

# Tuberous Sclerosis Alliance



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## Mission

Founded in 1974, the Tuberous Sclerosis Alliance works to find a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected. The alliance focuses on supporting those with TSC and funding research for a cure.

## Strategy/Approach

The alliance focuses its activities in three areas:

- **Accelerate research** – The TS Alliance stimulates and supports basic, translational, and clinical research on the various manifestations of tuberous sclerosis complex to further the development of clinical therapies and, ultimately, a cure. The TS Alliance works closely with NIH and other government agencies to ensure alignment of TSC-focused research funding. Through conferences and funding of consortia, the TS Alliance fosters collaborations among academic investigators, industry, government, and other non-profit organizations.
- The pillars of this research program include:
  - *the TSC Natural History Database;*
  - *a research grants program;*
  - *a drug screening program;*
  - *biomarker development; and*
  - *a TSC clinical research network.*
- **Support TSC care and empower consumers** – Helping those living with TSC is the primary focus of this organization. The TS Alliance works to increase the people being served across the lifespan and make sure all affected have accurate information about TSC services.
- **Educate and mobilize to increase investment** – The TS Alliance spreads its story to the public to increase awareness, support, and funding for TSC research and programs. It aims to increase annual revenue to \$5.5 million to support research, outreach, and advocacy programs and services from both philanthropic and non-philanthropic sources.

## Research Portfolio

The TS Alliance endeavors to stimulate, support and coordinate research that will lead to a cure for TSC while improving the lives of those affected. Resources available include:

- **Research Grants** – awarded to studies that accelerate the translation of basic research findings into improvements in quality of life for those affected by TSC.
  - *Up to \$75,000/year for two years*
- **Postdoctoral Fellowships** – awarded to an investigator who has recently earned a

doctorate or medical degree and is working with a sponsor to perform research relevant to TSC.

- *Up to \$66,000/year for two years*
- **TSC Natural History Database** – access to clinical data on >1300 individuals with TSC to investigators with relevant research questions.
- **TSC Biosample Repository** – high-quality biosamples associated with extensive clinical data (under development in 2014).
- **TSC Preclinical Consortium** – testing of candidate drugs in TSC-relevant *in vivo* models (under development in 2014).
- **TSC Clinical Research Consortium** – efficient and collaborative execution of clinical studies through shared infrastructure and enduring processes.

## Partnership Practices

The TS Alliance actively encourages partnerships that leverage input from individuals affected by TSC, academia, industry, and—when appropriate—government. For example, the TSC Natural History Database benefits from interactions with clinicians at 17 TSC Clinics, partial industry funding, academic and industry input into key questions of interest, and voluntary participation by TSC Clinic patients.

The TS Alliance has a corporate relationship policy enabling it to partner with industry in a variety of ways to advocate for the needs of those affected by TSC without endorsing specific companies or products.

## Financials

The TS Alliance is a 501(c)(3) charitable organization. The most recent financial information available is from 2013.<sup>1</sup>

Year ending 12/31/13:

- Revenue: \$4,151,246
- Net Assets: \$9,171,713
- Grants Paid: \$903,892
- Gifts Received: \$3,239,048
- Expenditures: \$4,085,981

## Key Accomplishments

- Funded more than \$17.3 million in research on TSC since 1984.
- Between 1984 and 2013, Principal Investigators who received a total of \$17.3 million from the TS Alliance garnered an additional \$190 million from the National

<sup>1</sup> TS Alliance Tax Return, <http://tsalliance.org/pages.aspx?content=7>, March 2014.

- Institutes of Health for TSC-related research and \$8.5 million from the Department of Defense's Congressionally Directed Medical Research Program.
- The TS Alliance's TSC Natural History Database identifies specific correlations between TSC gene mutations and the impact of the disease on a person's health over his or her lifetime. As of January 2014, 15 U.S.-based TSC clinics were entering data, with more than 1,300 TSC patients enrolled.
  - A TSC Clinical Consensus Conference was held in June 2012 to update international gold standards for the diagnosis, surveillance, and treatment of individuals with TSC.
  - The TS Alliance hosted the inaugural World TSC Conference in July 2014, bringing together the global TSC community, healthcare providers, industry and government representatives. In 2012-2013, the TS Alliance hosted eight Regional TSC Conferences to inform constituents of the new TSC Clinical Consensus Guidelines, updates in research, and support services available through the TS Alliance.
  - In 2012-2014, the TS Alliance earned the GreatNonProfits Top-Rated Award.
  - TSC Clinical Research Network awarded grants to initiate two clinical trials at five TSC clinics to find biomarkers for newly diagnosed infants.

## Leadership

TS Alliance is governed by a **Board of Directors** and counseled by a **Corporate Advisory Board**.

- **President and CEO:** Kari Luther Rosbeck, [krosbeck@tsalliance.org](mailto:krosbeck@tsalliance.org)
- **Chief Scientific Officer:** Steven L. Roberds, PhD, [sroberds@tsalliance.org](mailto:sroberds@tsalliance.org)
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- **Director of Donor Relations:** Lisa Moss, [lmoss@tsalliance.org](mailto:lmoss@tsalliance.org)
- **Vice President, Communications Strategy:** Jaye Isham, [jishman@tsalliance.org](mailto:jishman@tsalliance.org)