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Organizational Goals FY 2023

Approved by the TSC Alliance Board of Directors October 21, 2022

Vision Statement

The TSC Alliance is working toward a future where every person and family affected by TSC has what they need to live their fullest lives.

FY23 Focus Statement

The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with TSC. We drive research, improve quality care and access and advocate for all affected by the disease. The TSC community is our strongest ally. The collaboration of individuals and families, along with the partnership of other organizations, fuels our work to ensure people navigating TSC have support—and hope—every step of the way.

- We use a comprehensive approach to improve quality of life for people with TSC—fueling promising research while making sure that, day-to-day, individuals are diagnosed early and receive the highest quality care available. We also use our voice in policy around equitable healthcare access and federal funding for TSC research.
- Our work wouldn't be possible without the commitment of our community. Advancing research requires dedicated investigators, individuals with TSC, government and industry. Improving quality of and access to care demands healthcare professionals and dedicated volunteers. Raising awareness takes the work of families, individuals and volunteers.
- We want to create an environment where all individuals feel included, our organization reflects and serves the broad diversity of our community and we bridge health inequities.

Hope no matter how complex

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Strategic Plan

1. Engage board, community and staff representatives to serve on year-long Strategic Planning Committee by January 2023.
2. Incorporate the voice of the community as we develop a new strategic plan including fielding a constituent survey in early 2023 and holding a workshop at the 2023 Volunteer Leadership Summit in March.
3. Utilize input from all key stakeholders to develop a SWOT analysis by May 30, 2023.
4. Involve key staff members as goals are discussed throughout the planning process to co-develop strategies and measurements incorporating their viewpoint and expertise for capacity to implement.
5. Complete and present first draft of strategic plan and theory of change at the October 2023 board meeting and final approval at the December 2023 board meeting.
6. Announce new strategic plan at the beginning of 2024, our 50th anniversary year.

Science and Medical

1. Clinical Care
 - a. Continue rolling out and adapting recommendations of TSC Clinic Task Force to improve quality of care at TSC Clinics. Begin setting the groundwork for a TSC Learning Healthcare System by standardizing the systematic collection and analysis of metrics across all TSC Centers of Excellence (COEs) and Clinics regarding implementation of key clinical consensus guidelines.
 - b. Include clinical quality improvement research as part of the 2023 International TSC Research Conference to engage Advanced Practice Practitioners and other providers in efforts to improve quality of and access to care.
 - c. Working with the Clinical Research Consortium and industry partners, support a label change for preventative use of vigabatrin if data from the PREVENT study support doing so.
 - d. Continue to add resources to the TSC Navigator in collaboration with Community outreach that will optimize knowledge and access to care.
 - e. Compile a needs assessment on perinatal and maternal fetal medicine access on management of clinical care to formulate consensus guidelines with the Women's Health task force.
2. Translational Research - reach two clinical trial starts by 2025
 - a. Coordinate with an industry sponsor, contract research organizations, and clinical sites to begin enrollment of a clinical trial in individuals with TSC.



- b. Evaluate at least 5 new candidate therapeutics in preclinical models including those under development (e.g., L7-Cre-Tsc1 for TAND, Syn1-Cre-Tsc2 for epilepsy, stochastic model for epilepsy, GFAP-Cre-Tsc1 for sleep) via the Preclinical Consortium.
 - c. Secure budgeted 2023 contract revenue for industry preclinical or clinical studies and industry memberships.
 - d. Provide partial funding of research coordinators at five sites and a young investigator award for TSC-related research within the Developmental Synaptopathies Consortium (DSC).
 - e. Support the recruitment of under-represented groups to ongoing clinical research for the Diversity Supplement of the DSC grant.
 - f. Support the completion, analysis and dissemination of results from TACERN, PREVeNT, TSC-STEPS and DSC studies.
3. TSC Natural History Database (NHD) and Biosample Repository (BSR)
- a. Anya's Accelerator (TAND)
 - i. To identify biomarkers and predictors of specific aspects of TAND, drive biochemical and/or genetic analysis of existing biosamples (e.g., from DSC, TACERN, or elsewhere) by convening a workshop to develop an experimental plan and initiating analyses of biosamples based on that plan.
 - ii. Convene a focus group to develop a path toward development of quantifiable patient-reported outcomes (PROs) for the most impactful aspects of TAND utilizing the combined expertise of individuals and families living with TSC and clinical researchers.
 - iii. Continue working with Global Relations and the TANDem Consortium to contribute to the validation of the TAND Self-Quantified (SQ) Checklist and share learnings to and from Anya's Accelerator.
 - b. Continue advertising the NHD and BSR to obtain at least 25 requests for data and/or biosamples and fund at least three seed grants to utilize biosamples and NHD data in 2023 to grow the number of publications and advance new drug/biomarker targets in TSC research.
 - c. Improve racial diversity within the NHD and BSR by engaging with the Black and Asian communities with a goal of increasing the percentages of participants who identify as Black and Asian by 5% over our current enrollment numbers for those groups. Both groups are underrepresented by ~50% in NHD.
 - d. Grow the Biosample Repository by reaching 2,500 total blood, cheek swab, and/or tissue samples collected associated with data in the NHD.



- e. Continue whole genome sequencing to the extent supported by funds raised specifically to continue growing this sequencing data resource.
- 4. Stimulating Innovative Research
 - a. Award at least \$450,000 in new research grants to postdoctoral fellowships or to independent investigators meeting NIH criteria for Early-Stage Investigators.
 - i. Grow the diversity of applicants from underrepresented groups to at least 15% of applicants in 2023 (11% in 2021 and 11% in 2022). Continue to capture demographic data of the applicant pool and work with the ED&I Task Force to improve outreach to encourage a larger pool of candidates to apply for TSC Alliance research grant programs.
 - ii. Include adults with TSC and parents of children with TSC as consumer reviewers in the final round of grant application reviews and ensure consumer reviewers reflect the diversity of our community.
 - b. Host a successful in-person International TSC Research Conference in 2023 with at least 250 participants. Ensure the invited speakers and travel award recipients reflect gender, racial, and ethnic diversity.
 - c. Identify opportunities for strategic alliances with related disease organizations, such as CURE, the Child Neurology Foundation, Global Genes, the LAM Foundation, etc., and through participation in the Health Research Alliance to enhance the TSC Alliance's ability to improve access to FDA-approved medications, improve quality of care, drive research, and otherwise further its mission.

Outreach

- 1. Work with the Office of the President to incorporate the voice of the community as we develop a new strategic plan including fielding a constituent survey in early 2023 and holding a workshop at the 2023 Volunteer Leadership Summit in March.
 - a. Determine the met and unmet needs of constituents, inclusive of demographic information and questions related to ED&I and barriers to access in underserved parts of the community, as well as assess the effectiveness of programs established by the TSC Alliance to ensure that the organization continues to live up to its mission.
 - b. Provide key relevant findings from the constituent survey to each of the TSC Alliance Committees and Sub-Committees that will help develop strategies moving forward.
- 2. Distribute the "TSC Clinic Patient & Family Experience Care Survey" to individuals/caregivers through TSC Alliance social media channels and e-blasts throughout 2023 with a year-end response rate from English-speaking respondents at



each TSC Clinic/TSC Center of Excellence receiving at least 10 completed surveys from clinics with fewer than 100 patients, or 10% if 100 or more.

- a. educate the TSC Clinics and TSC families about the importance of receiving their anonymous feedback – consider changing how we deliver the feedback to the TSC Clinics – to keep the information anonymous.
3. Strengthen the Community Alliance structure and motivate the next generation of volunteers/advocates for the TSC Alliance.
 - a. Implement a new training module/course (Community Leader Basics – inclusive of ED&I and unconscious bias, peer-to-peer support, and crisis mgmt. training) with 100% completion by YE 2023.
 - b. Provide 600 volunteer training hours to the TSC Alliance Leadership in 2023.
 - c. Ensure 100% of new sponsored TSC community leaders advocates participating in the 2023 March on the Hill complete Advocacy Training prior to attending the event in person.
4. Increase peer-to-peer support annually by 10% over 2022 by inspiring volunteers/advocates to collaborate and enhance services provided on behalf of the TSC Alliance adding 100 new volunteers to the TSC Connect Network, with at least 15% representing the underserved and/or underrepresented communities.
 - a. Provide Quarterly Collaboration and Support opportunities for each peer-to-peer volunteer group (TSC Clinic Ambassadors, EPMs, DATRC (or SRC), Young TSC Adults with monthly TSC Adult calls with the ARC)
 - b. Launch a TSC Alliance Clinic Ambassador Program to grow from 15 serving 14 TSC Clinics to 30 serving of 30 by December 31, 2023.
 - c. Enhance and expand resources available at the state level to address all resources including education, transition, and dependent adults through the DATRC (Dependent Adult Transition Resource Coordinator) program with the creation of the State Resource Coordinator (SRC) growing those serving to 50 in 2023.
 - d. Support families in need of educational advocacy by attending or consulting on 150 school meetings in 2023 – including 75 school meetings, 50 IEP consultations, and 25 TSC 101 training.
5. **Host four (4) Regional Conferences** (in each time zone)
Locations under consideration:
 1. East- Washington DC (EST) Sept 2023 to coincide with the TSC Research Conference
 2. Central / South – Birmingham, Chicago or Tennessee
 3. Mountain – Denver / Utah
 4. Pacific - PNW (Seattle)



Communications

1. To help build and strengthen organization's key communication tool, redesign the TSC Alliance website and update its content.
 - a. Ensure new site design is consistent with current tools and navigation options.
 - b. Work with all internal department, community working group members and focus group participants as needed to update all page content, publications, videos, documents and other resource materials are current, impactful and accessible to diverse groups within the TSC community.
2. To support and empower constituents, create and produce print and digital resources reflective of the diversity of those living with TSC, thereby promoting health equity and inclusion, to keep the TSC community, supporters, donors, Board members and other stakeholders informed, through the following:
 - a. Hire new Social Media/Content Coordinator (January) responsible for implementing best practices from social media audit
 - b. Two issues of *Perspective* magazine (Winter and Fall 2023 issues)
 - c. Six issues of *TSC Matters* eNewsletter (bimonthly)
 - d. 12 issues of *TSC Alert* eNewsletter (monthly)
 - e. 12 *TSC Now* podcasts (monthly)
 - f. 2022 Annual Report (to mail before June 30)
 - g. Webinar series and open forums (TBD with Outreach and Community Programs)
 - h. Testimonials and/or short videos to highlight human interest stories and research breakthroughs, making sure these include diverse experiences and perspectives.
 - i. 2023 Board Election (August 15)
 - j. Social media channels (ongoing)
 - k. TSC Academy
 - l. Other materials as needed
3. To help improve equitable access and quality of care, promote government advocacy on federal and state levels and implement awareness campaigns, including:
 - a. Seizure Action Plan Awareness Week (second week of February)
 - b. The TSC Alliance's annual March on Capitol Hill (early March)
 - c. May TSC Awareness Month (United States) and May 15 Global TSC Awareness Day
 - d. Infantile Spasms Awareness Week (December 1-7)
4. To educate, particularly underserved and underrepresented populations, and mobilize to increase investment and help accelerate research, support fundraising efforts by:
 - a. Continuing to review, edit and/or write materials as needed for Investment to Accelerate Research Campaign (ongoing).



- b. Promoting participation in and reviewing materials for all major events including Step Forward to Cure TSC (May 20-21), Comedy for a Cure (April 2), Team TSC (November) and others as needed.
- 5. To broadcast the TSC and TSC Alliance story to widespread audiences and to position TSC Alliance as a leader in the rare disease community:
 - a. Promote Seizure Action Plan Awareness Week (February), May TSC Awareness Month (United States), TSC Global Awareness Day (May 15) and Infantile Spasms Awareness Week (December 1-7), resulting in 500 million impressions.
 - b. Utilize support from PR firm to publicize research advancements, new treatment approvals, stories of those living with TSC to demonstrate equity and inclusion and other organizational accomplishments and promote TSC Alliance senior staff members as thought leaders.

Global Relations

- 1. Grow depth and value of relationships with global partners through the development of country-specific strategic plans, helping increase each countries' constituencies by 5% from baseline and increasing the number of globally recognized TSC Clinics to 13 in 2023
 - a. Support and grow the existing Global Alliances by helping develop regional and country-specific needs
 - i. Host a series of webinars with the Global Alliances like the ones in the US for improving awareness (TAND, TSC, IS, etc.) appropriate to the care and resources available in their regions
 - ii. Refine the International TSC Clinic recognition process
 - b. Identify and cultivate two new Global Alliance prospects and three TSC Clinic applications
 - i. Explore continental and regional hub models leveraging existing TSC Global Alliances and/or TSCi Member Associations— (starting with Latin American TSC Conference as a model in 2023 as a model)
 - c. Partner with international organizations for clinician outreach and education in low- and middle-income countries
- 2. Ensure proper agreements and financial reporting are in place for TSC Alliance Global Alliances, including clarification of new TSC Alliance branding/logos/name use, etc.
- 3. Secure future funding support for both the Global Alliance program and TSCi.
- 4. Serve as the coordinating center for TSC International (TSCi) activities, including website maintenance and the inclusion of an educational information portal, TSC Global



Awareness Day on May 15 and physician education with the International Clinical Consensus Guidelines.

- a. Host workshop around 2023 International TSC Research Conference
- b. Ensure Global representation in person or virtually from TSCi members and additional countries in TSCi activities and initiatives
- c. Work with TSCi member organizations to translate relevant highlights to the International TSC Clinical Consensus Guidelines made available on the TSCi website
- d. Support research and access to clinical care in TSC globally (ex. NHD/registries, care delivery, implementation of the guidelines, access to medicines, etc.)
- e. Work with TANDem Consortium to promote TAND toolkit and resources and to validate TAND SQ
- f. Leverage existing accomplishments with the UN, WHO, RDI, and similar organizations to advance TSC care and access worldwide
- g. Develop international registry of TSC experts, clinics, and resources

Government Relations

1. Cultivate, educate, and empower a premier constituent advocacy group to advance TSC initiatives at federal, state, and/or district levels.
 - a. Develop and implement a strategy for both in person (if safe) and virtual March on Capitol Hill participants.
 - b. Empower state coordinators to conduct additional follow up based on feedback forms from virtual or local March on Capitol Hill meetings.
 - c. Work with community programs to engage underrepresented communities in the March on Capitol Hill in person and virtually and state days of advocacy. Including conducting a baseline assessment by race and gender of our March on Capitol Hill advocates.
 - d. Engage community volunteers in local advocacy in conjunction with Congressional recesses and Community Alliance events.
 - e. Incorporate TSC Academy as part of the pre-March on Capitol Hill Training with 100% participation with new sponsored attendees.
2. Continue advocacy to maintain or increase Tuberous Sclerosis Complex Research Program (TSCRCP) funding in the Department of Defense (DoD) budget. Further



- dialogue with Appropriations and Armed Services Committees to: 1) prevent damaging language in Authorizing bills, and 2) continue funding in the Appropriations bills.
- a. Identify new House Republican co-sponsor and continue developing relationships with House and Senate Dear Colleague Letter champions while maintaining level of co-signers obtained in FY23 (House Letter led by Representatives Mullin (R-OK) and Raskin (D-MD) supported by 205 signers; Senate Letter led by Senators Cramer (R-ND) and Heinrich (D-NM) supported by 35 signers).
 - b. Develop strategy to defend or secure \$10 million for the TSCRCP.
 - c. In select districts, partner with The LAM Foundation to increase congressional outreach around federal funding in select districts.
 - d. Participate in the Defense Health Research Consortium to protect the DoD appropriations; engage researchers and universities in advocating in case of threats to funding.
3. Work with Congressional sponsor to submit report language incorporating TSC/TSC research in final HHS Bill.
 4. Build and strengthen relationships to advocate for increased financial support of TSC initiatives from Department of Health and Human Services, including NIH, HRSA, PCORi, CDC, FDA, and ARPA-H.
 5. Explore expanded TSC advocacy initiatives to include opportunities to impact quality of life and access to research funding at state/regional/local levels.
 - a. Remain vigilant about access to all health care (including expanded telehealth) and insurance programs, including Medicaid, and advocate for access to TSC treatments.
 - b. Remain vigilant about medication access issues, including Patient Assistance Programs (PAP), co-pays, and insurance coverage.
 - c. Maintain state funding in Maryland and Missouri and selectively seize opportunities in Alabama or other states should they arise.
 6. Secure funding to support constituent training in advocacy and empowerment including virtual advocacy.

Development

1. Implement the Research Campaign with recommended goal to raise \$40 million over seven years (2019-2026) to urgently and efficiently grow capital for TSC research from



private sources that serve to complement, not duplicate, public funding. The goal is to drive TSC research toward better treatments and a cure, to alter the course of the disease through prenatal diagnosis and preventative treatments and to educate medical professionals with evidence-based standards of care.

- a. Raise \$5,085,000 in new private funds in 2023 with a stretch goal to raise \$6 million.
 - b. Secure contract revenue of \$1,091,980 from industry partners.
 - c. Secure 100% participation by Board and Research Campaign Committee in support of the campaign.
 - d. Hold two donor receptions in 2023 to stimulate fundraising.
2. Increase grants and sponsorships to support community outreach and unrestricted major gifts.
 - a. Secure funding to support the 2023 International TSC Research Conference by raising \$165,500 in sponsorships to underwrite a majority of expenses.
 - b. Increase industry partnerships to support major events and community education at \$615,800 (\$195,800 for walks, \$115,000 for Comedy, \$85,000 Volunteer Leadership Summit and March on Capitol Hill, \$107,500 Regional Conferences, \$97,500 Website Redesign, \$15,000 Infantile Spasms Awareness).
 3. Sustain 100% Board giving.
 4. Engage the community through innovative events that create positive interactions between staff, Board, volunteers, corporate partners and TS Alliance constituents and, as a result, increase participation and revenue.
 - a. Raise \$850,000 in a virtual **Step Forward to Cure TSC** Walk-Run-Ride (May 20-21) with expense ratio of no more than 15%.
 - b. Raise \$245,000 through local **Other Community Campaigns** with a 15% expense ratio, which includes \$25,000 in **Team TSC** endurance events.
 5. Grow the national brand of the TSC Alliance through major events by involving supporters and influencers and raising substantial awareness of TSC.
 - a. Leverage established Comedian Committee to involve A-level talent at **Comedy for a Cure**, grow attendance and maintain revenue to \$350,000 with an expense ratio of no more than 45%.

Compensation

1. Approve the salary pool and salary of the CEO, CFO and any other employee who will appear in the 990 tax return as follows:
 - a. 1st Quarter, prior to commencement of final field work of prior year audit:
 - i. Approve payout of the prior fiscal year's incentive-based compensation.



- ii. Approve any non-budgeted spot bonus payouts if applicable for employees not on the incentive compensation plan.
 - iii. Approve any changes to the current fiscal year's approved budgeted salary pool if applicable.
 - b. 3rd/4th Quarters:
 - i. Approve the overall proposed budgeted salary pool for the next fiscal year.
 - ii. Approve the specific salary/incentive comp ratios proposed for any employee who will appear on the 990 tax return for the next fiscal year.
2. Review and update all job descriptions as necessary and engage external consultant to perform salary/benefits analysis and benchmarking.
3. Evaluation and exploration of external HR company or hiring internal HR person to assist in classification, selection and labor relations in 2024.
4. Implement transition plan for retiring employees in 2023.
5. Ensure HR policies and practices are equitable, inclusive and focused on increasing recruitment of applicants from underrepresented, marginalized groups.
6. Conduct annual review of back-up planning procedures per each department and ensure cross training is conducted for each position.
7. Compensation Committee to review updated staffing plan that aligns with new 5-year strategic plan.
 - a. Review management structure, leadership training, succession planning

Governance (Nominating) Goals

1. Grow the number of members receiving electronic communication including voting electronically.
2. Identify, recruit and recommend up to six new Board members with emphasis on the following skill sets:
 - a. Financial means with the willingness to raise substantial funds to support research and community initiatives.
 - b. Experience with audit, finance, and individuals outside of the TSC community with corporate partner/industry experience.
 - c. Work with Outreach Committee to identify candidates in an effort to expand our Board membership, including underrepresented members of the community.
 - d. Ensure a minimum of 4 medical professionals or researchers on the board at all times.
 - e. Geographic representation of Board members and ensure the Adult constituency is represented.



3. Ensure compliance with bylaws ratio of Board members related to or a person with TSC at 50% annually.
4. Add potential Board candidates to standing Board Committees to cultivate future leadership and mentor nominees.
5. Implement (vibrant and evolving) officer succession planning.
6. Assist/work with TSC Alliance Endowment Fund to identify, cultivate and recruit candidates for its Board who have financial management experience.

Finance

1. Ensure accurate and timely preparation of monthly financial statements and maintaining sufficient cash reserves to facilitate operations.
 - a. For single-year donations over \$2,500,000 for the Research Fund, investment and fund usage should be tracked separately.
 - b. Monitor timing of pledges and cash payments for the Research Business Plan to ensure financial stability of the organization and provide detailed reporting on the campaign to donors.
 - c. Monthly financial statements should be sent to the Finance Committee by the end of the following month.
2. Use comprehensive reporting to periodically report on adherence to budget, organizational progress toward attaining the monetary Measures of the Objectives, Goals and Strategies in the Strategic Plan and gauge the success of the plan to accelerate the organization's investment in research.
3. Assist in strategies regarding investment of Operating Funds to optimize returns and minimize risk while adhering to the approved investment policy.
4. Utilize Charity Navigator and other charity rating services as a guide for the budget process and Form 990/financial statement presentation.
5. Review initial draft of the FY24 Annual Budget by no later than October board meeting and approve the final budget to be presented to the Board at its December meeting.
6. Support and advise staff in efforts to mitigate the financial and operational exposure to the organization created by potential future economic disruptions.

Audit

1. Select and engage an audit firm staying within the GAAP regulations regarding independence.
2. Assist management in designing and implementing of programs and controls to prevent and detect internal and external fraud.



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3. Review footnotes of the financial statements for 2023 particularly regarding estimates used by management.
4. Review the Form 990 for the most beneficial presentation for third-party ratings of the organization, staying within IRS regulations.
5. Inform and help support the organization's efforts to implement FASB changes accounting standards.
6. Review the calendar with CFO and auditors to adhere to milestone dates for timely filing of the audit and Form 990.
7. Keep general membership and Board informed of accounting updates during the year.
8. Assist management in the mitigation of cyber risk through the implementation of any remaining NIST recommendations to strengthen internal controls based on prioritization by Audit Committee.
9. Identify a prospective Audit Committee Chair for term beginning after 2025.

Endowment Fund

1. Market planned giving vehicles, including gift annuities, plus additional giving ideas such as qualified charitable distributions, and donations of appreciated property, with a goal of placement of stories in *Perspective* on planned giving, highlight one story in e-newsletter and program ads for major TS Alliance events.
2. Continue to implement plans to convert prospects identified in the Research Campaign Study into Endowment Fund contributions or planned gifts by conducting at least 10 meetings with prospective donors with a goal of adding \$250,000 in 2023.
3. Calculate the annual contribution to the TSC Alliance according to the investment spending policy and approve a budget by October 2023 for 2024. Maintain record of cumulative budgeted contributions not paid to the TS Alliance and held for future programmatic use.
4. Hold quarterly meetings to review investments and make adjustments to reflect market changes.
5. Continue having an Endowment liaison serve on the operating Nominating Committee to cultivate and vet potential Endowment Fund Board candidates keeping in mind those that reflect the diversity of our community and adding at least 2 new members in 2023 for terms beginning in 2024.
6. Stay informed of tax laws that impact planned or charitable giving for the Endowment Fund.