**Tuberous Sclerosis Alliance  
Board Committee Goals FY 2016**

*Approved by Board of Directors: October 24, 2015*

**Vision Statement:**

To bring about the day when no one has to endure the devastating effects of TSC

**FY16 Focus Statement:**

The TS Alliance will marshal the resources to champion the next essential scientific breakthroughs for treatment and preventative therapies for TSC and to provide community services that improve the quality of life for those affected by TSC in the United States and around the globe.

* Accelerate scientific advancements by funding research; driving the development of tools and consortiums that support basic, translational and clinical research; and advocating for research funding by partnering with government and industry sponsors and other patient organizations.
* Identify more individuals impacted by TSC and engage them through improved clinical and support services.
* Broaden and strengthen the base of financial support for TSC research, TS Alliance and TS Alliance Endowment Fund from both private and public sources.
* Facilitate more interaction among the national and international TSC community.
* Increase diversity of Board membership and enhance staff skill sets to ensure execution of the strategic plan and to maintain recognition of TSC as a linchpin disorder.

**Science and Medical Committee**

1. TSC Natural History Database
   1. Increase awareness by researchers of the database’s improved data consistency and usability, resulting in an increase in queries to at least ten in 2016.
   2. Add depth to the database through collection of longitudinal data in at least two specific areas of clinical unmet needs as determined by the Steering Committee with input from stakeholders including constituents.
   3. Secure private and corporate funding sufficient to operate the database while maintaining adherence to our corporate relationship policy.
2. Clinical Studies and Clinical Care
   1. Support external funding of and aggressive recruitment into clinical studies executed by the TSC Clinical Research Consortium and expand the consortium by at least two sites.
   2. Expand awareness of clinical consensus guidelines by health care providers through CME and in-person or webinar presentations by participants in the 2012 TSC Clinical Consensus Conference.
   3. Increase access of constituents’ local healthcare providers to TSC expert advice to enable local application of clinical consensus guidelines; methods might include telehealth, on-demand materials focused on specific guidelines, making one-on-one provider-to-provider connections for consultation, etc.
   4. Support TSC Clinic staff (with a focus on nurses and social workers) with education and TS Alliance publications or tools to help ensure comprehensive integrated clinical care and transition of care from childhood to adulthood and to implement care that is fully consistent with the Clinical Consensus Guidelines, including TAND and other best practices in TSC care.
3. Research Program
4. Grow the TSC Biosample Repository of samples associated with robust clinical data in the TSC Natural History Database and add at least three new participating clinical research sites.
5. Advance TSC Preclinical Consortium as evidenced by:
   1. Testing of candidate drugs as prioritized by the Steering Committee in neurological and behavioral animal models of TSC.
   2. Data analyzed from initial evaluations of tumor models of TSC with project plan developed for testing of candidate molecules.
   3. First pharma or biotech partnership established or NIH funding obtained.
6. Award at least $400,000 in new research grants with an emphasis on postdoctoral fellowships and independent investigators still within the first few years of establishing their laboratories. Include adults with TSC and parents of children with TSC as consumer reviewers in the final round of grant application reviews.
7. Identify co-funding opportunities with other organizations and utilize them as appropriate for furthering the mission of the TS Alliance.
8. Compile and distribute annual research report.
9. Scientific and Medical Conferences
10. Develop plans and apply for funding of an International TSC Research Conference hosted in the United States in 2017 to accelerate research on solutions to the most pressing needs of the TSC community.

**Outreach Committee**

1. Increase reach of existing TSC Clinics by expanding the TSC Clinic Ambassadors to 15 clinics (currently in 12), utilizing the off-site TSC Clinic Ambassador model when needed.
2. Encourage young adult involvement in the TS Alliance by refining the pilot Junior Leader Program developed in 2015.
3. Support the needs of our Spanish-speaking constituents by developing a plan to identify them, thereby laying the groundwork for a Spanish Support Program.
4. Support families of dependent adults and transitioning young adults in their efforts to navigate state resources by increasing the number of Dependent Adult Transition Resource Coordinators to 15 (currently 7).
5. Educate families/individuals dealing with TSC in rural and other areas not serviced by TSC Clinics by supporting use of new technologies at Community Alliance meetings and educational gatherings.
6. Build awareness of best practice diagnosis and treatments for TSC among health care, educational and other professionals, particularly medical professionals in rural or other areas not serviced by a TSC clinic, and mental health professionals.\*
7. Develop strategies to utilize social workers in TSC Clinics to provide families from other states and communities with “Diagnosis, Surveillance and Management of Individuals with TSC” CDs to their local doctors.
8. Develop strategies to utilize school nurses to reach out to local doctors in rural areas by providing them “Diagnosis, Surveillance and Management of Individuals with TSC” CDs to provide to local doctors and nurses.
9. Increase the number of adults and families affected by TSC represented in the TS Alliance database by a minimum of 3,000 with 40% newly identified.

*\*Goal to be carried out in coordination with another committee(s).*

***Communications***

Functions as a sub-committee of Outreach and works ad-hoc to support the work of other committees. For example:

Science & Medical

* Support and promote clinical trial recruitment activities.
* Increase awareness of clinical consensus guidelines by promoting CME activities and webinars as needed.
* Edit and help distribute annual research report.

Outreach

* Lead redesign of TS Alliance website.
* Support outreach efforts to increase number of TSC adults and families in constituent database by 3,000.
* Support video production for use in rural areas.
* Help with strategies to reach medical and other professionals to increase awareness of best practice diagnosis and treatments.

Global Relations

* Lead promotion efforts for TSC Awareness Month (May) and TSC Global Awareness Day (May 15).
* Maintain TSCi website as needed.

Government Relations

* Help promote Government Action Team (GAT) recruitment.
* Support constituency training.
* Help create/edit training materials as needed; maintain and update GAT web pages and online resources.

Development

* Promote and develop written and online materials for “Unlock the Cure: ACT NOW!” campaign.
* Support all major events (Step Forward to Cure TSC, Comedy for a Cure, MN Food and Wine) including developing promotional materials, branding and online activities.
* Monitor use of Luminate to ensure brand and messaging consistency.
* Write and produce annual report.

Governance/Nominating

* Write, edit and oversee mailing member/board ballots as needed.

**Global Relations Committee**

1. Identify, cultivate and add one additional Global Alliance.
   1. Sign agreement with Canada.
2. Ensure proper agreements and financial reporting are in place for TS Alliance of Israel.
3. TSC International
4. Serve as the coordinating center for TSC International (TSCi) activities, including website maintenance and TSC Global Awareness Day on May 15.
5. Secure continuing support for TSCi from private sources.

4. Explore future funding support for both the Global Alliance program and TSCi.

**Government Relations Committee**

1. Cultivate, educate, and empower a premier constituent advocacy group to advance TSC initiatives at federal, state, and/or district levels.

1. Educate (pre-train) each new community advocate one-on-one prior to coming to DC and assign mentors for the March on Capitol Hill.
2. Empower state coordinators to conduct additional follow-up with local visits based on feedback forms from DC visits.

2. Continue advocacy to maintain Tuberous Sclerosis Complex Research Program (TSCRP) funding in the Department of Defense (DoD) budget.

1. Identify and cultivate potential new Dear Colleague Letter sponsors.
2. Pilot program with LAM Foundation to partner on ways to increase funding beginning with its participation during the March on the Hill.
3. Assess whether additional organizations associated with the NIH Rare Disease Consortium (PTEN and Phelan McDermid Syndrome) would be interested in partnering for increased funding.

3. Advocate for Report language regarding importance of TSC/TSC research in HHS Bill.

4. Build relationships to advocate for increased financial support of TSC initiatives   
from Department of Health and Human Services, including NIH, HRSA, PCORi, CDC, and FDA.

1. Meet with FDA’s Office of Professional Affairs and Stakeholders Engagement to discuss plans to organize a Patient-Focused Drug Development meeting.
2. Plan a Patient-Focused Drug Development meeting to discuss early preventative trials and challenges of current vigabatrin risk evaluation and mitigation strategies (REMS) in 2016.

5. Coordinate TSC Global Awareness Day activities involving Congressional and Federal

agency stakeholders.

6. Explore expanded TSC advocacy initiatives to include opportunities to impact quality of life and access to research funding at state/regional/local levels.

1. Assess the opportunity for applying for SSA Compassionate Allowance for tuberous sclerosis complex in 2016.
2. Pursue state funding in Alabama or one additional state and maintain funding for existing state-funded programs in Michigan and Missouri.

7. Explore future funding to support constituent training in advocacy and empowerment.

### Development Committee

1. Continue to grow and promote “Unlock the Cure: ACT Now!” with a goal to focus fundraising themes on supporting current and emerging scientific initiatives such as Pre-Clinical Network, Clinical Research Consortium, TSC Natural History Database, Biosample Repository and TS Alliance Research Grants Program.
   1. Raise $25 million over three years of which $5 million will be raised by the TS Alliance and $20 million will be leveraged from government sources direct to clinical research consortium projects.
   2. Secure $1.5 million in contract revenue toward Unlock the Cure research initiatives.
   3. Raise additional $500,000 from private sources.
   4. Raise $50,000 from crowdfunded research challenge.
   5. Create a President’s Council comprised of a group of family members with substantial resources to come together to drive research forward through significant contributions to our Unlock the Cure campaign.
2. Increase major gifts and grants.
   1. Secure $50,000 in funding from 5 new prospects identified through Board contacts.
   2. Maintain and strengthen relationships through personal visits with current individual/corporate/foundation donors to increase major donor gifts by 53% over 2015.
   3. Analyze Major Donor LYBNT and send personalized solicitations asking for a gift in 2016, with a 50% positive response rate.
   4. Identify and apply for 10 new grants resulting in securing $50,000 in new grant funding.
   5. Sustain 100% Board giving and encourage Board give/get.
3. Utilize Luminate to expand opportunity for donor identification and cultivation through an improved database and communication system with accurate contact and relationship information.
   1. Convert 15% of new individuals added to the database in 2015 to organizational donors through the 360-communication process. (Individuals who joined through website pop-up or walks)
   2. Execute second year of crowdsourcing campaign to raise $50,000 using Luminate.
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.
   1. Step Forward to Cure TSC
      1. Raise $1.195 million (8% increase over 2015 actual with expense ratio of 7%.)
      2. Increase online registrations and teams by 10% over 2015.
      3. Add a minimum of 25 new volunteers to community walk committees by recruiting additional volunteers with a focus on adding newly diagnosed families and individuals.
      4. Grow Circle of Champion level ($10,000) fundraisers by 20% through incentive-based participation.
   2. Encourage online crowdsourcing and local community campaigns through implementation of Luminate platform.
      1. Raise $143,000 with less than a 3% expense ratio.
      2. Develop new tool kits for individual and community fundraising campaigns and share through social media and TS Alliance website.
      3. TEAM TSC – a program to promote fundraising for marathons, biking competitions.
      4. Dance for a Cure – a program to involve teenagers and college-age students in a dance-a-thon.
   3. Major Events
      1. Build the national brand of Comedy for a Cure, encouraging attendance from supporters and TSC families nationwide
      2. Increase event revenue by 28% or $235,000 returning to 2013 levels with expense ratio of 35%.
      3. Increase attendance from 200 to 250 individuals from across the country.
      4. Secure A-list celebrity to attend or perform.
      5. Secure three matching donations and grow Fund a Cure by 42% over 2015 or to $50,000.
      6. Plan and implement Fall Minnesota Food and Wine event with revenue target of $61,325 and no more than 25% expense ratio.

**Governance Committee**

1. Revise as necessary status as a membership organization, including revision of bylaws and articles of incorporation to reflect organizational changes.
2. Convene a sub-committee to develop and review messaging and communication for the change in organizational status from a membership to a constituent-based organization.
3. Mail ballot of organizational changes to membership and if successful, file appropriate documentation with the state of California.

**Nominating Committee**

1. Identify, recruit and recommend up to 5 new Board members with emphasis on the following skill sets:
2. Financial means with the willingness to raise substantial funds to support research and community initiatives.
3. Experience with fundraising/development, auditing, finance and global franchising.
4. Diversity to reflect our constituency, both domestically and globally.
5. Review geographic representation of Board members.
6. Ensure compliance with bylaws ratio of Board members related to or a person with TSC at 50% annually.
7. Add potential Board candidates to standing Board Committees to cultivate future leadership and mentor nominees.
8. Implement (vibrant and evolving) officer succession planning.
9. Assist/work with TS Alliance Endowment Committee to identify, cultivate and recruit candidates for its Board.

**Finance Committee**

1.   Assist in strategies regarding investment of Operating Funds to **optimize** returns and **minimize** risk **while adhering to** the **approved** investment policy; including through the investment sub-committee develop and propose investment options to the Board for TSC research initiatives aimed at moving important scientific discoveries forward.

2.   Utilize Charity Navigator and other charity rating services as a guide for the budget process and 990/financial statement presentation.

3.   Assist the Controller and Chief Financial Officer with our current year initiative:

a. Help the Compensation Committee review standard employee benefits and insurance policies to maintain a competitive compensation package, while seeking to keep benefits at 25.5% of salary expense. Make recommendations to management and the Board for possible changes in FY 2017.

4.   Establish a Balanced Scorecard for the purpose of monitoring and reporting on organizational progress toward attaining the monetary Measures of the Objectives, Goals and Strategies in the Strategic Plan to be presented to the Board at the December meeting.

5.   Review initial draft of the FY 2017 Annual Budget by no later than October and approve the final budget to be presented to the Board at the December meeting.

**Compensation Committee**

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:

1st Quarter, prior to commencement of final field work of prior year audit:

1. Approve payout of the prior fiscal year’s incentive-based compensation.
2. Approve any non-budgeted spot bonus payouts if applicable for employees not on the incentive compensation plan.

c. Approve any changes to the current fiscal year’s approved budgeted salary pool if applicable.

            3rd/4th Quarters:

1. Approve the overall proposed budgeted salary pool for the next fiscal year.
2. Approve the specific salary/incentive comp ratios proposed for any employee who will appear on the 990 tax return for the next fiscal year.
3. Conduct salary and employee benefits survey to evaluate competitive benchmarks for compensation to continue to attract and retain professional employees and provide career development opportunities tied to the staffing plan and Strategic Plan objectives.
4. Review insurance coverages, particularly short-term disability, to ensure appropriate level of benefits for employees.
5. Conduct formal staff training about benefits of retirement plan and distribute value of total compensation during annual evaluations. Investigate incorporating additional stakeholder feedback into the annual evaluation process to obtain 360 degree feedback. This would include asking Board members to provide feedback on certain employees.
6. Develop back-up planning procedures per each department and ensure cross training is conducted for each position.

**Audit Committee**

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 fraud.
3. Review Footnotes of the financial statements particularly regarding estimates used by management.
4. Review the 990 for the most beneficial presentation for third-party ratings of the organization staying within IRS regulations.
5. Inform and support the organization as FASB changes accounting standards.
6. Review the calendar with Controller and 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. Train and transition to new Audit Chair in 2016.

**Endowment Fund**

1. Conduct meetings with five TS Alliance Endowment Fund Major Donor prospects and secure six new planned giving bequests.
2. Market planned giving vehicles, including gift annuities, with a goal of three newsletters, placement of stories in *Perspective* on planned giving and program ads in major TS Alliance events.
3. Calculate annual contribution to the TS Alliance operating according to the investment spending policy and approve a budget by September of each year. 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. Assign Endowment liaison to serve on operating Nominating Committee to cultivate and vet potential Endowment Fund Board candidates.
6. Nominate a new Board member in FY16 with experience in managing investment portfolios.
7. Develop a stewardship handbook.