

Global Relations Programs

Global Alliance Program

Officially launched in 2014 with the TSC Alliance of Israel, the TSC Alliance Global Alliance Program was created as a way to address unmet needs within the global TSC community at the country level. This program provides the opportunity for the TSC Alliance to share experiences and assist in the start-up or support of TSC-related organizations in other countries.

A Global Alliance is a structured group of empowered and caring volunteers who work closely with the TSC Alliance to accomplish the following: facilitate local connections for individuals and families affected by TSC, raise revenue, and increase awareness while supporting the mission of the organization. The Global Alliance program forges stronger links between the TSC Alliance, communities, and individuals around the world.

As of December 2024, the TSC Alliance has the following formal global partnerships in place:

- TSC Alliance of Israel (2014, renewed 2019)
- Tuberous Sclerosis Canada Sclérose Tubéreuse (2016, renewed 2019)
- TSC Alliance of Mexico (2016)
- Hungarian Foundation for Tuberous Sclerosis (2017)
- TCS Alliance of India (2018)

The TSC Alliance currently recognizes 14 global TSC Clinics: five in Canada, four in Israel, two in Mexico, and three in India.

The TSC Alliance is actively working to expand Natural History Database (NHD) activity internationally and has partnered with TSC Canada ST to expand the NHD and Biosample Repository internationally at the TSC Clinics in Montreal. The TSC Alliance is also working with the TSC Alliance of Mexico and TSC Alliance of India on compatible versions of the NHD in their countries.

Additional International Activity

The TSC Alliance is working to expand its global footprint and identify collaboration opportunities on a global level. Currently, the TSC Alliance is involved in the following:

- The Rare Diseases International (RDI) and World Health Organization's (WHO) Collaborative Global Network for Rare Diseases (rarediseasesinternational.org/collaborative-global-network/), which aims to ensure individuals with rare diseases have access to care no matter where in the world they live.

- The TSC Alliance also works closely and is represented in the TANDem Consortium, an international collaboration looking at TSC-Associated Neuropsychiatric Disorders (TAND). tandconsortium.org/

Tuberous Sclerosis Complex International (TSCi)

The TSC Alliance is an active member of TSCi, a world-wide consortium of existing tuberous sclerosis complex associations and organizations, serving as an avenue of support for those affected by tuberous sclerosis complex (TSC), including individuals, families, caregivers, educators and health care providers. In addition, TSCi provides a forum to share information, exchange ideas and methods, co-fund research projects, and promote increased international awareness of TSC. As of December 2024, TSCi consists of 38 countries from six continents. The TSC Alliance continues to serve as the TSCi coordinating center and is co-chaired by Katie Smith (TSC Alliance) and Eva Schoeters (be-TSC, Belgium).

Currently TSCi is focusing on global clinical trials in TSC and best ways for TSC organizations, healthcare providers, and industry partners to collaborate.