

Objective	To find a cure for TSC while improving the lives of those affected. <i>Approved by the TSC Alliance Board of Directors: December 12, 2018; Revisions Approved: March 5, 2020</i>		
Goals	Accelerate Research	Improve Access and Quality of Care	Support and Empower Constituents
Strategies	<ul style="list-style-type: none"> •Collaborate and extend partnerships with other nonprofits, academic institutes and industry to advance TSC research •Advocate for Federal research funding •Increase Preclinical Consortium productivity by engaging researchers, improving models, adapting to priorities of members •Expand capabilities of centers in the Clinical Research Consortium and fund pilot or add-on studies with pathways to outcomes. •Increase rate of biosample collection by enrolling individuals anywhere in US •Invest research grant funding in postdoctoral trainees and highly novel research ideas •Convene targeted workshops on urgent research problems and follow-up with funds 	<ul style="list-style-type: none"> •Advocate for state funding for research and/or Centers of Excellence •Develop a support hub to navigate access to FDA approved therapies •Build evidence for what constitutes high quality care for TSC •Expand knowledge of evidence-based, best practices of TSC clinical care among TSC Clinic healthcare professionals and other medical providers involved in the treatment of TSC •Expand access to care for people in regions with no TSC Clinic or TSC-knowledgeable healthcare professionals. •Improve access and delivery of evidence-based, high quality clinical care for patients with TSC, including comprehensive adult care for inpatient and outpatient services 	<ul style="list-style-type: none"> •Create a premier support services volunteer corps through Clinic Ambassadors, Junior Leaders, Dependent Adult Transition Resource Coordinators, Adult Regional Coordinators, Spanish Support Network, Education Parent Mentors and Community Alliance leadership •Expand skills of parents/caregivers and young adults to advocate for and access appropriate educational services to improve quality of life •Grow collaborations with other nonprofit organizations internationally, nationally and locally to ensure access to resources, support services, transition tools and information •Expand reach of education and support through use of technology •Increase scientific knowledge in the TSC community •Grow and advance the Global Alliance Program
Measures	<ul style="list-style-type: none"> •Invest \$20.4 million in research over the next five years to drive projects, workshops, and collaborations •Maintain a minimum of \$6 million annually for TSCRCP •Reach 75 mechanisms or combinations tested in Preclinical Consortium with working relationship with 12 industry partners •Clinical Research Consortium receives \$30 million federal or industry funding for trials •Reach 2500 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 •\$450K paid annually on research grants, 2/3 for postdocs. •Annual innovation workshop held with follow-up research funded by innovation fund 	<ul style="list-style-type: none"> •Grow state initiatives to four states •Increase partnerships with specialty pharmacies, payers, industry, private foundations to support at least 200 individuals/families annually by 2023 •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 Directors for approval and implementation by 2020 •Conduct 7 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 designs •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 136 from TSC Clinics and 80 outside TSC Clinics •Develop a telehealth network “TSCNet” to expand access to TSC quality care by 2023 	<ul style="list-style-type: none"> •Grow peer to peer support from 20,246 (2017) to 35,867 (10% annually) <ul style="list-style-type: none"> ▪ Recruit 225 new volunteers into Support Services programs by 2023 ▪ Provide 1,200 hours of volunteer training per year •Increase the Education Parent Mentor program to support school meetings from 74 to 475 by 2023 •Build and maintain working partnerships with 15 national organizations/collaboratives (ARC, CNF, CTF, EF/REN, LAM Foundation, ATS-PAR, ELC, Global Genes, ISAN, NORD, RDCRN, TSCi) •Establish relationships between all Community Alliances and local Arc Chapters where existing by 2023 utilizing Associate Partnership with The Arc US •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 •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

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Goals	Educate and Mobilize to Increase Investment	Build and Strengthen Organization
Strategies	<ul style="list-style-type: none"> •Dramatically increase capital for growth of research platform through partnerships with corporations, foundations, state organizations and individuals •Emphasize the role and opportunities associated with Endowment via estate planning and gift annuities •Leverage the unique capacity of each Community Alliance to create community-specific campaigns by rebranding and strengthening Step Forward to Cure TSC and offering menu of other event options •Grow individual participation in crowd-funded initiatives •Broadcast the TSC and TSC Alliance story to widespread audiences via effective and efficient communications •Engage an outside PR/marketing firm to implement a new awareness campaign, bolster branding and educate the public at large about TSC 	<ul style="list-style-type: none"> •Adhere to financial management best practices for efficient and effective operations consistent with Charity Navigator (CN) Guidelines while maintaining appropriate infrastructure for organization growth •Maintain database of current, reliable information of individuals with TSC their families and TSC Alliance supporters complying with GDPR •Serve as a leader in the rare disease community, sharing scientific and medical link of TSC to other diseases among peer diseases and disorders organizations, medical and related professionals, foundations, potential donors and constituents •Develop board of directors with skill set needed to realize the strategic plan •Invest in staff expansion/skill development to drive results
Measures	<ul style="list-style-type: none"> •Raise \$29.26 for research over the next five years •Grow the Endowment Fund to \$10 million by 2023 and realize the maximum allowable annual contribution. •Mobilize grassroots community through budgeted special events to raise \$1.5 million average net annually over next 5 years •Increase the number of people donating online to crowd-funded events from 1,257 (2017) to 2,514 (2023) •Secure at least 200 million impressions annually via multiple and varied outlets with minimum investment •Achieve additional 30 million impressions through new awareness campaign and 3,500 contacts to the database per year of the campaign 	<ul style="list-style-type: none"> •Maintain a 4-star CN rating and meet or exceed an 80/20 program/supporting expenses ratios by 2022 in accordance with the five-year Research Business Plan •Implement in depth review to ensure integrity of constituent data with less than 1% duplicates by 2020 and maintain thereafter •Participate/present at 25 professional/industry conferences per year •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 •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 infrastructure to support growth while maintaining 80% retention outside of retirements •Create transition plan for senior staff retirements