

COMMUNITY ALLIANCE OVERVIEW

WHAT IS A COMMUNITY ALLIANCE?

The words *community* and *alliance* mean, “joining together for a common Purpose.” A community alliance is an informal, yet structured, group of empowered and caring volunteers who work closely with the TS Alliance to facilitate local connections for individuals and families affected by TSC, raise revenue, and increase awareness while supporting the mission of the organization. The Community Alliance program fosters stronger links between the TS Alliance, communities and individuals across the country.

The Community Alliance Program was developed specifically to drive forward the TS Alliance mission on a local level. Local volunteers are able to more effectively support an area’s individuals and families with TSC all while furthering the TS Alliance mission and expanding the services available. Through the mirror of the mission statement and similar goals, the Community Alliances in summary deliver the organization’s mission to each local area.

MISSION STATEMENT

Each local Community Alliance is dedicated to finding a cure for tuberous sclerosis complex while improving the lives of those affected.

PURPOSE STATEMENT

Each local Community Alliance is committed to improving the quality of life for individuals and families affected by tuberous sclerosis complex (TSC) through:

- The stimulation and generation of revenue for the purpose of furthering and funding research into the diagnosis, cause, management and care for TSC via the national TS Alliance research programs;
- The delivery of support programs providing individuals with TSC and their families access to support services, resource information and health care professionals engaged in the diagnosis, treatment and management of TSC;
- The implementation of the educational advocacy program supporting individuals and families in the areas of school services, housing, employment and independent living; and
- The implementation of the clinic ambassador program in those communities that are serviced by a TSC clinic.

COMMUNITY ALLIANCE PROCEDURES

NAME

The Tuberous Sclerosis Alliance authorizes the formation of a Community Alliance to be known as the Tuberous Sclerosis Alliance of _____ (specific area) to cover the geographic area of _____.

AFFILIATION

The Community Alliance, though self-governing, operates under the Certificate of Incorporation and Bylaws of the TS Alliance and by the TS Alliance's policies and procedures. A Community Alliance is not separately incorporated.

PURPOSE

The Tuberous Sclerosis Alliance is committed to improving the quality of life for individuals and families affected by tuberous sclerosis complex (TSC) through:

- the stimulation and sponsorship of research into the diagnosis, cause, management and care for TSC;
- the development of programs providing individuals with TSC and their families access to support services, resource information and health care professionals engaged in the diagnosis, treatment and management of TSC; and
- the development and implementation of public and professional education programs designed to heighten awareness of TSC, thereby prompting early, accurate diagnosis and effective treatment of TSC.

MEETINGS

Community Alliance members meet at least once annually at a date to be determined by the Community Alliance chair in a location within the Community Alliance geographic area.

The purpose of the meeting is to inform and update alliance members of support group meetings, educational meetings, a community gathering such as a picnic or a large community special event such as a walkathon. You decide what works best for your community. Again, the TS Alliance staff will provide materials, support and guidance.

Community Alliance members need to be informed of meetings at least one month in advance. Communication regarding the date, time and place of the meeting may be by letter, flyer, or e-blast done by the TS Alliance.

COMMUNITY ALLIANCE LEADERSHIP

The leadership of a Community Alliance is a chair/co-chair and possibly vice chair. The Community Alliance chair/co-chairs are responsible for participation in individual and family support, community fund raising. The leadership follows the policies and procedures of the TS Alliance.

- **Terms of Service** - The terms of service for chairs and committee coordinators is two (2) years. Chairs may choose to renew their commitment at the conclusion of their term.
- **Vacancies** - Vacancies in the Community Alliance chair may be filled by a Community Alliance member. In an alliance with an active vice chair, the vice chair fulfills the remaining term of the chair.
- **Compensation** - Alliance chairs serve without compensation and cannot be employees of the TS Alliance.

COMMUNITY ALLIANCE POSITIONS

The goals of the community alliances are attained through the generous and compassionate support of local volunteers. These are unpaid positions that are supported and managed through the TS Alliance offices. The structure of each Community Alliance may differ depending on local needs, strengths and desires of the local community. In general it is recommended that the following roles be filled in each community alliance to maximize the opportunity and attainment of the Community Alliance mission and goals.

- **Chair**

The responsibilities of the Community Alliance chair are as follows: provide one-on-one support to those that contact the TS Alliance seeking a connection in the local area; to organize social activities like picnics or holiday parties, support groups or educational sessions with featured speakers. The chair should be the point of contact for individuals and families seeking more information on local services, professional services, and TS Alliance programs; communicates information from the Community Alliance to the TS Alliance and from the TS Alliance to the Community Alliance; and manages an operational budget provided for by the TS Alliance CEO. The chair is expected to attend the annual March on Capitol Hill and leadership training meetings in the beginning of each year through obtaining appointments and meeting with Congressmen for their Alliance's area of coverage to discuss government research funding for TSC. This position is supported by the Community Outreach Manager.

- **Vice Chair (Chair Elect)**

The Community Alliance vice chair is vested with the powers and duties of the Community Alliance chair and becomes chair in the event of the absence or disability of the Community Alliance chair. The vice chair performs such other duties as the chair may from time to time prescribe. This position is supported by the Chair.

- **Adult Initiatives Coordinator**

The Adult Initiatives Coordinator provides local support to adults living with TSC. They work with the chair to plan and organize activities within the Community Alliance that encourages the participation of adults living with TSC. This position is supported by the Director of Advocacy and Education.

- **Education Liaison**

The Educational Liaison will be responsible for contacting the Parent Training and Information (PTI) Centers in their State (Region). They will provide the PTI Centers with a packet (provided by the National Office) of information and an introductory letter introducing themselves and the TS Alliance. Parent Training and Information Centers provide parents/caregivers with free trainings, advocacy, and information on Special Education. This will open the door for the Educational Liaison to connect families to the PTI Center's trainings and supports in the area of educational advocacy. It will be the Education Liaison task to build relationships with at least one contact person at each PTI. This position is supported wholly by the Director of Advocacy and Education. It will be the responsibility of the Director of Education and Advocacy to educate the Educational Liaison in IDEA, 504, and ADA (as needed) and in government legislation advocacy as it relates to educational law such as the reauthorization of IDEA.

- **Clinic Ambassador**

The Clinic ambassador is responsible for providing emotional assistance to newly diagnosed families, including the development of relationships with parents to help in the navigation of care for their child diagnosed with TSC. Assist in helping them navigate through the specialists that are crucial to their child's care and provide local as well as regional resources. Keep them informed and updated of the services and the work that the TS Alliance is accomplishing as well as informing them about their local Community Alliance. This position is supported by the Community Outreach Manager, Director of Clinical Projects/Clinic Liaison, and the Director of Education and Advocacy.

- **Special Events Chair**

Organizer of special event(s) in your local community to raise funds for the TS Alliance. The funds generated by special events are integral in the organization's mission to provide funding for individual and family support, research to find a cure and outreach efforts to increase the visibility of TSC and the TS Alliance through local media. This position is supported by the Community Outreach Manager.

TSC CONNECT – ADDITIONAL COMMUNITY RESOURCES

The Tuberous Sclerosis Alliance TSC Connect (formerly the Support Network and Matching Program) is an organized partnership of individuals whose lives have been affected by tuberous sclerosis complex (TSC). The volunteers are committed to offering support and sharing their experiences with others who are faced with the challenges of tuberous sclerosis complex. Across the nation, TSC Connect is providing the latest medical information, education and support to those individuals who are seeking understanding about the genetic disorder and offering them words of encouragement and empowerment. Volunteers come to the network with a wealth of knowledge, awareness and experiences. The TS Alliance TSC Connect is designed to connect individuals either by specific geographical area, manifestations, or age of TSC individual and lets volunteers choose the issues that they have personal experience with and are willing to discuss with others. The TSC Connect is supported wholly by the Director of Advocacy and Education.