



# FY 2024 Strategic Plan Progress Report and Effectiveness Assessment

## Objective

To improve quality of life for everyone affected by tuberous sclerosis complex by catalyzing new treatments, driving research toward a cure and expanding access to lifelong support.

## Goals

### 1. Accelerate Research

Measures	Recommended Changes to Measurement	Results as of Dec. 31, 2024	Effectiveness Assessment
<b>Better understand and stratify disease:</b>			
Implement a centralized data library that researchers can access (2025). Provide tools for researchers to work with the library of data by implementing a virtual “sandbox” (2028).	None	Identified potential partners for hosting a centralized data library. Currently, genome sequences are hosted on AWS, preclinical data on SharePoint.	We have data on sharing platforms. Implementation of a <i>centralized</i> platform in 2025 is dependent on dedicating enough science team time, as it must hold various data types from all preclinical and clinical projects. Types of data include biochemical, genome sequence,

			histology, EEG, MRI, neuropsych and quality of life assessment data.
<p>Ensure at least 10% Black or African American and 4.5% Asian representation in NHD and BSR (U.S. population is 13.6% and 6.1%, respectively).</p> <ul style="list-style-type: none"> <li>• From the baseline of 5.9% Black or African American and 2.8% Asian in 2023.</li> </ul>	<p>Change to: Increase the number of participants from underrepresented groups (Black or African American, Asian) by adding 5-10 in each group annually.</p>	<p>In 2024, the NHD BSR enrolled 7 Black/African American and 6 Asian participants, but also enrolled additional White and Hispanic participants, so representation is now 5.7% Black or African American and 2.8% Asian.</p>	<p>We have added participants from underrepresented groups, but without ceasing to add White or Hispanic participants, the percentages remain stable. Because it is more important to add all interested participants, we suggest changing the measurement to reflect numbers added rather than impact on the percentages. We are striving to reach underrepresented groups by going directly in communities through Step Forward to Cure TSC Walks and highlighting this effort in NHD/BSR clinic quarterly updates.</p>
<p>Collect quantitative data related to TAND and to reproductive and perinatal health.</p>	<p>Add to the end of the measurement: ...” outcomes from at least 300 TSC-affected individuals.”</p>	<p>Added six TAND and 20 reproductive and perinatal health outcome variables to the NHD.</p>	<p>The necessary changes to the database have been made. The measurement is currently not quantified, so we suggest adding a specific number of participants to shoot for.</p>
<p>Ensure BSR contains serial blood samples from at least 250 individuals with TSC and access to at least 100 typically-developing, non-TSC individuals and at least 100 individuals with TSC but without neurological signs or symptoms.</p>	<p>None</p>	<p>Collected 271 serial blood samples from individuals with TSC in 2024. Developed project plans to access blood samples from non-TSC individuals.</p>	<p>Successful at exceeding the goal for serial blood samples through strong effort in community outreach to cultivate repeat donors in NHD BSR via personal and social media outreach.</p>
<p>Establish biomarker panel for most impactful manifestations of TSC utilizing samples in BSR and data from clinical studies and NHD.</p>	<p>Change to: Establish a blood-based data set (e.g., DNA, RNA, protein) from 200 pediatric and 200 adult individuals with TAND</p>	<p>Collected protein and whole genome sequencing on 78 TSC patients and 6 sibling control blood samples.</p>	<p>Few samples in BSR/NHD are associated with clinical scores for standardized tests for aspects of TAND, so we launched a recruitment</p>

	and appropriate controls necessary for research efforts to establish a blood-based biomarker panel for manifestations of TAND.		effort through social media, a new TSC Alliance web page and presentations at community events (e.g., regional conferences). We suggest changes to the wording of the measurement to reflect the TSC Alliance's direct contribution to a biomarker panel is generating the data sets, not defining the panel, which would be done by researchers. Also, we now have specific numerical goals we can add to the measurement to quantify it.
Through external collaborations, generate necessary preliminary data (2025) and pilot newborn screening assay (2028).	Change to: Actively participate in external collaborations to pilot newborn screening for TSC, raising awareness among our community, and when appropriate, advocate for inclusion of TSC genetic testing in newborn screening.	TSC Alliance joined the Early Check Consortium. Early Check is a North Carolina-specific research project piloting whole genome sequencing (WGS) of newborns to identify potential disease-causing variants in dozens of diseases, including TSC. We are also tracking the GUARDIAN study, an academic pilot study of WGS in newborns, which also includes TSC genes.	The potential for newborn screening using genetic assays has dramatically increased in the last few years. Pilot studies are ongoing. These change the landscape so that the TSC Alliance is not needed to play a major role in the development of the technical assay. Rather, our role will be critical for advocacy to get the assays (including TSC) adopted by state newborn screening programs. The technology may or may not be ready for advocacy by 2028.
Establish TAND PRO instrument to quantitatively assess the most impactful TAND symptoms for an individual by 2025 and validate in a clinical study by 2028.	Change to: Establish consensus on a Core Outcome Set of assessment tools to standardize measures of TAND manifestations in clinical research and care by 2028.	Established an international steering committee of TAND clinicians and community experts. Funded a four-year project entitled "Towards a core outcome set for TSC-Associated Neuropsychiatric Disorders (TAND): Harmonizing current practice and further development of the TSC-PROM."	Multiple conversations with Anya's Accelerator PRO steering committee led to the development and approval of a project led by Agnies van Eeghan. The focus is first to establish a TAND core outcome set of assessment tools. As part of the effort, a TSC-PROM (patient reported outcome measures) that measures an

			individual's functioning (e.g., social, physical and executive) will be further characterized in adults and developed for pediatrics. To align with current terminology and the funded project, we suggest a slight rewording of the measurement.
<b>Increase diversity of technologies entering clinical trials:</b>			
Maintain at least seven industry partners per year participating in the Preclinical or Clinical Consortia.	None	Maintained 10 industry partners.	We are ahead of this goal for 2024. Industry participation is fluid, as some companies rotate off due to lack of drug effectiveness or lack of funding. It is important to maintain diversity in drug targets to maximize approaches to all TSC manifestations. Maintaining 10 industry partners required cultivation of at least 18 companies in 2024.
Test at least 20 compounds or other therapeutic technologies paid for by TSC Alliance in preclinical models including exposure and biomarker response.	Change to: Support the testing of at least 20 compounds or other therapeutic technologies in the Preclinical Consortium for industry or academia.	Evaluated eight distinct compounds in the preclinical consortium (2024). Seven compounds were tested by industry and one compound was paid for by TSC Alliance funding. TSC Alliance also paid for the development and characterization of two additional mouse models needed to improve the breadth of models targeting TSC1- and TSC2-driven neurological changes.	Effective outreach to industry keeps experiments running around the clock, and the TSC Alliance funds have been prioritized by the steering committee for addition of important new models. Given that testing of new therapeutics is critical regardless of whether they are industry- or TSC Alliance-paid, we suggest a rewording of the measurement. Since including exposure and biomarker response is at the discretion of industry if they pay for the study, we suggest removing that specific statement.

Establish and make available cell-based neurology model and assay(s) suitable for drug screening.	Remove this measurement.	Identified potential partners for developing cell-based models.	The demand for cell-based assays from preclinical partners has been low. Industry partners and academic researchers are deploying cell-based models in their laboratories. The greatest value to preclinical partners is translational animal models for TSC, and we have been very successful at that as demonstrated in the goals above.
Extend participation in Clinical Research Consortium to all TSC clinics in the U.S., attracting at least two industry or government funded clinical trials to utilize the Clinical Research Consortium.	Change each occurrence of “Clinical Research Consortium” to “Clinical Research Network”	We developed a draft framework for a TSC Clinical Research Network, using the word “Network” to distinguish the new broader network from the existing Clinical Research Consortium. One industry partner from our Preclinical Consortium is now completing Phase 1 studies and we are cultivating three additional companies, each of whom could utilize the Clinical Research Network for Phase 2 trials in the next few years.	This network will leverage the expertise of TSC clinical researchers and will engage the community. We are talking with many stakeholders for input on how the Network should best be organized and how it can be leveraged for revenue from industry partners. We suggest editing the measurement to reflect the new wording.
<b>Increase innovative research:</b>			
Increase TSCRCP funding from \$8 million to \$10 million annually.	None	Our House Dear Colleague Letter ask for FY25 was for \$10 million but the TSCRCP is currently in the budget for the existing level of \$8 million.	FY25 has not yet been finalized by Congress. The TSC community did an incredible job advocating for the TSCRCP. The House Dear Colleague Letter in support of TSC research had 185 signers and the Senate letter had 41.
Obtain state funding for five TSC centers (currently three states funding four clinics).	None	State funding was maintained for 4 clinics in 3 states. \$275k in Alabama, \$500k in Maryland, and \$500k in Missouri for FY25.	A total of \$1.275 million in state funding was obtained for Alabama, Maryland, and Missouri for FY25.

<p>Fund a minimum of three merit-based research grants per year while growing the diversity of applicants to an average of 15% of applicants from underrepresented populations over five years.</p>	<p>None</p>	<p>Three merit-based research grants were awarded in 2024. However, the diversity of applicants remained at 11%, where it has been for four years.</p>	<p>Despite increased outreach to groups of underrepresented scientists, we are not attracting more diverse applicants. We would like to keep the goal and continue finding new ways to reach out to these populations. That said, only scientists working in labs pursuing TSC-related projects will apply to TSC Alliance, thus our target population depends on who is recruited to TSC laboratories, which is beyond control of the TSC Alliance.</p>
<p>Annually capture and report outcomes from funded grants (e.g., follow-on funding, promotion, publications, patents, etc.).</p>	<p>None</p>	<p>We incorporated Crossref DOI numbers to all awarded grants from the last ten years and, for new grant contracts beginning in 2024, we require the use of this DOI number with all published results to ensure we can track publications, patents, etc.</p>	<p>With Crossref DOI numbers, it is much easier to track and link future publications to our grant awards. In the coming years we will also add a system for regular outreach to past awardees to learn about impacts on promotion and follow-on funding, which are more subjective and not easily trackable even with DOI numbers.</p>

## 2. Improve Access and Quality of Care

Measures	Recommended Changes to Measurement	Results as of Dec. 31, 2024	Effectiveness Assessment
Expand healthcare access:			
<p>Develop framework for the PAB for review and approval by the Board of Directors in 2024.</p> <ul style="list-style-type: none"> <li>• Hold two meetings per year, beginning in 2025, to identify issues impacting access to care and treatments and potential solutions.</li> </ul>	None	The PAB charter was approved and 10 members were appointed by the Chair upon recommendation by the Science and Medical Committee.	We are on track to add more members in 2025 and begin having regular meetings to engage this important advisory board.
<p>In 2024, survey recognized TSC Clinics, COEs and affiliated providers for gaps in TSC FDA-approved medications on state Medicaid formularies and assess the prevalence of prior authorization denials.</p> <ul style="list-style-type: none"> <li>• In 2025-2028, work with industry and health policy legislators to advocate for change in access criteria in a minimum of five states.</li> <li>• Develop medical necessity letters for therapies which have the most frequent denials or obtain new FDA-approvals and disseminate them to healthcare professionals.</li> </ul>	Remove this measurement but retain an annual goal for Government Relations to advocate for access to treatment and/or bring issues to PAB when medical necessity letters are required.	TSC Alliance staff worked with TSC clinicians on medical necessity letter at the end of 2024/beginning of 2025 for Ganaxalone®. Though the trial for TSC failed to meet overall endpoints, a subset of participants were super responders. We worked with TSC clinicians to help ensure these individuals had access to Ganaxalone® since it had already been approved for CDKL5. This letter was then circulated to all TSC Clinic Directors.	This measurement was developed in 2023 when there were formulary issues with Epidiolex® (not recognized for TSC in MN) and Sabril®/vigabatrin (where there were additional steps required for access in TN). We continue to work on state advocacy as part of coalitions or as specific issues regarding access to TSC approved medications arise as part of our annual government relations goals. However, these issues, in subsequent conversations with clinicians, are not as extensive as originally thought and we recommend removing this goal to focus on other priorities.
Annually update website to indicate which clinics offer telehealth across state line.	None	A telehealth question was added to the clinic application in 2024, so only six clinics applied in fall of 2024 and have answered it. The	Data collection has begun and we are on track to update the website in 2025.

		question is added to the annual update form so we will have complete data in 2025 and will add it to the website at that time.	
Improve quality and comprehensiveness of healthcare:			
Develop a transition plan template based on input from Clinic Committee by 2025 and require its use by 100% of recognized clinics by 2028.	None	On track. Timeline sketched out.	In 2024 we laid some preparations for this 2025 goal.
In 2024, assess baseline number of TSC Clinics and COEs that have action plans describing TAND service capabilities for both pediatrics and adults. By 2028, double the number of those with action plans relative to baseline.	Change to: In 2024, assess baseline number of TSC Clinics and COEs describing TAND service capabilities for both pediatrics and adults. In 2025 and annually thereafter update website to include which clinics have dedicated subspecialty services for management of TAND within their clinic or which refer out.	Of 75 clinics, 43 see pediatrics and adults, and 37 (86%) have dedicated subspecialty services within their clinic for management of TAND. The remaining 6 coordinate care and assist with referrals to an outside specialist. Of 28 pediatric-only clinics, 21 (81%) have dedicated TAND subspecialty services within their clinic, and the remaining 5 refer out. Of 4 adult-only clinics, all 4 have dedicated TAND subspecialty services within their clinic.	All TSC Clinics and COEs have a process for dealing with TAND issues, and 83% of them have internal subspecialty services for management of TAND. Given the high percentage of clinics who have internal subspecialists and that the remaining clinics state they coordinate care and assist with referrals to outside specialists, there is no longer a need to increase the number of Clinics and COEs with action plans.
Build evidence base to support updates to best practice guidelines for TSC clinical care:			
Collaborate on initiatives to build evidence to address gaps on 2 understudied aspects of TSC. <ul style="list-style-type: none"> <li>• Publish updated consensus guidelines for surveillance and management of TSC for areas previously unaddressed and identified as high priority by the community (e.g., reproductive and perinatal health, SUDEP).</li> </ul>	None	In March 2024, an in-person workshop in Memphis gathered 21 in-person attendees and 6 virtual attendees interested in reproductive and perinatal health. Efforts are underway to conduct a systematic review of literature for an update of pregnancy management recommendations.  The SUDEP quality improvement survey received 377 responses from the TSC community and 39 responses from healthcare	This is moving forward. Also, we plan to update the overall clinical consensus guidelines in 2026 and to include recommendations in these new areas in that update, also.



		providers by March 2024. Responses were analyzed and presented on a poster at the 2024 AES Annual Meeting.	
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### 3. Support and Empower Constituents

Measures	Recommended Changes to Measurement	Results as of Dec. 31, 2024	Effectiveness Assessment
Develop a more collaborative and inclusive volunteer network to mentor the next generation:			
Fully implement 15 regions by 2024, with key leadership roles represented in each region by December of 2028.	Adjust from 15 to 14.	Established 14 regions with 138 active leaders.	At the request of the regions, merged two California regions to foster a more collaborative approach, as they shared TSC Clinics and access to medical care.
Develop an intranet platform that facilitates effective communication, training and resource sharing among our volunteer leadership team by 2024 with 90% utilization annually 2025-2028.	None	Community Leadership Hub officially went live January 21, 2025.	Launch was delayed from 2024 to January 2025 due to competing priorities. Community Programs will monitor use throughout 2025 with goal to hit 90% through Google Analytics.
Develop a benchmark for peer-to-peer support in 2024 and increase documented meetings and interactions by 10% annually in 2025-2028.	None	Benchmark has been established. The benchmark was established at 3,890 in 2024.	In October 2024, we launched a new reporting design with an incentive mechanism and detailed volunteer role tracking, aimed at fostering more targeted engagement. In 2025, we aim to grow our support from 3,890 to 4,279, aligning with our goal of a 10% annual growth.

Recruit and train at least one government advocate in each state by 2028.	None	Government Action Leads have been identified in 38 states as of December 31, 2024.	All states are regionally represented through our community support network, and our government advocacy efforts continue to focus on building relationships and meeting with all Congressional offices, while continuing to identify Government Action Leads in each state.
Strengthen the relationship between healthcare providers and community members at a local and regional level:			
Grow Clinic Ambassador/Medical Liaison program from 20% to 45% of TSC Clinics by 2028.	None	Maintained 26 clinic ambassadors/medical leads as of December 31, 2024.	In 2025, the goal is to maintain 25 active Clinic Ambassador/Medical Liaisons in TSC Clinics by December 2025.
Support and educate 75 TSC families through the IEP and transition processes annually.	Adjust from 75 to 90 families through the IEP and transition processes annually.	88 families were supported through the IEP and transition process as of December 31, 2024.	In 2025, the annual goal is to support and educate 90 TSC families through the IEP and transition process.
Increase the number of engagements through the TSC Support Navigators by 10% annually from a baseline of 50 in 2023.	None	290 families and individuals were supported as of December 31, 2024, with 23 one on one Support Navigator calls scheduled.	In 2025, the goal is to increase engagements through the TSC Support Navigators by 10% annually from 290 engagements to 319.
Maintain working partnerships with at least 15 national and international organizations/collaboratives (i.e., ARC, CNF, CTF, F/REN, LAM Foundation, ATS-PAR, ELC, Global Genes, ISAN, NORD, RDCRN, TSCi, Mind the Gap, Got Transitions, TANDem).	None	Working relationships with 17 organizations/collaboratives: Angelman Syndrome Foundation, ARC, ATS-PAR, CNF, CTF, DHRC, Dravet Syndrome Foundation, ELC, Global Genes, ISAN, LAM Foundation, LGS Foundation, NORD, PAME, RDCRN, REN, TANDem, and TSCi.	One of our core values is building value-based relationships. We pride ourselves on generating alliances internally and externally by continuously identifying and acting on those things that will create success for the organization and its constituents, researchers, health care professionals and communities.

Foster international relationships and development of resources to better serve the worldwide TSC community:			
Grow global clinics from 13 to 25 by 2028.	None	Currently we recognize 14 Global Alliance TSC Clinics: 5 TSC Clinics in Canada, 3 in India, 4 in Israel, and 2 in Mexico.	Two Global Alliance TSC Clinics were added in 2024: one in Canada and one in Israel, which would have been a total of 15 TSC Global Alliance Clinics recognized. The adult TSC clinic in Toronto closed, leaving us now with 14 total global clinics.
Work with TSCi to increase the number of countries participating in TSC clinical trials by 25% by 2028.	None	TSCi held the TSCi and Industry Forum in November 2024 with key stakeholders in the TSC space, including TSCi member organizations, clinicians, researchers, and industry partners. Attendees included 32 people from 18 countries; it was sponsored by 6 industry partners.	The goal of the forum to develop a roadmap for global clinical trials in TSC. Key forum take aways included the need to: increase global access and representation in clinical trials, improve clinical trial preparation and delivery, create best practices guidance for TSC clinical trials globally, have ongoing partnership and communication between all stakeholders, and maintain consistency throughout the clinical trial process.
Foster partnerships in 10 low- or middle-income countries with no association representation by 2028.	None	We continue to explore partnership opportunities in Latin America and Southeast Asia. Countries that have expressed interest in TSC Clinic development include Egypt, Turkey, Trinidad and Tabogo, and Saudi Arabia.	This is an ongoing initiative. We are also working with TSC Clinics in the US to identify possibly connections. Challenges have been identified around TSC awareness and finding interested families and clinicians, capacity of volunteers, and fundraising opportunities in low- and middle-income countries.

## 4. Educate and Mobilize to Increase Investment

Measures	Recommended Changes to Measurement	Results as of Dec. 31, 2024	Effectiveness Assessment
Raise \$23,250,000 for research over the next five years to complete the \$40 million capital campaign.	None	Raised \$2,593,609 in 2024 for the Research Campaign.	Our goal was to raise \$3,487,000 in 2024. These efforts fell a little short from a GAAP perspective and with the focus on the 50 <sup>th</sup> anniversary. We did, however, receive a \$1,000,000 cash gift that increased our ability to invest in research in real time.
Grow the Endowment Fund to \$7 million by 2028 and realize the maximum allowable annual contribution.	None	Endowment balance at the end of 2024 was \$6,844,816, of which \$573,625 is rainy day funds held at the Endowment Fund.	Endowment Fund balance has continued to grow and \$508,318 in donations and expectancies were received in 2024.
Increase annual net revenue from community-driven and corporate-sponsored events to 15% of total revenue.	None	Revenue net \$2,409,922 or 27% of \$9,081,267 total revenue.	We exceeded 15% of our annual net revenue from community-driven and corporate-sponsored events, with the 50th Anniversary Gala being a key contributor. In 2025, we aim to maintain and grow our corporate sponsorships and continue hosting successful community-driven events.
Generate unrestricted revenue equal to 5% of total revenue from Preclinical and Clinical Research Consortia memberships and indirect costs of industry-sponsored studies.	None	Achieved \$388,654 of unrestricted revenue from industry membership fees in the Preclinical Consortium. This accounted for 4.27% of the total revenue	The Preclinical Consortium is a self-funded mechanism that has greatly accelerated drug development in TSC. Expansion of the Clinical Research Consortium will allow compounds developed preclinically to translate to human trials more easily.

<p>Annually obtain a minimum of 900 million news release impressions and at least 45,000 social engagements and increase use of digital platforms (podcasts, video views and eNewsletters) by 10% each year.</p>	<p>Adjust from 45,000 engagements to 55,000 engagements.</p>	<p>In 2024, 8 news releases garnered 1.1 billion impressions. There were 63,033 social media engagements in 2024. Video views increased 9.54% across all channels, but podcast listens decreased 36.25%, and the email audience for eNewsletters decreased 3.9%.</p>	<p>News releases continue to be important to getting the word out about the organization's major initiatives. Social media is our most powerful tool for engaging the TSC community. The TSC Alliance's email audience has been declining year over year and a thorough data audit is necessary for effective email communication moving forward. Similarly, podcasts need to be released on a more consistent schedule and promoted to help grow the audience for that resource.</p>
<p>Add 350 new families or individuals with TSC contacts to the TSC Alliance database annually.</p>	<p>None</p>	<p>236 new families or individuals with TSC contacts were added to the TSC Alliance database in 2024.</p>	<p>There is a discrepancy between constituents being served by the TSC Alliance and those being added to the database. A thorough data audit is needed to identify how/where we collect data, so we don't miss opportunities to convert interactions to new contacts. Re-evaluate goal after completing data audit in 2025.</p>
<p>Obtain 500 physician web page visits each year.</p>	<p>Adjust from 500 physician web page visits to 1,500 physician web page visits and 200 email signups each year.</p>	<p>Paid digital ads targeting physicians resulted in 7,089 web page visits and 247 email signups in 2024.</p>	<p>While digital advertising proved effective at driving traffic to the website, it was hard to parse new physicians from spam, so this strategy needs to be honed and complemented with other strategies like having flyers with QR codes at professional meetings.</p>
<p>In 2024, create a web page visit baseline, then identify pages to target</p>	<p>None</p>	<p>A website tracking sheet evaluating page visits for the top 10 pages was created in December</p>	<p>With the new website launching in 2024 it was important to establish a new baseline for web traffic to</p>

each year and increase targeted page visits 10% annually.		2024, identifying pages most visited for tracking in 2025.	understand which parts of the new site were most frequented. Now that the baseline is in place, we can develop a strategy to drive increased traffic to those pages moving forward.
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## 5. Build and Strengthen Organization

Measures	Recommended Changes to Measurement	Results as of Dec. 31, 2024	Effectiveness Assessment
Maintain a highest rating among watchdog organizations and meet or exceed an 78/22 program/supporting expenses ratio.	None	TSC Alliance received a 4-star rating on Charity Navigator, Platinum Chairty on Candid, Better Business Bureau Wise-Giving accreditation, 2024 Top-Rated Nonprofit by Great Nonprofits.  Program ratios are: 78.08% expenses going toward programs and 21.92% for support services for fundraising, management and administration.	The TSC Alliance continues to be recognized as a premier nonprofit by watchdog organizations and takes our accountability and transparency seriously. In addition, we have a goal to maintain a minimum of 78% program services without sacrificing appropriate infrastructure to be successful.
Engage with staff and community leaders to improve accuracy of contact information in the database, utilizing 2024 as a baseline, so there is less than 2% returned mail for appeals, annual reports and special event mailings annually thereafter.	None	Approximately 1.3% of all mail sent out was returned.	In 2024, over 50,000 pieces of mail were sent out through our campaigns and notices to the community, with only 670 pieces returned.
Recruit three to six new Board members annually to achieve a board with:	None	Added nine new operating Board members with expertise in finance and audit, community outreach and adult services, global and government relations, translational research	We recruit board members with identified skill sets that allow us to fulfill the strategic plan.

<ul style="list-style-type: none"> <li>• Expertise in financial investment, management and auditing; community outreach through the lifespan; global relations with sensitivity to different countries' needs; basic and translational research or clinical care with a particular expertise in adult care (e.g., nephrology, pulmonology and reproductive health); fundraising strategy; and ability to raise substantial unrestricted donations or for targeted initiatives including research or community.</li> <li>• Grow and maintain diversity with respect to race/ethnicity, disability, age, gender, relationship to TSC, education, sexual orientation and/or geography.</li> </ul>		<p>and clinical care (LAM, adult neurology and neurosurgery):</p> <ul style="list-style-type: none"> <li>• 4 women and 5 men</li> <li>• 2 from diverse backgrounds</li> <li>• 1 adult living with TSC and 1 parent of young adult with TSC</li> <li>• 3 clinician/researchers – 2 focusing on adult care</li> <li>• 2 from DC; 2 from Texas; 2 from Northeast; 1 from California; 1 from NC; 1 from Canada</li> </ul> <p>For the Endowment Fund, we added two members, both with finance and investment experience. 1 from New York and 1 from Minnesota and both male.</p>	
<p>Leverage staff core competencies and skill sets to align with mission and key objectives:</p> <ul style="list-style-type: none"> <li>• Implement Career Roadmap with training and professional development plans created for each employee.</li> <li>• Create transition plan for senior staff retirements.</li> <li>• Maintain 80% retention outside of retirement.</li> <li>• Build and maintain diversity with respect to language, race/ethnicity, gender, disability, sexual orientation.</li> </ul>	None	<p>In 2024, we implemented professional development plans for all 24 staff members while achieving 92% retention overall.</p> <ul style="list-style-type: none"> <li>• 18 female and 6 male</li> <li>• 4 non-white</li> <li>• 3 of 5 executive team members are female</li> <li>• 3 LGBTQ</li> </ul>	<p>We believe in a culture that grows talent internally and builds competencies that align with the key goals of the organization. Relationships are at the core of our ability to meet the strategic plan, therefore, retention is critical as is planning for any future transitions or retirements.</p>