



FY 2019 STRATEGIC PLAN PROGRESS REPORT

OBJECTIVE

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

GOALS

1. Accelerate Research

Measures	Dec. 31, 2019
Invest \$56 million in research over the next five years to drive projects, workshops, and collaborations	Goal changed to \$40 million over seven years following a campaign study and on recommendation of our capital campaign consultants. TS Alliance spent \$2,590,463 into research in 2019.
Maintain a minimum of \$6 million annually for TSCRCP	\$6 million was appropriated for the TSCRCP for FY19 and FY20.
Reach 75 mechanisms or combinations tested in Preclinical Consortium with working relationship with 12 industry partners	<ul style="list-style-type: none">• 35 mechanisms or combinations have been tested.• 5 companies remain active members at the end of 2019.• 2 companies moving into clinical trials from resources utilized from Preclinical Consortium and Biosample Repository.
Clinical Research Consortium receives \$30 million federal or industry funding for trials	\$7.5 million awarded to the Clinical Research Consortium for a 5-year renewal of the RDCRN grant from NIH.
Reach 2500 biosamples with serial blood samples on 250 individuals and 150 tissues, with each genetically tested & 12 use requests annually with clinical data captured in the Natural History Database	<ul style="list-style-type: none">• 967 biosamples• Serial blood samples on 36 individuals• 10 tissues• 12 NHD data requests, including 5 for biosamples + NHD data
\$450K paid annually on research grants, 2/3 for postdocs	<ul style="list-style-type: none">• \$314,914 paid on research grants, 2/3 of new grants awarded to postdocs

	<ul style="list-style-type: none"> • \$40,000 paid on biosample use seed grants • \$50,000 paid on Clinical Research Consortium grant • \$404,914 total
Annual innovation workshop held with follow-up research funded by innovation fund	Biennial International TSC Research Conference held in 2019. Plan developed for first innovation workshop to be on newborn screening in June 2020.

2. Improve Access and Quality of Care

Measures	Dec. 31, 2019
Grow state initiatives to four states	Active state advocacy initiatives in 2 state with secured appropriations of \$250,000 in Missouri and \$500,000 in Maryland.
Increase partnerships with specialty pharmacies, payers, industry, private foundation to support at least 200 individuals/families annually by 2023	<ul style="list-style-type: none"> • 20 individuals/families received assistance in accessing FDA approved medications. Added partnership with a major specialty pharmacy. • Ongoing relationships with 12 industry partners and four specialty pharmacy partners
Form task group of key stakeholders (medical professionals, patients/families) to critically evaluate current TSC Clinic designation standards and recommend new organizational structure and requirements to the TS Alliance Board of Directors for approval and implementation by 2020	TSC Focus Group established draft guidelines for the “standards of care” part of new clinic guidelines and will present full recommendations to the Board in 2020.
Conduct 7 studies between 2019-2023 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	TSC Focus Group standards of care will include measurements of outcomes, but this will begin in 2021.
Develop bi-annual curriculum (e.g. CME/CNE or TSC workshops at professional association meetings) that exposes TSC Clinic Directors and other health care providers to current evidencebased practices for TSC diagnosis, surveillance, and management	200 child neurologists participated in the Harmful and Disruptive Behaviors CME Symposium at CNS, developed by the Child Neurology Foundation with the TS Alliance as lead advocacy partner and assisting in curriculum development.

<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	Not in 2019 goals.
Increase TSC clinics providing services to children and adults, inpatient and outpatient services, to 65% by 2023	54.2% (39 of 72) TSC designated clinics see individuals of all ages.

3. Support and Empower Constituents

Measures	Dec. 31, 2019
<p>Grow peer to peer support from 20,246 (2017) to 35,867 (10% annually)</p> <ul style="list-style-type: none"> Recruit 225 new volunteers into Support Services programs by 2023 Provide 600 hours of volunteer training per year 	<p>32,932 peer to peer support contacts in 2019.</p> <ul style="list-style-type: none"> 60 new volunteers added to Support Services program and 117 new volunteers overall 1,429 volunteer hours of training provided
Increase the Education Parent Mentor program to support school meetings from 74 to 475 by 2023	128 school meeting supports provided.
Build and maintain working partnerships with 15 national organizations/collaboratives (ARC, Bcureful, CNF, CTF, EF/REN, LAM Foundation, ATS-PAR, ELC, Global Genes, ISAN, NORD, RDCRN, TSCi)	<p>Built and maintained working partnership with 14 national organizations/collaborations</p> <ul style="list-style-type: none"> TS Alliance CEO serves as Chair of the ATS-PAR. The Improving Partnerships and Lives Grant was developed in 2019 to encourage working relationships with new 501c3 orgnaizations. Continued emphasis on ISAN and collaborating with multiple organizations to focus on the challenges of infantile spasms, including pulic awareness and access to care. Participated in the Transition of Care Summit along with rare eplilpesy partners to identify needs across the spectrum in partnership with CNF and Greenwich Biosciences. Hosted TSCi meeting at International TSC Research Conference in Toronto. Co-hosted 6 Regional TSC and LAM Conferences in collaboration with the LAM Foundation. CEO and CSO served as guest presenter at Global Genes Data DIY. Established the Bcurefull Travel Fund at the TS Alliance.

Establish relationships between all Community Alliances and local Arc Chapters where existing by 2023 utilizing Associate Partnership with The Arc US	67 referrals from our Community Alliances to local Arc Chapters to build new working relationships.
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	<ul style="list-style-type: none"> 31% (430 of the 1,405 attendees) of Community Alliance attendance at meetings was done virtually. <i>TSC Now</i> podcast series launched in May; 8 monthly episodes were produced in 2019 with 1,426 total downloads/listens.
Implement TSC Academy by 2020 with 100% of sponsored March on Capitol Hill advocates completing required units for certificate by 2021 (avg score of 80% on post-test for required advocacy units/70% for required science units). Increase # of units accessed by 100% per year between 2020-2023	TSC Academy launched on January 31, 2020 for the 2020 March on Capitol Hill.
Expand to 10 Global Alliances by 2023, growing each countries' constituencies by 15%, increase global TSC Clinics to 18, and develop country-specific strategic plans	<ul style="list-style-type: none"> Maintained 6 global partnerships, including renewals of TS Alliance of Israel and TS Canada ST. Recognized 1 new global TSC Clinic, bringing the total number of internationally recognized clinics to 9 (3 in Israel, 3 in Canada, 2 in Mexico, and 1 in India).

4. Educate and Mobilize to increase investment

Measures	Dec. 31, 2019
Raise \$56 million for research over the next five years	Goal changed to \$40 million over seven years following a campaign study and on recommendation of our capital campaign consultants. TS Alliance raised \$2,650,212 in 2019.
Grow the Endowment Fund to \$10 million by 2023 and realize the maximum allowable annual contribution	Total net assets for the TS Alliance Endowment Fund are \$5,915,804 as of 12/31/19.
Mobilize grassroots community through budgeted special events to raise \$1.5 million average net annually over next 5 years	\$2,421,439 net was raised through special events in 2019.

Increase the number of people donating online to crowdfunded events from 1,257 (2017) to 2,514 (2023)	1,182 individuals donated online to crowdfunded events through Luminate and 4,016 donated through Facebook
Secure 95 million impressions annually via multiple and varied outlets with minimum investment	Four news releases in 2019 garnered 313 million impressions.
Achieve additional 30 million impressions through new awareness campaign and 3,500 contacts to the database per year of the campaign	Marketing firm was contracted to conduct research on current messaging, branding and awareness with recommendations to be presented in 2020.

5. Build and Strengthen Organization

Measures	Dec. 31, 2019
Maintain a 4 star CN rating and meet or exceed an 85/15 program/supporting expenses ratios by 2021 in accordance with the five year Research Business Plan	TS Alliance received a 4-star Charity Navigator rating, Better Business Bureau Wise Giving accreditation, and Platinum Guidestar status in 2019. Expense ratios were 72.9% program/27.1% admin and fundraising for FY19.
Implement in depth review to ensure integrity of constituent data with less than 1% duplicates by 2020 and maintain thereafter	Constituent database was reviewed and 1.2% dupes remain.
Participate/present at 25 professional/industry conferences per year	TS Alliance staff attended or participated in 40 professional/industry conferences.
Recruit 3-6 new Board members annually, reflecting the diversity of our constituency, with financial management, global relations, technology, scientific/medical expertise and ability to raise substantial unrestricted donations or for targeted initiatives including research or community initiatives	<p>Added 8 new board members (6 elected, 2 fulfilling other terms) with expertise in financial management, global relations, IT technology, HR, outreach to Spanish speaking community, event planning, legal, nonprofit leadership/fundraising.</p> <ul style="list-style-type: none"> • 5 are women and 3 are men • 2 from diverse backgrounds • Geographically: 1 from DC; 1 from CA; 1 from the West; 2 from Midwest; 2 Northeast; 1 from the Southeast • 7 of the 8 have relatives with TSC. 1 is a corporate partner
Grow Science and Medical team to 9.5 FTEs to accelerate research and improve quality of care by 2021 and corresponding staff (e.g., financial,	<ul style="list-style-type: none"> • Hired a new Associate Director, Research, taking the Science and Medical team to 5 FTEs. • Added Director of Digital Platforms to support communications.

fundraising, communications, support services) and infrastructure to support growth while maintaining 80% retention outside of retirements	
Create transition plan for senior staff retirements	Transition plan created for VP of Support Services for retirement in April 2022.