TSC Alliance®
Silver Spring, Maryland

Research Project Assistant

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, increase 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 $8.1 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. Reporting to the Senior Manager, Research Projects (SMRP), the Research Project Assistant (RPA) will contribute to the success and impact of our TSC Natural History Database (NHD) and Biosample Repository (BSR) to help industry partners, academic researchers, and other organizations to better understand and treat TSC. The RPA will receive all necessary training for the protection of Human Subject's research, obtain informed consent from individuals to participate in the NHD BSR projects, complete clinical-related data entry, interact with TSC Alliance staff members, and contribute to other TSC Alliance research initiatives as needed.

This will be a temporary part-time position (three days per week in office, max 24 hours), where the work will be performed in-person at the TSC Alliance office in Silver Spring, MD. This position will begin November 2024 and may continue through April 2025 with possibility of extension.

ORGANIZATIONAL STRUCTURE AND INTERFACES

Reports to: Senior Manager, Research Projects (SMRP)
Primary Interfaces (internal):   Chief Scientific Officer (CSO); Science Project Manager (SPM); entire Science & Medical Department; CEO; CFO; Chief of Staff; Senior Accountant; Development Systems Manager.
Primary Interfaces (external):   Electronic data capture system vendor, TSC database site personnel, TSC Biorepository site personnel, individuals with TSC and their families.

MAJOR FUNCTIONS

- In partnership with the Senior Manager, Research Projects (SMRP), CSO, and other TSC Alliance staff, contribute to the growth and quality of a TSC research program by coordinating collection of

biosamples, obtaining medical records, and completing skillful data entry into a data capture system from individuals with TSC.

RESPONSIBILITIES

TSC Natural History Database and Biosample Repository:

- Complete data entry from medical records obtained from external institutions for consented TSC patients into the TSC Natural History Database (NHD).
- Consent individuals for participation in TSC Alliance research projects.
- Send medical record requests and schedule in-home mobile phlebotomy visits with individuals with TSC and/or their caregivers.
- Communicate via email, phone or fax as needed to TSC Database site personnel.

Other Duties:

- Assist Science and Medical Department by tracking tasks and external relationships within project management platforms.
- Other duties as assigned.

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

- Minimum Bachelor's (BA or BS) degree preferred, preferably in a science/medical field.

- Experience in medical terminology preferred by not required.

- Completion of human subjects' research protection (CITI / GCP) training within two weeks of initiating job will be required. A copy of the certification of completion of the CITI training is required.

- Comfort with technology is required, including utilization of data entry software (ex: StudyTrax, Qualtrics, REDCap), setting up and utilizing web meetings, teleconferences (ex: Zoom), online secure sharing of documents, faxing, and scheduling meetings across multiple time zones. Proficiency in Microsoft Word, PowerPoint and Excel is expected.

- A desire to work with patients and caregivers in rare disease communities as partners in research.

- Good interpersonal skills and ability to work in a non-profit environment.

- Strong organizational skills and attention to detail with minimal supervision.