

TSC Alliance
Silver Spring, Maryland

Senior Community Programs Manager

The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with tuberous sclerosis complex (TSC). We drive research, improve quality care and access and advocate for all affected by the disease. The TSC community is our strongest ally. The collaboration of individuals and families, along with the partnership of other organizations, fuels our work to ensure people navigating TSC have support—and hope—every step of the way.

- We use a comprehensive approach to improve quality of life for people with TSC—fueling promising research while making sure that, day-to-day, individuals are diagnosed early and receive the highest quality care available. We also use our voice in policy around equitable healthcare access and federal funding for TSC research.
- Our work wouldn't be possible without the commitment of our community. Advancing research requires dedicated investigators, individuals with TSC, government and industry. Improving quality of and access to care demands healthcare professionals and dedicated volunteers. Raising awareness takes the work of families, individuals and volunteers.
- We want to create an environment where all individuals feel included; our organization reflects and serves the broad diversity of our community; and we bridge health inequities.

With an annual budget of \$7.1 million, the TSC Alliance advocates with and on behalf of our community to ensure everyone living with TSC has what they need to live their fullest lives. Across the United States, 36 volunteer branches of our organization, called Community Alliances—along with Adult Regional Coordinators, Future Leaders, Resource Coordinators, and TSC Clinic Ambassadors—help educate local individuals and families about advances in TSC research and treatments and provide support to those living with the daily challenges of TSC. A vibrant social media community also offers peer support through Inspire, Facebook and Instagram, some of whom are not currently involved in the TSC Alliance in any other way. In addition, community special events provide a way for individuals and families to feel empowered in the fight against TSC, help fuel our ability to fund local educational meetings and drive TSC research forward. In 2020, special events accounted for 24% of our organizational budget. Community Outreach is an important and vital component of our strategic plan and delivery of our mission.

The Senior Community Programs Manager is responsible for developing and implementing programs that build, grow and advance a national volunteer outreach network. In this role, the Senior Manager will establish and execute strategies to reach underrepresented communities to provide meaningful support, advocate for and connect to comprehensive care clinics and create an environment where all individuals living with TSC feel included in leadership and volunteer activities. The Senior Manager will work with the Community Programs Manager, create support and educational activities for individuals of all ages and their families affected by TSC, expand public and professional awareness, further advance government outreach in the local community, and organize a portfolio of community-based special events. In addition, the Senior Manager will lead all adult specific programming including the Regional Adult Coordinators and Future Leaders as well as any open forums, support groups or educational events specific for this population.

ORGANIZATIONAL STRUCTURE AND INTERFACES

Reports to: Vice President, Community Programs

Primary Interfaces (internal): CEO, Vice President of Donor Relations, Director of Medical Affairs, Director of Clinical Projects and TSC Clinic Liaison, Senior Vice President of Strategic Communications, Director of Digital Platforms, Director of Global and Government Affairs, Development Systems Manager

Primary Interfaces (external): Volunteers, board of directors

DIRECT REPORTS

- Community Alliance leaders
- Adult Regional Coordinators
- Future Leaders
- Grassroots volunteers
- Activities of the Outreach Committee of the TSC Alliance Board of Directors.

RESPONSIBILITIES

Recruit, train and recognize volunteers of the organization in order to create stronger, inclusive support networks, educational programming and visibility of the organization. Serve as a mentor to the Community Programs Manager to ensure the success of the entire program.

Volunteer Management:

- Oversee and provide strategic program development for Community Alliance initiatives, including budget development and management, which reflect the diversity of our community.
- Recruit volunteers in coordination with local Community Alliance leadership, TSC Clinics, other community volunteers and social media. Clearly communicate expectations and review job descriptions.
- Develop, lead and implement adult programming including Adult Regional Coordinators and Future Leaders.
- Reach out to underrepresented communities to establish relationships and cultivate volunteer leaders.
- If the volunteer is a new Community Alliance Chair, provide training on policies and procedures per the Community Alliance agreement and outline expenses.
- Develop strategies for identifying and serving families via social media. Monitor the message postings for social networks including, but not limited to Facebook, Instagram and Inspire, on a daily basis.
- Recognize volunteer achievement in a timely fashion.
 - Develop and implement annual volunteer appreciation campaign.
 - Assist with Volunteer and Community Alliance of the Year Nominations process and awards ceremony.
- Develop succession planning for leadership within the Community Alliance to ensure stability of volunteer network.
- Work with Vice President, Community Programs on developing and leading volunteer training, including revisions to current processes and agenda of training programs.
- Plan and organize annual Volunteer Leadership Training in Washington, DC.
- Coordinate and lead quarterly Community Alliance Chair webinars and assist in any necessary follow-up.

Planning and Reporting:

- Coordinate with Community Programs team and volunteers to plan and implement educational and support forums in their local communities.
- Intentionally work to organize events in underrepresented communities through webinars for those who have access to internet or deliver information from events through peer-to-peer support.
- Assist adult leaders in the development of national and local educational and support meetings both in person and virtually.

- Facilitate volunteer requests including database lists/labels, fulfilling meeting venue application, providing certificate of insurance and fulfilling purchase orders and information requests.
- With Vice President, Community Programs, assist in the development of the entire Community Programs budget and track expenses to ensure the program follows annual budgeted expenses.
- Update Community Alliance activity report weekly; utilize information for CEO report and annual State of the TSC Communities Report.
- Track volunteer involvement (hours, roles, history) in the TSC Alliance database.
- Review, approve and submit volunteer expense reports and track reimbursement.

Marketing and Visibility:

- Assist Community Alliances in any special mailings, e-blasts or posts that need to be coordinated, materials that need to be created and necessary follow-up.
- Ensure any images used in marketing meetings or events are representative of our entire community and reflect those of all ages, abilities and races.
- Develop Community Programs initiatives and assist volunteers in implementing campaigns aimed at increasing the visibility of TSC and the TSC Alliance.
- With Adult Regional Coordinators and Future Leaders, provide updates to Adult and Young Adult web page, including creation of new content.
- Manage programs and create materials that increase and enhance professional outreach.
- As needed, write and submit articles for *Perspective* magazine and social media channels.
- Solicit and prepare updates as needed to the Volunteer Outreach Program and Community Alliance web pages.

Government Outreach:

- Work with grassroots volunteers on implementation of government outreach initiatives aimed at increasing TSC research funding from governmental sources.
- Assist Director of Global and Government Affairs with March on Capitol Hill, preparation of materials and follow-up.
- With Director of Global and Government Affairs, develop strategies to support the Government Action Team to grow activity and advance relationships in home congressional districts.
- Grow the participation in government advocacy on a federal and local level by individuals who reflect the diversity of our community.

Community Special Events

- Serve as a resource and staff support to assigned Step Forward to Cure TSC events.
- Identify and cultivate volunteers to chair and lead special events and work with the chairs to recruit and maintain volunteer committees.
- Create planning timelines and check lists for assigned special events and ensure tasks are completed in a timely fashion.
- Work with volunteer committees on all aspects of planning including overseeing logistics; securing venue and permits; recruiting additional committee members; soliciting honorary chairs, sponsorships, in-kind items and prizes; and processing expense reports or vendor invoices.
- Consider locations that are inclusive of underrepresented community members or provide a means for their active participation.

- Develop and implement strategies to generate interest in events and track progress for achieving the event goals (revenue and expense items).
- Assist volunteer committees in maximizing event potential.

Other:

- Serve as staff liaison to the Equity, Diversity and Inclusion Task Force.
- Enhance professional growth and competence through study and participation in conferences, workshops and professional related organizations.
- Represent the organization at special events, Community Alliance meetings and other public functions.
- Attend administrative meetings as required.
- Act as a team player and communicate Community Alliance and volunteer information within the organization.
- Maintain positive relationships with volunteers, colleagues, board members and other constituents.
- Perform other duties as directed.

CORE VALUES

Build Value-Based Relationships: Generating alliances internally and externally by continuously identifying and acting on those things that will create success for the organization and its constituents, researchers, health care professionals and communities.

Contribute to Team Success: Actively participating as a committed member of a team and working with other team members to help complete goals and deliverables.

Customer Focus: Making customers (external and internal) and their needs a primary focus of one's actions; developing and sustaining productive relationships; and creating and executing plans and solutions in collaboration with team members internally and externally.

Provide and Accept Feedback: Objectively observing, analyzing, and sharing perception of other people's performance to help reinforce or redirect behavior to improve performance and results and providing feedback that is timely, specific, behavioral, balanced and constructive.

Work Standards: Setting high standards of performance for self; assuming responsibility and accountability for successfully completing assignments or tasks; and self-imposing standards of excellence rather than having standards imposed.

Consult: Providing timely, specific information, guidance, and recommendations to help volunteers, Community Alliances and fellow staff members make informed committed decisions that will lead to sustainable impact.

Establish Collaborative Working Relationships: Developing and using collaborative relationships to accomplish work objectives; developing relationships with other individuals by listening, sharing ideas; and appreciating others' efforts.

Equity, Diversity and Inclusion: Ensure equity, diversity and inclusion permeate our organization and our work.

Successful completion of the projects noted in the success factors above requires cooperation with our staff team, board, volunteers, donors and key corporate and foundation partners. Quickly establish working relationships to complete projects as described above.

QUALIFICATIONS

- Bachelor's degree (preferably in Communication, English, Journalism, Marketing or other related field).
- Four or more years of experience in volunteer coordination or grassroots advocacy.
- Excellent written and verbal communication skills as well as organizational skills.
- Experience working with volunteer committees and board of directors.
- Ability to work independently while contributing to team efforts.
- Proficiency in MS Office (Word, Excel, Access, etc)
- Proficiency in Blackbaud "Raiser's Edge" (or similar) database a plus including "Classy."
- Must be comfortable with public speaking.
- Willingness to travel as well as able to work a flexible schedule, including evenings and weekends.