This report represents National Tuberous Sclerosis Association Inc's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

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**Mission:**
The Tuberous Sclerosis Alliance is dedicated to finding a cure for tuberous sclerosis complex while improving the lives of those affected.

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1. What are we aiming to accomplish?

Goal 1: Accelerate research. We will accelerate the progress in TSC research through federal funding, a database, TS Alliance funded research, collaborations and a clinical network. Goal 2: Support and empower consumers. We will support quality TSC care and empower consumers in diverse communities to access it. Goal 3: Educate and mobilize to increase investment. We will educate the public about those affected by TSC and the benefits of increased investment in TSC research for related disorders such as Autism, Epilepsy, and LAM, and mobilize them to join and support our programs in order to increase annual revenue from $4.185 million (FY13) to $5.5 million by 2018 from both philanthropic and non-philanthropic sources. Goal 4: Build and strengthen organization. We will build organizational unity and capacity to strengthen the economic viability and growth of the TS Alliance in order to achieve our mission.

2. What are our strategies for making this happen?

Goal 1: Accelerate research. Advocate for federal and state funding of novel and innovative therapies. Expand usage of Natural History Database. Develop TSC Biosample Repository as an asset to the medical community. Focus TS Alliance Grants to promising researchers starting their careers. Foster partnerships that synergize with consortium grants and industry sponsorships. Grow Clinical Research Consortium. Goal 2: Support and empower consumers. Identify additional persons affected by TSC to broaden reach of initiatives. Attract patients and physicians with services and resources at TSC Clinics. Enhance online presence of Community Alliances (CAs) and Adult Regional Coordinators (ARCs). Attract new volunteers via appeal to a broad range of demographic segments. Expand Global Alliance program. Goal 3: Educate and mobilize to increase investment. Broadcast the TSC and TS Alliance story to widespread audiences via effective and efficient communications. Implement new development campaigns and partnerships with foundations, state organizations and individuals. Emphasize the role and opportunities associated with Endowment via estate planning and gift annuities. Explore the use of crowdsourcing techniques to complement current technology already in use. Goal 4: Build and strengthen organization. Continue emphasis on systems and processes that encourage efficient and effective operations consistent with Charity Navigator (CN) guidelines. Trumpet the scientific and medical link of TSC to other diseases and disorders as the "face" of TSC among peer diseases and disorders organizations, medical and related professionals, foundations, potential donors and constituents. Build the board of directors around skill sets needed to realize the strategic plan and remain engaged with outgoing directors. Invest in staff/skill development.

3. What are our organization's capabilities for doing this?

With a professional staff of 16, the TS Alliance is governed by a 19-member Board of Directors comprised of people affected directly by the disease and business professionals. The organization placed strategic focus on improving business operations and achieved a four-star rating from Charity Navigator, the Guidestar Gold Exchange Seal, and named a 2015, 2014, 2013 and 2012 Top Nonprofit from GreatNonprofits. The staff and Board are supported by an army of more than 1,800 volunteers who work together to improve the quality of life for every individual affected by TSC by focusing on three main pillars: Research: TS Alliance supports basic, translational and clinical research and believes a multi-pronged approach to research is the key to finding better treatments and a cure. We have awarded more than $18 million research grants since 1984, and launched the Unlock the Cure Campaign in 2011 to fund the next wave of TSC-specific research needed to move potential treatments from pre-clinical testing to clinical trials in the community. TS Alliance-funded research has led to major discoveries, including the identification of the two genes that cause TSC, the development of a genetic test, the first TSC Natural History Database and some of the first clinical trials that have now led to two FDA approved indications to shrink brain and kidney tumors associated with TSC. Research is directed by CSO Steve Roberds with guidance from an International Scientific Advisory Board. Advocacy: For 15 years, grassroots volunteers have worked tirelessly to create a vibrant government advocacy program with the goal of making sure the Federal government continues to focus time, energy and dollars on TSC research. These efforts have translated into more than $268 million in Federal funding for TSC research.
since 2002 through the National Institutes of Health and appropriations to the Department of Defense's Congressionally Directed Medical Research program. Outreach: Our community outreach encompasses a broad spectrum of activities, each designed to offer support and provide education. We have diversified the way we support the TSC community including the addition of social media, TSC clinic ambassadors, dependent adult transition resource coordinators, adult regional coordinators, educational liaison program, videos on relevant topics, and active leadership in TSC International. We continue our traditional support programs: robust website; full-time advocate; Community Alliances/volunteer branches of the organization in 35 locations; educational meetings; informational teleconferences; TSC Connect offering peer support; publications including a national magazine, targeted brochures and information sheets on TSC manifestations; and a professional advisory board.

4. How will we know if we're making progress?

Goal 1: Accelerate research Reach a level of annual research funding of $3.25MM by 2018 Enroll 2,000 participants in Natural History Database by 2015 Plan/implement a TSC Biosample Repository by 2015; collect 100 blood samples and 200 tissue samples from Nat. History Database participants by 2018 Issue 6 grants annually in the total amount of $450K By 2018, establish working relationship with 4 industry partners actively developing new TSC therapeutics Add 3 additional sites to expand geographical and lifespan diversity of the Clinical Research Consortium and obtain $20 million in industry/government funding to conduct clinical studies from 2014-2018 Goal 2: Support and empower consumers Establish new relationships with 10,000 individuals/families added to constituent database including 4,000 newly identified individuals with TSC by 2018 By office visit or telemedicine, increase the number of individuals with TSC to 6,500 being served by a TSC Clinic and assure 80% of clinics provide services to both children and adults by 2018 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 presence Identify and cultivate a minimum of 200 new CA volunteers by 2018 with eye toward possible community leadership, board or committee roles Establish two global alliances by 2015 and three additional by 2018 Goal 3: Educate and mobilize to increase investment Secure 10 million impressions annually via multiple and varied outlets with minimum investment Create 1-2 new research fundraising campaigns with $5 million in incremental funding Realize $250,000 contribution from Endowment Funds on an annual basis by 2018 Mobilize grassroots community through budgeted special events to raise $1.5 million average net annually over next five years Goal 4: Build and strengthen organization Achieve at minimum 3% annual increase in program expenses with balanced budget; 80/20 program/expense ratio with revenue of $5.5 million by 2018 while obtaining 4 star CN rating Participate in 15 professional and industry conferences (nat'l/int'l) annually Recruit 2-5 diverse new Board members 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 Maintain a 70% staff retention rate outside of retirements and build redundant skill sets among current and/or planned staff members Develop succession plans for top executive staff

5. What have and haven't we accomplished so far?

• Accelerate research: We completed 2015 with $1,705,098 in research funding; the Natural History Database finished 2015 with 1,850 participants from 17 TSC Clinics; workshops were held for the development of a 5-10 year research plan hosted by NINDS and for the development of the TSC Biosample Repository and Preclinical Consortium; samples from the RDCRN were sent to begin the collection at the Biosample Repository and contracts with Miami Children's and Texas Scottish Rite Hospital were executed as pilot locations for sample collection; $730,081 was awarded for four new research grants; active discussions continue with industry particularly around the development of the Preclinical Consortium; a grant pending at NIH for $5 million will also expand the Clinical Research Consortium to 2 additional sites in 2016. • Support and empower constituents: more than 4,358 new constituents were added to the database in 2015; discussions continue with TSC Clinics regarding adult and transition care and two new TSC Clinics were added; in 2015 peer support increased to 7,413; 51 new volunteers were recruited in 2015; discussions were held with four prospective Global Alliances but no new ones were added in 2015. • Educate and mobilize increase investment: May 15, 2015 awareness day satellite media tour, sponsored by...
Novartis, reached 4.8 million; #IAMTSC PSAs led to 22,665,735 impressions as of November 30; Unlock the Cure: ACT Now! campaign launched; current TS Alliance Endowment Fund contribution is $202,000 annually; FY2015 unaudited Special Event net was $1,429,000. • Build and sustain organization: program expenses increased 5.7% from 2013 to 2014 with 76.5% program to 23.5% administrative ratios; staff members participated in 18 national and international professional conferences in 2015; five new board members were elected and begin terms in January 2016, one with auditing experience, one with professional government advocacy experience, one a President of a company and TSC parent with HR experience and financial acumen, and a grandparent who has served as CFO of his company; staff retention was at 85.7% in 2015.