



community leadership



Purpose Statement

Grow a collaborative leadership network that puts the TSC community center – focusing on local resources, support services, and access to medical care – in conjunction with energizing the current and future volunteer leaders to propel the TSC Alliance to the next level.

TSC Alliance Community Alliance Leadership Opportunities

Thank you for your interest in volunteering to support the TSC Alliance and its community. Our greatest ally is the TSC community, and we rely on the commitment and help of our volunteers.

Through community-based outreach and services, fund-raising campaigns, and educational programs, volunteers can feed their desire to deepen their engagement to their community. We wish you success, development, and fulfillment in your role as a TSC Alliance Community Leader.

You are a welcome addition to the group! To make volunteering a richer experience for you, do not be afraid to share your thoughts and inquiries with us.

TSC Alliance Community Programs Team Contact Information

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Position: Community Alliance Lead (CA Lead)

Key Role:

Work in partnership with the TSC Alliance, Community Alliance Co-Lead, TSC Clinic Ambassador/Medical Resource, and Adult Resource and Support Lead to provide and promote access to local medical professionals, grow and strengthen community relationships.

Responsibilities:

- Host at least one social meeting and two educational gatherings in collaboration with a TSC Clinic or local experts appointed by the TSC Alliance.
- Build and nurture (new and existing) relationships within the TSC community.

Skill Set/Requirements:

- Willingness to collaborate with the local community to develop and
- maintain a network of professionals that support and serve local families.
- Willingness to develop effective communication skills to convey information among the TSC Alliance, local leaders and the TSC community.
- Ability to plan, host and organize community events and meetings.
- Ability to analyze problems and develop solutions.

Training:

TSC Alliance will provide on-going training and mentoring opportunities, including orientation training and quarterly leadership meetings. Specialized training will be shared periodically to broaden knowledge and support about unconscious bias and underrepresented populations in your region.

The volunteer in this position **may** also receive an invitation to attend our annual Volunteer Leadership Summit in Washington, DC.

Term Options: minimum of 3 years

Position: Community Alliance Co-Lead

Key Role:

Work in collaboration with the Community Alliance Lead to provide and promote access to local health professionals, host local gatherings and provide oversight and leadership.

Responsibilities:

- Work with the Community Alliance Lead to organize at least one social meeting and two educational gatherings in collaboration with a TSC Clinic or local experts.
- Work with the Community Alliance Lead to strengthen relationships in the TSC community.
- Provide oversight and leadership in the absence of the Community Alliance Lead.

Skill Set/Requirements:

- Willingness to collaborate with the local community to develop and maintain a network of professionals that support and serve local families.
- Willingness to develop effective communication skills to convey information among the TSC Alliance, local leaders and the TSC community.
- Ability to plan, host and organize community events and meetings.
- Ability to analyze problems and develop solutions.

Training:

TSC Alliance will provide on-going training and mentoring opportunities, including orientation training and quarterly leadership meetings. Specialized training will be shared periodically to broaden knowledge and support about unconscious bias and underrepresented populations in your region.

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Term Options: minimum of 3 years

Position: Community Fundraising Lead

Key Role:

Cooperate closely with the TSC Community to encourage, conduct, and take part in community fundraising activities.

Responsibilities:

- Assist in planning and executing community fundraising activities.
- Create strong and productive working connections with members of the community to foster a collaborative environment.
- Encourage new donors to donate while staying connected with and strengthening connections with current donors.

Skill Set/Requirements:

- Ability to organize, prioritize and meet deadlines.
- Ability to inspire and motivate supporters.
- Demonstrable interpersonal and relationship building skills.
- Ability to analyze problems and develop solutions.

Training:

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Term Options: minimum 2 years

Position: Community Support Lead

Key Role:

Maintain and expand the community support system and give the TSC Alliance up-to-date, correct information. Create and maintain relationships with individuals with TSC and their families who are looking for local support along their journey.

Responsibilities:

- Network with local families to identify and maintain the TSC Connect network and provide a variety of support opportunities for families.
- Lead at least one annual support meeting in the alliance and motivate others.
- Track and report monthly interactions (peer-to-peer report and inquiry form).

Skill Set/Requirements:

- Willingness to collaborate with people who have TSC to create and sustain a peer network that supports and serves the TSC community.
- Willingness to develop effective communication skills to convey information among the TSC Alliance, local leaders and the TSC community.
- Ability to analyze problems and develop solutions.

Training:

TSC Alliance will provide on-going training and mentoring opportunities, including orientation training and quarterly leadership meetings. Specialized training will be shared periodically to broaden knowledge and support about unconscious bias and underrepresented populations in your region.

The volunteer in this position **may** also receive an invitation to attend our annual Volunteer Leadership Summit in Washington, DC.

Term Options: minimum of 3 years

Position: Community Resource Lead

Key Role:

Develop new and existing relationships with people who have TSC and their families who ask for information about state and local resources (waivers, Medicaid, Medicare, SSI).

Responsibilities:

- Provide relevant resources that are local/state level to maximize their independence within their community. General resources and specialty resources include:
 - **Dependent Adult Transition Resource Coordinator** – specializing in dependent adults' transition and
 - **Education Peer Mentor** – specializing in providing educational resources that are local/state based to peers, and school systems to determine eligibility.
- Track and report monthly interactions (peer-to-peer report and inquiry form).

Skill Set/Requirements:

- Give preference to people who have relevant expertise securing local or state resources. Availability to take part in specialist training during your term.
- Willingness to develop effective communication skills to convey information among the TSC Alliance, local leaders and the TSC community.
- Ability to analyze problems and develop solutions.

Training:

TSC Alliance will provide on-going training and mentoring opportunities, including orientation training and quarterly leadership meetings. Specialized training will be shared periodically to broaden knowledge and support about unconscious bias and underrepresented populations in your region.

The volunteer in this position **may** also receive an invitation to attend our annual Volunteer Leadership Summit in Washington, DC.

Term Options: minimum of 3 years

Position: Adult Support and Resource Lead

Key Role:

Establish and cultivate (new and existing) relationships with adults with TSC to maximize their independence by offering assistance and resources.

Responsibilities:

- Attend TSC-related events, conferences, and gatherings on a local level as a TSC Alliance liaison.
- Network and build relationships with adults with TSC.
- Track and report monthly interactions (peer-to-peer report and inquiry form).

Skill Set/Requirements:

- Give preference to people who have relevant expertise working with individuals with TSC and local/state resources.
- Willingness to develop effective communication skills to convey information among the TSC Alliance, local leaders and the TSC community.
- Ability to analyze problems and develop solutions.

Training:

TSC Alliance will provide on-going training and mentoring opportunities, including orientation training and quarterly leadership meetings. Specialized training will be shared periodically to broaden knowledge and support about unconscious bias and underrepresented populations in your region.

The volunteer in this position **may** also receive an invitation to attend our annual Volunteer Leadership Summit in Washington, DC.

Term Options: minimum of 3 years

Position: TSC Clinic Ambassador OR Medical Access Lead

Key Role:

A liaison who works in collaboration with the local TSC Clinics to connect families with the TSC Alliance and medical resources. The liaison will provide support to local families and TSC Alliance resources.

Responsibilities:

- Works in collaboration with the Community Alliance Lead and/or Co-Lead on providing access to medical care options that exist locally.
- Provide TSC Alliance resources, support services, and networking opportunities to new TSC families.
- Help identify and strengthen the underrepresented populations within your region.

Requirements:

- Network and build relationships with individuals with TSC and their families that receive care at TSC Clinics and /or a Clinic of Excellence.
- Track and report monthly interactions (peer-to-peer report and inquiry form).
- Annually attend training provided by the TSC Alliance, inclusive of unconscious bias to expand knowledge and support of underrepresented populations within your region.

Skill Set Required:

- Demonstrable interpersonal and relationship building skills.
- Willingness to develop effective communication skills to convey information among the TSC Alliance, local leaders and the TSC community.
- Ability to analyze problems and develop solutions.

Training:

TSC Alliance will provide on-going training and mentoring opportunities, including orientation training and quarterly leadership meetings. Specialized training will be shared periodically to broaden knowledge and support about unconscious bias and underrepresented populations in your region.

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Term Options: minimum of 3 years

Position: Government Action Lead

Key Role:

Over the course of the year, develop relationships with 10 to 15 designated federal U.S. House of Representatives and/or Senate offices.

Responsibilities:

- Remain up to date on TSC research initiatives funded by the Department of Defense and other US government agencies.
- Coordinate and follow up with assigned congressional office visits.
- Track and report interactions with assigned congressional offices.

Skill Set Required:

- Experience in communicating with congressional offices.
- Professional communication skills
- Planning and organizational skills

Training:

TSC Alliance will provide TSC Advocacy training and mentoring opportunities, including orientation training and quarterly leadership meetings. Specialized training will be shared periodically to broaden knowledge and support about unconscious bias and underrepresented populations in your region.

The volunteer in this position **may** also receive an invitation to attend our annual Volunteer Leadership Summit in Washington, DC.

Term Options: minimum of 2 years