p> <ul style="list-style-type: none"> • 2 are women and 2 are men • 1 from diverse background • Geographically: 1 from AL; 1 from TN; 2 from VA <p>2 of the 4 are impacted or are a parent of an individual with TSC. 3 are medical professionals</p>	<p>Added 8 new board members (6 elected, 2 fulfilling other terms) with expertise in financial management, global relations, IT technology, HR, outreach to Spanish speaking community, event planning, legal, nonprofit leadership/fundraising.</p> <ul style="list-style-type: none"> • 5 are women and 3 are men • 2 from diverse backgrounds • Geographically: 1 from DC; 1 from CA; 1 from the West; 2 from Midwest; 2 Northeast; 1 from the Southeast <p>7 of the 8 have relatives with TSC. 1 is a corporate partner</p>
<p>Grow Science and Medical team to 8.5 FTEs to accelerate research and improve quality of care by 2021 and corresponding staff (e.g., financial, fundraising, communications, support services) and</p>	<p>7 FTEs in Science and Medical Staff at the end of 2023. The Director of Research left in March and in July the team added a Science Project Coordinate and Science Project Manager. Our</p>	<p>6 FTEs in Science and Medical Staff. The Research Project Manager joined the Science and Medical team in October 2022. We also added two positions: Manager of Partnerships and Annual</p>	<p>6 FTEs in Science and Medical Staff in 2021. 3 additional positions added: consultant Grant Writer to Development to assist with the research campaign; Executive Assistant to support CEO and executive team; and</p>	<ul style="list-style-type: none"> • Hired a new Director, Medical Affairs, taking the Science and Medical Team to 6 FTEs, including approximately 0.5 FTE dedicated to constituent support services. 	<ul style="list-style-type: none"> • Hired a new Associate Director, Research, taking the Science and Medical team to 5 FTEs. • Added Director of Digital Platforms to support Communications.

<p>infrastructure to support growth while maintaining 80% retention outside of retirements</p>	<p>total staff at the end of FY23 was 24.</p> <p>Overall staff retention at 96% outside of retirements.</p>	<p>Giving and a Community Programs Manager. Our total staff at the end of FY22 was 22.</p> <p>Overall staff retention at 86% outside of retirements.</p>	<p>Director of Community Education and Resources to supplement Community Programs (Shelly Meitzler promoted to this position in November).</p> <p>Overall staff retention at 95% outside of retirements.</p>	<ul style="list-style-type: none"> 90% of staff retention outside of COVID-19 related layoffs. 	
<p>Create transition plan for senior staff retirements</p>	<p>The transition plan for VP of Community Programs was executed through April 2023.</p> <p>A Career Roadmap was developed and approved in 2023 to provide guidance for professional growth and advancement within the TSC Alliance for every department. As part of the work of the strategic plan, a revised staff structure was finalized in October and implemented in January 2024.</p>	<p>The transition plan for the VP Community Support was created. This plan included promotion of Director of Community Outreach and Support and Director of Community Programs co-leading Community Programs division after March 1, 2023, and the creation of the Office of the President to provide strategic and cross-organizational logistical support.</p>	<p>The transition plan for VP Support Services was executed in early 2021. A transition plan for the CFO position was created.</p>	<p>VP of Support Services retiring early at the end of January 2021. Implemented transition plan in order to ensure continuity of care and service.</p>	<p>Transition plan created for VP of Support Services for retirement in April 2022.</p>