



FY 2018 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

Leading Indicators	Dec. 31, 2013	Dec. 31, 2014	Dec. 31, 2015	Dec. 31, 2016	Dec. 31, 2017	Dec. 31, 2018
Enroll 2,000 participants in the TSC Natural History Database by 2015	1,300 enrolled	1,504 enrolled	1,849 enrolled	2,070 enrolled	2,124 enrolled	2,179 enrolled
Plan/implement a TSC Biosample Repository by 2015; collect 1,000 blood samples and 200 tissue samples from TSC Natural History Database participants by 2018	Initial funding obtained	Contract signed with Van Andel Research Institute	First samples collected through RDCRN; two sites awaiting final contract negotiations	176 blood samples, no tissue samples collected	397 samples: 247 blood or buccal cell from NHD; 4 tissue from NHD; 146 blood from RDCRN and PREVeNT	756 samples: 514 blood or buccal cell from NHD, 10 tissue from NHD, 174 blood from RDCRN, 58 blood from PREVeNT.
Fund 6 grants annually for \$450,000	Awarded 5 new grants for \$457,681	Awarded 4 new grants for \$525,000	Funded 11 grants for \$512,898; awarded 5 new grants for \$780,081	Funded 15 research grants for \$912,607. Awarded 6 new grants for \$575,000	Funded 8 grants for \$567,099. Awarded 4 new grants for \$477,505.	Funded 13 grants for \$451,689 paid in 2018. Awarded 4 new biosample use seed grants for \$69,313 and 3 new research grants for \$348,173 (total \$417,486 in new grants)

<p>By 2018, establish working relationship with 4 industry partners actively developing new TSC therapeutics</p>	<p>Novartis launches EXIST-3</p>	<p>EXIST-3 ongoing</p>	<p>Novartis, GW, UCB active</p>	<p>Preclinical Consortium members GW, UCB, PIQUR</p>	<p>Seven active relationships: Novartis for NHD plus six Preclinical Consortium Members</p>	<p>Eleven active relationships with companies developing new TSC therapeutics: three developing topical formulations, seven Preclinical Consortium Members, and an additional start-up planning to join the Preclinical Consortium.</p>
<p>Add 3 additional sites to expand geographical and lifespan diversity of the Clinical Research Consortium by obtaining \$20 million in industry/government funding to conduct clinical studies from 2014-2018</p>	<p>Running 3 clinical studies</p>	<p>Received RCDRN Award from NCATS for \$5 Million</p>	<p>PREVeNT would add two sites and \$5 million in funding; an NIH grant in preparation would add another site and \$3 million in funding; Drs. Bissler & Henske added to steering committee</p>	<p>Seven sites running PREVeNT trial (\$8 million total); supporting TSCure coordinator to develop protocol and help apply for funding, which would add sites.</p>	<p>Autism biomarker and RCDRN studies fully enrolled and ongoing. PREVeNT is ongoing and planning addition of 8 more sites. \$7 million NIH grant request in progress for testing effects of everolimus on attention skills in infants with TSC at risk of social impairments or autism.</p>	<p>Autism biomarker and RCDRN studies are fully enrolled; 80% and 25% of participants in each study, respectively, have completed all visits. PREVeNT has enrolled 43 and added 3 additional active sites with 5 more sites pending. \$7 million NIH grant was not funded, but consortium is looking at other options.</p>

2. Support and Empower Constituents

Leading Indicators	Dec. 31, 2013	Dec. 31, 2014	Dec. 31, 2015	Dec. 31, 2016	Dec. 31, 2017	Dec. 31, 2018
Establish new relationships with 4,000 newly identified individuals with TSC by 2018	940 newly identified individuals	374 newly identified individuals	4,358 new constituents added to the database	5,072 new constituents added to the database	3,583 new constituents added to the database	1,324 new constituents added to the database
Increase the number of professionals at TSC Clinics who are implementing TSC consensus guidelines	42 TSC Clinics follow consensus guidelines	48 TSC Clinics follow consensus guidelines	49 TSC Clinics follow consensus guidelines	52 TSC Clinics follow consensus guidelines	68 TSC Clinics follow consensus guidelines	71 TSC Clinics follow consensus guidelines
Increase participants educated on TSC consensus guidelines via CMEs	PeerView Institute CME program launched November 2013	3,084 participants through PeerView Institute CME program	150 participants through the CNF/CNS/TS Alliance co-hosted CME	New Course launched through Axis Medical in 2016	77 participants in Axis Medical live webinar in 2017.	1,908 participants in Axis Medical archived webinar on SEGA and seizure management.
Increase website hits/downloads annually by 25% from 2014 to 2018	15,310,512 total hits 1,533,695 total downloads	16,777,699 total hits (9.5% increase) 1,695,816 total downloads (10.5% increase)	17,410,841 total hits (3.7% increase) 1,385,579 total downloads (18% decrease)	18,741,615 total hits (7.6% increase) 1,672,323 total downloads (20.6% increase)	211,054 total unique users; 9,026 total downloads	422,582 total unique users; 12,348 total downloads
Lead sessions and maintain active presence at 15 national/international professional meetings annually	14 national/international professional meetings	20 national/international professional meetings	32 national/international professional meetings	27 national/international professional meetings	36 national/international professional meetings	38 national/international professional meetings

By office visit or telemedicine, increase the number of individuals with TSC being served by a TSC Clinic to 6,500 and assure 80% of clinics provide services to both children and adults by 2018	See 2014	Baseline: 5,564 individuals seen in TSC Clinics with 62.4% providing care to children and adults	5,611 individuals seen in TSC Clinics with 59.2% providing care to children and adults.	6,247 seen at TSC clinic/60% children and adult care	6,722 seen at TSC clinic/54% children and adult care	8,280 seen at TSC clinic/58% children and adult care.
Increase (and track) 1:1 educational advocacy support contacts, educational training for parents, IEP meetings by state each month	1,072 through training; 26 through school meetings/IEP	1,766 through training; 34 through school meetings/IEP	1,885 through posted trainings; 39 school meetings/IEP	2,344 through posted trainings; 65 school meetings/IEP	3,005 through posted trainings; 74 school meetings/IEP	4,473 through posted trainings; 83 school meetings/IEP
Through the Clinic Ambassador program, document baseline staff interactions and contacts made by Ambassadors to reach an increasing number of people through the program who are not currently in the TS Alliance constituent database	238 individuals/families reached	503 individuals/families reached	648 individuals/families reached	1,515 individuals/families reached	2,014 individuals/families reached	2,573 individuals/families reached
Increase peer-to-peer support from ARCs, Clinic Ambassadors, Dependent Adult Transition Resource Coordinators and CA meetings and gatherings from 2,200 to 4,400 by 2018, facilitated by online	2,418 peer to peer support	4,185 peer to peer support	7,413 peer to peer support	13,540 peer to peer support	20,246 peer to peer support	24,852 peer to peer support

presence						
Establish 2 Global Alliances by 2015 and 3 more by 2018	Began negotiations with support group in Israel	TS Alliance of Israel established as first Global Alliance	Advanced negotiations with Canada as possible second Global Alliance	TS Canada ST, TS Alliance of Mexico, TS Alliance of ASEAN Foundation signed Global Alliance agreements	Hungarian Foundation for Tuberous Sclerosis signed Global Alliance agreement completing goal of 5 Global Partnerships by 2018	TS Alliance of India Global Alliance agreement signed and exceeding our goal with a total of 6 Global Partnerships
Identify and cultivate a minimum of 200 new Community Alliance volunteers by 2018 with eye toward possible community leadership, Government Action Team, board or committee roles	7 new Community Alliance Chairs identified	50 new volunteers recruited	51 new volunteers recruited	72 new volunteers recruited	77 new volunteers recruited	147 new volunteers recruited

3. Mobilize to increase investment

Leading Indicators	Dec. 31, 2013	Dec. 31, 2014	Dec. 31, 2015	Dec. 31, 2016	Dec. 31, 2017	Dec. 31, 2018
Secure 10 million impressions annually via multiple and varied outlets with minimum investment	Global Awareness Day radio media tour reaching 9.7 million listenership	Global Awareness Day radio media tour reaching 10.4 million listenership; Novartis-sponsored media tour around National Special	Global Awareness Day satellite media tour, sponsored by Novartis, reached 4.8 million; #IAMTSC PSAs led to 22,665,735 impressions	Total impressions 85 million including TSC Global Day 13.6 million impressions; LIDS National Walk	Total impressions: 91.5 million including DC Sound Bites (12.2 million impressions); Comedy for a Cure (17.8 million	Total impressions: 93,955,743 including six TS Alliance news releases garnered 91.8 million impressions; ISAW

		Olympics and TSC Athletes reaching 37 million		<p>Sponsor News Release 11.8 million impressions; IAMTSC PSAs January to February garnering 3.6 million impressions; Missouri State Support release 13.5 million impressions; Engles Family Fund release 12.2 million impressions; IS Awareness week included: 16 Radio and TV interviews with 30 placements with 6 million impressions; ISAW main news release: 12.7 million impressions; ISAW Hero/Hope Awards news release: 11.6 million impressions.</p>	<p>impressions); TSC Global Awareness Day (12.1 million impressions); TS Alliance of Mexico (12.4 million impressions); Voice the Patient Report (18.8 million impressions); IS Hope and Heroes Awards (16.8 million impressions); ISAW media tour results (16 placements with possible 1.2 million impressions); and ISAW Facebook advertising (reached 175,200).</p>	<p>campaign added another 77,821 impressions (ER docs), 17,156 impressions (family docs), 6,064 AES attendees for media wall; 254,702 impressions on Facebook; radio tour reached a potential 1.8 million</p>
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Create 1-2 new research campaigns raising \$5 million in incremental funding	Unlock the Cure raised \$435,375	Unlock the Cure raised \$751,171 and finished campaign with \$4,687,571 in revenue	Launched second phase of campaign, Unlock the Cure: ACT Now! and raised \$665,145	Unlock the Cure: ACT Now! Raised raised \$3,628,673 in 2016 and \$4,293,818 overall.	Unlock the Cure: ACT Now! raised \$ 1,202,506 in 2017 and \$5,496,324 overall.	Unlock the Cure raised \$2,250,630 in 2018 and \$12,434,525 total since the inception of the Unlock the Cure campaign in 2011.
Realize \$250,000 annual contribution from Endowment Fund on an annual basis by 2018	\$197,200 annual contribution	\$97,500 (deferred second \$97,500) annual contribution	\$202,000 annual contribution	\$0 (deferred \$206,000) annual contribution	\$403,000 contribution from Endowment. This includes deferred contribution and \$75,000 to fund an additional research grant.	\$0 taken of annual \$285,000 contribution. However, the Endowment Board voted to support a research grant for \$50,000.
Mobilize grassroots community through budgeted special events to raise \$1.5 million average net annually over next 5 years	\$1,351,792 net revenue	\$1,470,814 net revenue	\$1,466,447 net revenue	\$1,361,359 net revenue	\$1,323,959 net revenue	\$1,519,508 net revenue

4. Build and Strengthen Organization

Leading Indicators	Dec. 31, 2013	Dec. 31, 2014	Dec. 31, 2015	Dec. 31, 2016	Dec. 31, 2017	Dec. 31, 2018
Achieve at minimum 3% annual increase in program expenses with balanced	Program Expense Growth: 16.4% Ratios: 76/24	Program Expense Growth: 5.7% Ratios: 76.5/23.5 Revenue: \$4,414,605	Program Expense Growth: -13.2% Ratios: 72/28	Program Expense Growth: 32% Ratios: 76.26/23.74	Program Expense Growth: 8.37% Ratios: 76.3/23.7	Program Expense Growth: 13% Ratios: 78.2/21.8

<p>budget; 80/20 program/expense ratio with revenue of \$5.5 million by 2018 while obtaining 4 star Charity Navigator rating</p>	<p>Revenue: \$4,185,858</p>	<p>Obtained 4 Star Charity Navigator rating</p>	<p>Revenue: \$4,040,686</p> <p>Maintained 4 Star Charity Navigator rating, Gold Level Guidestar Charity</p>	<p>Revenue: \$5,240,880</p> <p>Received 3 Star Charity Navigator rating, Better Business Bureau Wise Giving Program Recognition, Platinum Level Guidestar Charity</p>	<p>Revenue: \$4,764,418</p> <p>Received 4 Star Charity Navigator rating, Better Business Bureau Wise Giving Program Recognition, Platinum Level Guidestar Charity</p>	<p>Revenue: \$5,970,961</p> <p>Received 4 Star Charity Navigator rating, Better Business Bureau Wise Giving Program Recognition, Platinum Level Guidestar Charity</p>
<p>Recruit 2-5 diverse new Board members annually with financial acumen, clinical or scientific expertise, biotech/pharma business experience, or ability to raise substantial funds to support research and community initiatives</p>	<p>3 new board members added:</p> <ul style="list-style-type: none"> • TSC Clinical Experience • TSC Researcher • International Corporate Franchising Expertise 	<p>4 new board members added:</p> <ul style="list-style-type: none"> • Corporate Contract Law • Employment Law • Pharmaceutical Marketing and Commercialization • Commercial Real Estate and Financial Forecasting 	<p>5 new board members added:</p> <ul style="list-style-type: none"> • Auditor • Professional Government Advocacy • Corporate Leadership with HR and financial acumen • CFO and Managing Partner of Commercial Real Estate Company • Pharmaceutical Global Marketing 	<p>4 new board members added:</p> <ul style="list-style-type: none"> • Government Affairs • Accounting • Executive in Hospitality Procurement • CFO and founder of nonprofit 	<p>7 new board members added:</p> <ul style="list-style-type: none"> • Financial and Venture Capital Expertise • Executive Leadership • International • Legal • TSC Clinical and Research Experience • Community Experience • Adult with TSC 	<p>6 new board members added:</p> <ul style="list-style-type: none"> • Audit • Community Experience and Blogging • Information Technology • Legal • TSC Basic and Clinical Research Experience • Community Experience

Maintain a 70% staff retention rate outside of retirements and build redundant skill sets among current and/or planned staff members	86% staff retention; cross training tracked through professional development schedule	80% staff retention; cross training tracked through professional development schedule	85.7% staff retention; cross trained internal staff and professional development included in annual performance reviews	81.25% staff retention; redundant skills identified in Emergency Back Up Plan and cross trained internally	87.5% staff retention; cross training based on redundant skills identified in Emergency Back Up plan and Business Plan created for 2018-2020 including staffing plan with retirements	83.4% staff retention; cross training based on skills needed as identified and updated in the Emergency Back Up plan.
Develop succession plans for top executive staff	N/A	CFO resigned in 2014 and search for new CFO initiated	Hired New Controller/CFO and Director of Special Events and Corporate Partnerships	Developed Emergency Back Up Plan for every department and every position, short and long-term. Hired New Director of Special Events and Corporate Partnerships	Reviewed Emergency Back Up Plan at annual Staff Retreat; wrote TS Alliance Business Plan which includes staffing transition and success plans through 2022.	Updated Emergency Back Up Plan at annual Staff Retreat. Staffing plan followed as written in the TS Alliance Business Plan.