Mission: To find a cure for TSC while improving the lives of those affected.

From Where (Referral Sources)	For Whom (Populations, *listed in order of life stage*)	Assumptions (Theory of Change)	Strategies/Activities (Program Interventions)	Leading Indicators	Outcomes	Impact
Google / TS Alliance website Social media sites Community clinicians TSC Clinics International TSC groups CDC, NIH websites Other parents / caregivers Community Alliances (CAs) / walks and other local events Other advocacy organizations Industry apps / outreach Case managers of government benefits	1. **Parents/caregivers of infants and children (under 18):** a. Diagnosed with TSC b. Undiagnosed 2. **Young adults with TSC (18-26)** a. Semi-independent and independent adults diagnosed with TSC and their family members b. Parents/caregivers/family members of dependent adults diagnosed with TSC c. Undiagnosed 3. **Adults (26+)** a. Semi-independent and independent adults diagnosed with TSC and their family members b. Parents/caregivers/ family members of dependent adults diagnosed with TSC c. Undiagnosed	**Tuberous sclerosis complex (TSC) is a genetic disorder that causes non-malignant tumors to form in different organs, primarily in the brain, eyes, heart, kidney, skin and lungs, and affects approximately 50,000 individuals in the USA and 1 million worldwide. It is the leading genetic cause of epilepsy and autism.** **TSC is considered a linchpin disease, meaning that every advance made in our search for answers and a cure may also lead to answers and advances in other more prevalent diseases like epilepsy, autism and cancer.** **The Tuberous Sclerosis Alliance (TS Alliance) is dedicated to finding a cure for TSC while improving the lives of those affected.** **The TS Alliance believes that by using a multi-pronged approach that includes efforts directed at both research for a cure as well as support and education for the TSC community, it will maximize its impact and improve the lives of those affected with TSC. This includes:** • **Focusing on targeted research to understand course of the disease to identify new treatments and a cure** • **Altering the course of the disease through prenatal diagnosis and preventative treatment to improve the quality of life of those with TSC and to enable them to live as independently as possible** • **Educating medical professionals to achieve faster diagnosis and better treatment aligned with consensus guidelines** • **Community building to empower those living with and caring for those with TSC**	**Accelerate Research** • Grow participation in the TSC Natural History Database, enabling greater understanding of the course of the disease • Develop and use TSC Biosample Repository to identify person-to-person variation in effects of the disease • Distribute research funding for basic biology studies, development of new therapeutics • Grow clinical research consortium to include more clinics, clinicians, and the number of patients in clinical trials to alter the course of the disease	**Accelerate Research** • Enroll 2,000 participants in TSC Natural History Database by 2015 • 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 • Issue 6 new 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 by obtaining $20 million in industry / government funding to conduct clinical studies from 2014-2018	**Short Term Research Outcomes** Within two years: • Increase the number of clinical trials / clinical trial participants testing therapeutic interventions (testing FDA-approved therapeutics for new indications) **Long Term Research Outcomes** Within 5 to 10 years: • Increase understanding of new targets to validate, new therapeutics to shrink / kill tumors • Develop interventional therapies (e.g., prevention of infantile spasms, autism; improved cognition)	**As a result of investing directly in TSC research and in infrastructure to support TSC research, identify treatments that can improve the clinical outcomes and disease burden of individuals affected by TSC.**
			Support and Empower Constituents • Identify more individuals and families affected by TSC • Expand access to quality clinical care for TSC by: ○ Ensuring broad clinician awareness and knowledge of best practices in diagnosis and management of TSC ○ Maximizing availability of TSC Clinics across the lifespan or via telemedicine across the lifespan ○ Referring individuals and families to quality clinical resources, including TSC Clinics and clinicians with TSC experience • Provide educational counseling and referrals • Provide peer / social support via Community Alliances, Adult Regional Coordinators, Dependent Adult Transition Resource Coordinators, regional and world conferences, TSC Connect, and social media • Attract new volunteers via appeal to a broad range of demographic segments for delivery of programs	**Support and Empower Constituents** • Establish new relationships with 4,000 newly identified individuals with TSC by 2018 • Increase the number of professionals at TSC Clinics who are implementing TSC consensus guidelines • Increase participants educated on TSC consensus guidelines via CMEs • Lead sessions and maintain active presence at 15 national / international professional meetings annually • 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 • By directing people to resources via TS Alliance website or contact with staff; ○ Increase website hits / downloads annually by 25% from 2014 to 2018. ○ Increase (and track) 1:1 educational advocacy support contacts, educational training for parents, IEP meetings by state each month • 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 • 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 • Establish 2 Global Alliances by 2015 and 3 more by 2018 • Identify and cultivate a minimum of 200 new CA volunteers by 2018 with eye toward possible community leadership, Government Action Team, board or committee roles	**Short Term Support Outcomes** Within 2 years: • Increase awareness of clinical guidelines • Increase engagement in educational advocacy and improve tailoring of educational services to needs of individuals with TSC • Increase development of peer support among TSC-affected individuals and their families / caregivers **Long Term Support Outcomes** Within 5 to 10 years: • Increase quality of clinical care for TSC by increasing adherence to clinical guidelines • Increase knowledge of procedures of self-advocacy in clinical and educational settings • Increase self-reported social support experienced by individuals and families affected by TSC	**As a result of expanding access to quality clinical care for TSC, improve the clinical outcomes and quality of life of individuals affected by TSC.** **As a result of providing educational, peer and social support, improve the cognitive outcomes and quality of life of individuals affected by TSC and their family members.**