**Tuberous Sclerosis Alliance  
Board Committee Goals FY 2015**

*Approved by Board of Directors, December 10, 2014*

**Vision Statement:**

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

**FY15 Focus Statement:**

The TS Alliance will marshal the resources to champion the next essential scientific breakthroughs for treatment and preventative therapies for TSC and 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 that support basic, translational and clinical research, and advocating for research funding by partnering with government and industry sponsors.
* 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 Staff skill sets to ensure execution of the strategic plan and maintained 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 eight in 2015.
   2. Achieve total enrollment of 2000 participants in 2015.
   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
3. Support external funding of and aggressive recruitment into clinical studies executed by the TSC Clinical Research Consortium.
4. 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.
5. Produce a report of the barriers to utilization of telehealth and which states allow cross-state licensure, if any, and then develop a plan to implement a pilot program at a clinic in a state (or states) which have forward-thinking policies towards telehealth.
6. 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.
7. Research Program
8. Maintain research grant funding at least at $400,000 annually 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 review.
9. Initiate standardized and centralized collection of biological samples associated with robust clinical data in the TSC Natural History Database and implement guidelines and processes to provide access to biosamples and data to any qualified researcher with a relevant purpose.
10. Implement guidelines and processes for researchers to access services of a TSC Preclinical Consortium for testing of candidate therapies in rodent models relevant to the neurologic and neuropsychiatric manifestations of TSC, with testing performed in standardized fashion to meet NIH guidelines for reproducibility and rigor of preclinical translational research.
11. Identify co-funding opportunities with other organizations and utilize them as appropriate for furthering the mission of the TS Alliance.
12. Compile and distribute annual research report.
13. Scientific and Medical Conferences
14. Co-host with the TSA the 2015 International TSC Research Conference in London.
15. Facilitate attendance of US-based researchers at the research conference through extraordinary levels of travel funding supported by NIH grants, private funding, or both.
16. Serve on the Steering Committee, provide logistical support and sponsor meals for National Institutes of Health TSC Research Plan: “Unlocking Treatments for TSC: 2015 Strategic Plan”

**Executive Committee**

1. Establish a Global Relations Committee to facilitate international engagement of the organization.

*Global Relations Committee*

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

**Outreach Goals**

1. Increase reach of existing TSC Clinics by expanding the TSC Clinic Ambassadors to twelve clinics (currently in 10), utilizing the off-site TSC Clinic Ambassador model when needed.
2. Encourage young adult involvement in the TS Alliance by developing a video that welcomes young adults and discusses how they can get involved, and posting it on the Young Adult webpage.
3. Measure the impact of the World Conference on quality of life by conducting an online post-conference survey with 10% return in July 2015.

* Survey will be sent to conference attendees and non-attendees to identify factors contributing to changes in quality of life of individuals with TSC and their families.

1. Identify the needs of our Spanish-speaking constituents by developing a Spanish Support Task Force.
2. 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 by two (currently one pilot Coordinator in the state of LA).
3. Develop strategies to educate families/individuals dealing with TSC in rural areas and other areas not serviced by TSC Clinics, particularly in the areas of:

* Management and Treatment of TSC
* Educational Advocacy
* Emotional Support

1. Build awareness of best practice diagnosis and treatments for TSC among healthcare, educational and other professionals, particularly medical professionals in rural or other areas not serviced by a TSC clinic, and mental health professionals.\*
   1. Distribute fact sheets on consensus guidelines and TSC-Associated Neuropsychiatric Disorders (TAND; when available) to the TSC community in an effort to educate community members and disseminate new guidelines to the professionals that serve them.
   2. Promote professional collaboration between our TSC Clinics and other healthcare professionals in an effort to reach families.
2. Increase the number of adults and families affected by TSC that are represented in the TS Alliance database by a minimum of 1,000.

*\*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

* Work with department to assess current website navigation and to update relevant medical/science information as needed.
* Help promote enrollment in TSC Natural History Database.
* Promote clinical trial recruitment via social media and other methods as needed.
* Support creation of and distribution of annual research report.
* Promote registration and provide materials as needed for 2015 International TSC Research Conference.
* Oversee distribution of TAND training featuring Petrus de Vries.

Executive/Global Relations

* Manage TSCi website, promote TSC Global Awareness Day and support release of translated information as needed
* Support TS Alliance of Israel communication efforts, website development.

Outreach

* Oversee production of new video for Young Adult webpage.
* Oversee production of new video on Infantile Spasms with updated information on early diagnosis and treatment.
* Implement campaign to heighten awareness and physician education during Infantile Spasms Awareness Week.
* Use social media and website tools to capture and increase number of people in TS Alliance database by 1,000 and to provide support and information as needed.
* Work with The Matale Line to assess current branding messaging and update/change as needed.
* Oversee update of annual State of TSC Communities report.

Government Relations

* Promote Government Action Team participation.
* Edit and post March on Capitol Hill materials as needed.

Development

* Oversee branding of new Unlock the Cure ACT Now! campaign, hone messaging, help create needed materials and promote as needed.
* Support implementation of Luminate platform; ensure all communications via new system are branded and consistent.
* Promote major events such as Step Forward to Cure TSC, Comedy for a Cure, Philadelphia Food and Wine, and Four Decades One Community play roadshow.
* Edit and create support materials as needed for any fundraising efforts.
* Write and produce direct mail appeals.
* Endowment: help edit newsletter and other materials when needed.

Finance

* Write and produce FY14 annual report according to bylaws.
* Oversee strategic plan progress report.
* Support implementation of Theory of Change process and develop web page and other materials as needed.

Nominating

* Write and oversee production/mailing of annual board ballot.

### Government Relations Committee

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

* Recruit a minimum of 10 state coordinators.
* Educate (pre-train) each new community advocate one-on-one prior to coming to DC and assign mentors for the March on Capitol Hill.
* Empower state coordinators to conduct additional follow-up with local visits based on feedback forms from DC visits.

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

* Pilot program with LAM Foundation to partner on ways to increase funding beginning with its participation during the March on the Hill.
* Assess whether additional organizations associated with the NIH Rare Disease Consortium (PTEN and Phelan McDermid Syndrome) would be interested in partnering for increased funding.

1. Advocate for Report language regarding importance of TSC/TSC research in HHS Bill.
2. 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.
   * Meet with FDA’s Office of Professional Affairs and Stakeholders Engagement to discuss plans to organize a Patient Focused Drug Development meeting.
   * Plan a Patient Focused Drug Development meeting to discuss early preventative trials and challenges of current vigabatrin risk evaluation and mitigation strategies (REMS).
3. Coordinate TSC Global Awareness Day activities involving Congressional and federal agency stakeholders.
4. Explore expanded TSC advocacy initiatives to include opportunities to impact quality of life and access to research funding at state/regional/local levels.
5. Assess the opportunity for applying for SSA Compassionate Allowance for tuberous sclerosis complex in 2015.
6. Pursue state funding in Missouri and identify a minimum of one additional state funding opportunity.
7. Explore future funding to support constituent training in advocacy and empowerment.

### Development Committee

1. Create a new branded research fundraising campaign, similar to “Unlock the Cure,” with a goal to focus fundraising themes on supporting current and emerging scientific initiatives such as Pre-Clinical Research Network, Clinical Research Consortium, TSC Natural History Database, Biosample Repository and TS Alliance Research Grants Program.
2. Design and implement campaign to 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.
3. Raise $500,000.
4. Solicit and obtain a matching challenge grant for individual and foundation donors as well as for those creating crowdsourcing events.
5. 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 10% over 2014.
   3. Identify and apply for 10 new grants resulting in securing $100,000 in new grant funding.
      1. Secure $25,000 in funding to produce a new video to promote infantile spasms awareness and share information surrounding earlier diagnosis, better treatments and outcomes.
   4. Sustain 100% Board giving and encourage Board give/get.
6. Utilize Luminate to expand opportunity for donor identification and cultivation through an improved database and communication system with accurate contact and relationship information.
7. Implement a 360-communication process to interact with 15,000 potential donors through this targeted communication system and streamline the online donation process.
8. Develop and execute a research crowdsourcing campaign to raise $50,000 ($20,000 over previous research appeals) using Luminate.
9. 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.
10. Step Forward to Cure TSC: Maintain the “Super Hero” theme to continue to reinvigorate walks; strengthen community walk committees by recruiting additional volunteers with a focus on adding newly diagnosed families and individuals; improve team fundraising, online capabilities and incentive-based participation; increase walk revenue equal to 5% greater than 2014 actual with expense ratio of 7%.
11. Encourage online crowdsourcing and local community campaigns through implementation of Luminate platform.
    1. Raise $150,000 with less than a 3% expense ratio.
12. Major Events:
    1. Continue focus on honoring and featuring a TSC family at Comedy for a Cure to increase sponsorships, attendance, auction donors and purchasers; focus on year-round relationship building with celebrities to increase their attendance and secure new honorary chair; increase event revenue 12% to $230,000 and expense ratio of 35%.
    2. Plan and implement spring food and wine event in Philadelphia, PA with a revenue target of $75,000 and no more than a 18% expense ratio.
    3. Design a simplified event that carries the Four Decades | One Community play through three new locations (Washington, DC; Boston, MA; and Minneapolis, MN) and promotes participation among all TS Alliance constituencies.
    4. Meet revenue target of $150,000 with cost ratio of less than 30% for all three events.
    5. Copyright, register and publish script and promote availability for purchase through online sales.
    6. Community reading across the country on May 15 TSC Global Awareness Day.

**Finance Committee**

1. Assist in strategies regarding investment of Operating Funds to **optimize** returns and **minimize** risk **while adhering to** the **approved** investment policy;
2. Utilize Charity Navigator and other charity rating services as a guide for the budget process and 990/financial statement presentation;
3. Assist Chief Financial Officer with current year initiatives:
4. Update of the Accounting Manual of Procedures to be consistent with GAAP including the new COSO Internal Control – integrated framework;
5. Review, revise, approve and implement Retention and Destruction Policies in accordance with IRS and legal counsel guidelines; and
6. Long term CFO Succession Planning.
7. Establish and monitor appropriate Objectives, Goals, Strategies and Measures (“OGSMs”) in concert with the Strategic Plan; and
8. Review initial draft of the FY16 Annual Budget by no later than October and approve the final budget to be presented to the Board at the December meeting.

**Governance Committee**

1. Review and revise as necessary status as a membership organization.
2. Revise bylaws to reflect any organizational change to membership and necessary organizational changes.

**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. Diversity to reflect our constituency - both domestically and globally.
4. Government relations experience, financial acumen and fundraising/development.
5. Ensure compliance with bylaws ratio of directors related to or a person with TSC at 50% annually.
6. Add potential Board candidates to standing Board Committees to cultivate future leadership and mentor nominees.
7. Implement (vibrant and evolving) officer succession planning.
8. Assist/work with TS Alliance Endowment Committee to identify, cultivate and recruit candidates for its Board.

**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:

1. Approve payout of the prior fiscal year’s incentive based compensation.
2. Approve any non-budgeted spot bonus payouts if applicable.
3. Approve any changes to the current fiscal year’s approved budgeted salary pool if applicable.

  3rd/4th Quarter:

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.

2.   Review frequently-used HR-related documents including offer letters, promotion/salary adjustment memo, employee review documents, terms and conditions of incentive compensation program, letters accompanying incentive payouts, and severance agreements and termination cover letters for potential updates if applicable.  Include legal review and approval where appropriate.

3.   Evaluate staffing plans and skill development for existing staff to support future growth of the organization and review succession plans for retirement of top executive or management staff.

**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. Reviewing the calendar and milestone dates for timely filing of the audit and form 990.
7. Keep general membership and board informed of accounting updates during the year.

**Endowment Fund**

1. Market Gift Annuities to key prospects in CA, NY, CT, and MD.
2. Identify other states to implement Gift Annuity Program.
3. Market planned giving vehicles featuring gift annuities, with a goal of three newsletters, placement of stories in *Perspective* on planned giving and program ads in major TS Alliance events.
4. Conduct meetings with three TS Alliance Endowment Fund Major Donor prospects.
5. Calculate annual contribution to the TS Alliance operating according to the investment spending policy and approve a budget by September of each year.
6. Hold meetings as needed to review investments and make adjustments to reflect market changes.
7. Assign Endowment liaison to serve on operating Nominating Committee to cultivate and vet potential Endowment Fund Board candidates.
8. Nominate a new Board member and assign new Secretary for the organization for FY15.