FY 2025 Strategic Plan Progress Report

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	Results as of Dec. 31, 2025	Results as of Dec. 31, 2024
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).	All whole genome sequencing data are on AWS, and we began migrating preclinical data onto AWS to share with researchers. Also generated internal dashboards for tracking previously tested compounds, which can be used for conversations with potential collaborators.	Identified potential partners for hosting a centralized data library. Currently, genome sequences are hosted on AWS, preclinical data on SharePoint.
Increase the number of participants from underrepresented groups (Black or African	In 2025, the NHD BSR enrolled 8 Black/African American and 4 Asian participants. Additional White and Hispanic participants were also enrolled.	In 2024, the NHD BSR enrolled 7 Black/African American and 6 Asian participants, but also enrolled additional White and Hispanic participants, so

American, Asian) by adding 5-10 in each group annually.	Representation for underrepresented groups is currently 5.8% Black or African American and 2.8% Asian.	representation is now 5.7% Black or African American and 2.8% Asian.
Collect quantitative data related to TAND and to reproductive and perinatal health outcomes from at least 300 TSC-affected individuals.	The “Generalized Anxiety Disorder 7-item" (GAD-7) measure survey was added to the NHD Self-Report Portal, and 9 surveys were collected. We continue to build quantitative data captured in the NHD through clinical data within 22 participating clinics.	Added six TAND and 20 reproductive and perinatal health outcome variables to the NHD.
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.	Collected a total of 415 serial blood samples from individuals with TSC in 2025. We are working on external collaborations with researchers to access blood samples from non-TSC individuals.	Collected 271 serial blood samples from individuals with TSC in 2024. Developed project plans to access blood samples from non-TSC individuals.
Establish a blood-based data set (e.g., DNA, RNA, protein) from 200 pediatric and 200 adult individuals with TAND and appropriate controls necessary for research efforts to establish a blood-based biomarker panel for manifestations of TAND.	Completed RNA-seq, whole genome sequencing and protein analysis on 78 patient and 6 sibling control blood samples. Continued extended community outreach regarding participation in sample donation through social media and regional conferences.	Collected protein and whole genome sequencing on 78 TSC patients and 6 sibling control blood samples.
Actively participate in two 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.	Continued tracking Early Check and GUARDIAN progress. No TSC babies have been reported yet.	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.
Establish consensus on a Core Outcome Set of assessment tools to standardize measures of TAND manifestations in clinical research and care by 2028.	Multi-year project was officially launched. Throughout 2025, several initiatives took place to advance the project. Completed review of the literature, surveyed and conducted focus groups with clinicians and TSC	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

	community towards understanding the most burdensome outcomes in TAND (e.g., anxiety, aggression, etc.). Next step is to establish consensus on outcomes and assessment tools.	(TAND): Harmonizing current practice and further development of the TSC-PROM.”
Maintain at least seven industry partners per year participating in the Preclinical or Clinical Consortia.	Maintained 12 industry partners.	Maintained 10 industry partners.
Support the testing of at least 20 compounds or other therapeutic technologies in the Preclinical Consortium for industry or academia.	In 2025, achieved the goal of testing at least 20 compounds. The consortium evaluated 17 compounds (14 funded by industry, 2 funded by the TSC Alliance, 1 co-funded with an industry partner). Extended testing capacity by initial characterizing the Tsc2-Syn1 model for TAND-like features and epilepsy.	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.
Extend participation in Clinical Research Network to all TSC clinics in the U.S., attracting at least two industry or government funded clinical trials to utilize the Clinical Research Network.	Launched the TSC Clinical Research Network (CRN) in 2025 with TSC Alliance serving as the central hub for patient-focused clinical research across all US and Canada recognized clinics. Cultivated 2 industry partners from the Preclinical Consortium to engage the CRN in clinical trial design and feasibility, each targeting a Phase 2 trial in 2026.	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.
Increase TSCRP funding from $8 million to $10 million annually.	Due to a continuing resolution, the TSCRP was not funded in FY25 but tuberous sclerosis complex was named as a qualifying condition in the Peer Reviewed	Our House Dear Colleague Letter ask for FY25 was for $10 million but the TSCRP is currently in the budget for the existing level of $8 million.

	Medical Research Program. The TSCRP was reinstated with a $2 million increase for FY26 at $10 million.	
Obtain state funding for five TSC centers (currently three states funding four clinics).	State funding was maintained for 4 clinics in 3 states. $275k in Alabama, $500k in Maryland and $500k in Missouri for FY26.	State funding was maintained for 4 clinics in 3 states. $275k in Alabama, $500k in Maryland, and $500k in Missouri for FY25.
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.	Three merit-based research grants were awarded in 2025. 12.8% were from underrepresented populations.	Three merit-based research grants were awarded in 2024. However, the diversity of applicants remained at 11%, where it has been for four years.
Annually capture and report outcomes from funded grants (e.g., follow-on funding, promotion, publications, patents, etc.).	All grants we award now come with a DOI tracking number, with inclusion in the contract to reference the grant award in publications to improve outcome tracking.	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.

2. Improve Access and Quality of Care

Measures	Results as of Dec. 31, 2025	Results as of Dec. 31, 2024
Develop framework for the PAB for review and approval by the Board of Directors in 2024. **• Hold two meetings per year, beginning in 2025, to identify issues impacting access to care and treatments and potential solutions.**	Added 8 additional members to the PAB. Did not hold an annual meeting but PAB members are involved in several steering committees and attended the annual Clinic Director's Meeting, ensuring their input on ongoing projects.	The PAB charter was approved and 10 members were appointed by the Chair upon recommendation by the Science and Medical Committee.

Annually update website to indicate which clinics offer telehealth across state line.	Continuing to collect telehealth information on clinic application form. With large number of clinic applications due in 2026, we will have a more wholistic view of out of state telehealth capabilities for the website.	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 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.
Develop a transition plan template based on input from Clinic Committee by 2025 and require its use by 100% of recognized clinics by 2028.	Collaborating with the Kennedy Krieger team to create transition plan templates, hoping to be completed by April 2027.	On track. Timeline sketched out.
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.	82% of our recognized clinics and COEs report to having on-site dedicated TAND services.	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.
Collaborate on initiatives to build evidence to address gaps on 2 understudied aspects of TSC. **• 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).**	In 2025 the Reproductive and Perinatal Health Initiative taskforce initiated a systematic review of the literature and collection of real-world data through the natural history database and the development of a series of short surveys to the TSC community	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 providers by March 2024.

		Responses were analyzed and presented on a poster at the 2024 AES Annual Meeting.

3. Support and Empower Constituents

Measures	Results as of Dec. 31, 2025	Results as of Dec. 31, 2024
Fully implement 14 regions by 2024, with key leadership roles represented in each region by December of 2028.	Engage 14 regions with 149 active leaders. Of the 10 leadership roles across all regions, key roles are identified as follows and filled as indicated: Region Lead (86%), Government Action Lead (100%), Adult Support Lead (36%), Clinic Ambassador/Medical Access Lead (50%), and Education Peer Mentor (43%), reflecting ongoing progress toward full leadership coverage by 2028.	Established 14 regions with 138 active leaders
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.	The Community Hub is fully operational, supporting communication, training, and resource sharing among our volunteer leadership team. Full-year engagement reached 89.37%, reflecting strong adoption and demonstrating that the platform is effectively meeting the needs of our volunteers.	Community Leadership Hub officially went live January 21, 2025.
Develop a benchmark for peer-to-peer support in 2024 and increase documented meetings and interactions by 10% annually in 2025-2028.	Peer-to-peer support interactions reached 6,613 in 2025, surpassing the goal of 4,279 and exceeding the 10% annual growth target with approximately 70% growth over 2024, demonstrating strong engagement and expanded support across the TSC community.	Benchmark has been established. The benchmark was established at 3,890 in 2024.

Recruit and train at least one government advocate in each state by 2028.	Government Action Leads have been identified in 40 states as of December 31, 2025.	Government Action Leads have been identified in 38 states as of December 31, 2024.
Grow Clinic Ambassador/Medical Liaison program from 20% to 45% of TSC Clinics by 2028.	26 Clinic Ambassador/Medical Liaison leads in place as of December 31, 2025 (no change from 2024).	Maintained 26 clinic ambassadors/medical leads as of December 31, 2024.
Support and educate 90 TSC families through the IEP and transition processes annually.	As of December 31, 2025, 102 TSC families were supported through the IEP and transition process, exceeding the annual goal by 13%.	88 families were supported through the IEP and transition process as of December 31, 2024.
Increase the number of engagements through the TSC Support Navigators by 10% annually from a baseline of 50 in 2023.	317 families and individuals supported by TSC Support Navigators as of December 31, 2025, exceeding the 2023 baseline of 50 and the annual 10% growth target.	290 families and individuals were supported as of December 31, 2024, with 23 one on one Support Navigator calls scheduled.
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).	Working relationships with 18 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.	Working relationships with 18 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.
Grow global clinics from 13 to 25 by 2028.	Currently we recognize 16 Global Alliance TSC Clinics: 7 in Canada, 3 in India, 4 in Israel, and 2 in Mexico	Currently we recognize 14 Global Alliance TSC Clinics: 5 TSC Clinics in Canada, 3 in India, 4 in Israel, and 2 in Mexico.
Work with TSCi to increase the number of countries participating in TSC clinical trials by 25% by 2028.	TSC International (TSCi) met in June 2025 brought together key stakeholders in the TSC space, including TSCi member organizations, clinicians, researchers, and industry partners to discuss global clinical trials in	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

	TSC. 35 representatives from 18 countries attended the meeting. Five industry partners sponsored and participated in the meeting	included 32 people from 18 countries; it was sponsored by 6 industry partners.
Foster partnerships in 10 low- or middle-income countries with no association representation by 2028.	We are continuing to explore partnership opportunities in Latin America, specifically looking at Argentina, Egypt, Kenya, Philippines, and Vietnam.	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.

4. Educate and Mobilize to Increase Investment

Measures	Results as of Dec. 31, 2025	Results as of Dec. 31, 2024
Raise $23,250,000 for research over the next five years to complete the $40 million capital campaign.	Raised $3,361,574 in 2025 or the Research Campaign for a total of $5,955,183 since 2024.	Raised $2,593,609 in 2024 for the Research Campaign.
Grow the Endowment Fund to $7 million by 2028 and realize the maximum allowable annual contribution.	Endowment balance at the end of 2025 was $7,938,982 of which $332,785 is rainy day funds held at the Endowment Fund.	Endowment balance at the end of 2024 was $6,844,816, of which $573,625 is rainy day funds held at the Endowment Fund.
Increase annual net revenue from community-driven and corporate-sponsored events to 15% of total revenue.	Community-driven and corporate-sponsored events generated $1,192,170, representing 13.5% of total revenue.	Revenue net $2,409,922 or 27% of $9,081,267 total revenue.
Generate unrestricted revenue equal to 5% of total revenue from Preclinical and Clinical Research Consortia memberships and indirect costs of industry-sponsored studies.	Total Preclinical/Clinical Revenue from industry contracts and membership was $2,317,892 (26% of total revenue). Of this, we achieved $505,391 of unrestricted revenue, which accounts for 5.72% of total revenue.	Achieved $388,654 of unrestricted revenue from industry membership fees in the Preclinical Consortium. This accounted for 4.27% of the total revenue.

Annually obtain a minimum of 900 million news release impressions and at least 55,000 social engagements and increase use of digital platforms (podcasts, video views and eNewsletters) by 10% each year.	In 2025, 5 news releases garnered 802 million impressions. There were 84,829 social media engagements in 2025. Video views increased 10% across all channels, podcast listens increased 41.6% and email audience decreased 10%, in part due to a shift in platforms from Mailchimp to Hubspot.	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%.
Add 350 new families or individuals with TSC contacts to the TSC Alliance database annually.	293 new families or individuals with TSC contacts were added to the TSC Alliance database in 2025.	236 new families or individuals with TSC contacts were added to the TSC Alliance database in 2024.
Obtain 1,500 physician web page visits and 200 email signups each year.	2,270 impressions were generated from 40 video views on content on Vumedi, resulting in 5 new contact requests. In addition, 80 physician/researchers signed up to receive TSC Alert in 2025. The organization decided not to run a digital marketing campaign targeting physicians in 2025.	Paid digital ads targeting physicians resulted in 7,089 web page visits and 247 email signups in 2024.
In 2024, create a web page visit baseline, then identify pages to target each year and increase targeted page visits 10% annually.	In 2025, traffic to top 10 pages increased 7% on average.	A website tracking sheet evaluating page visits for the top 10 pages was created in December 2024, identifying pages most visited for tracking in 2025.

5. Build and Strengthen Organization

Measures	Results as of Dec. 31, 2025	Results as of Dec. 31, 2024
Maintain a highest rating among watchdog organizations and meet or exceed an 78/22 program/supporting expenses ratio.	TSC Alliance received a 4-star rating on Charity Navigator, Platinum Charity on Candid, Better Business Bureau Wise-Giving accreditation, 2025 Top-Rated Nonprofit by Great Nonprofits.	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.

	79.6% expenses going toward programs and 20.4% expenses for support services for fundraising, management and administration.	Program ratios are: 78.08% expenses going toward programs and 21.92% for support services for fundraising, management and administration.
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.	Approximately 1.8% of all mail sent was returned.	Approximately 1.3% of all mail sent out was returned.
Recruit three to six new Board members annually to achieve a board with: **• 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.** **• Grow and maintain diversity with respect to race/ethnicity, disability, age, gender, relationship to TSC, education, sexual orientation and/or geography.**	Added 4 new operating Board members with expertise in research, clinical care (nephrology), finance, outreach and adult services: • 1 woman and 3 men • 1 adult living with TSC, 1 parent/grandparent, • 1 clinician focusing on kidneys and providing pediatric and adult care • 1 from AZ, 1 from Iowa, 1 from FL, 1 from Texas For the Endowment Fund, added 2 new members: • 2 male • 2 caregivers of children with TSC • 1 with legal and 1 with marketing experience • 1 from New Jersey and 1 from CA	Added nine new operating Board members with expertise in finance and audit, community outreach and adult services, global and government relations, translational research and clinical care (LAM, adult neurology and neurosurgery): • 4 women and 5 men • 2 from diverse backgrounds • 1 adult living with TSC and 1 parent of young adult with TSC • 3 clinician/researchers – 2 focusing on adult care • 2 from DC; 2 from Texas; 2 from Northeast;1 from California; 1 from NC; 1 from Canada 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.
Leverage staff core competencies and skill sets to align with mission and key objectives: **• Implement Career Roadmap with training and professional development plans created for each employee.** **• Create transition plan for senior staff retirements.**	In 2025, we offered professional coaching and training for 7 employees managing other staff. All current 23 staff members developed professional development plans which were reviewed on a quarterly basis.	In 2024, we implemented professional development plans for all 24 staff members while achieving 92% retention overall. • 18 female and 6 male • 4 non-white

• Maintain 80% retention outside of retirement. **• Build and maintain diversity with respect to language, race/ethnicity, gender, disability, sexual orientation.**	The CFO left the organization in early February, and after an in-house search her replacement started eight days later. We successfully implemented our backup plan to maintain operations during the transition. The Chief Outreach Officer retired, unexpectedly, in April, and as a result created a COR (Communications, Operations, Relationships) team and implemented a transition plan. In the last quarter of 2025, we developed a CSO transition-plan, which will take place over the next year, culminating in Steve Roberds' retirement in December 2026. 92% retention rate (not including one retirement) overall. • 17 female and 6 male • 4 non-white • 2 of 4 executive team members female • 2 LGBTQ	• 3 of 5 executive team members are female • 3 LGBTQ