

TSC Alliance
Silver Spring, Maryland

Research Project Manager

The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with 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 \$9.9 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 Director, Research (DR), the Research Project Manager (RPM) will contribute to the success and impact of our TSC Natural History Database (NHD) and Biosample Repository (BSR) and will implement workshops to develop innovative approaches to better understand and treat TSC-associated neuropsychiatric disorders. The RPM will receive all necessary training for the protection of human research subjects, obtain informed consent from individuals to participate in the NHD and BSR projects, interact with many TSC Alliance staff members and dozens of external researchers and healthcare professionals, and contribute to other TSC Alliance research initiatives as needed.

This is a full-time position, and the work may be performed remotely or at the TSC Alliance office in Silver Spring, MD.

ORGANIZATIONAL STRUCTURE AND INTERFACES

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| Reports to: | Director, Research (DR) |
| Primary Interfaces (internal): | DR; Director, Medical Affairs (DMA); Chief Scientific Officer (CSO); Chief Executive Officer (CEO); Science Project Manager (SPM); Vice President, Translational Research (VPTR); Manager, Translational Research (MTR); Senior Staff Accountant (SSA); Communications Department; Community Programs Department |
| Primary Interfaces (external): | Electronic data capture system vendor, TSC Database site personnel, TSC Biosample Repository site personnel, individuals with TSC and their families |

RESPONSIBILITIES

In partnership with the Director, Research, contribute to the growth and quality improvement of a program to collect biosamples, medical records, and patient-reported outcomes from individuals with TSC.

- Complete data entry from medical records into the TSC Natural History Database. Monitor the database and conduct audits for accuracy and completion.
- Consent individuals for participation in TSC Alliance research projects.

- Track and report to internal and external constituents on progress toward milestones and goals.
- Work with researchers, community members, Science Department staff, the Communications Department, Community Programs, and global collaborators to get input and design patient-reported outcomes fields to be added to the TSC Self-Report Portal and implement those changes to the database.
- Administrative duties such as:
 - Sending medical record requests and scheduling in-home phlebotomy visits with individuals with TSC or their caregivers.
 - Communicating by email, phone, or fax as needed to pathology departments at clinic sites to assess historical tissue availability.
 - Communicating by email, phone, or fax as needed to TSC Database Site Personnel to resolve issues with database entries.
 - Coordinating meetings and workshops.

Contribute to stimulating innovative TSC research in partnership with other Science Department staff.

- Help plan and implement Innovation Workshops on under-resourced areas such as TSC-associated neuropsychiatric disorders.
- Administer contracts to fund research priorities identified at Innovation Workshops, track progress towards goals, and recommend steps to address unexpected issues.

Cross-train with Science Department staff to ensure project commitments (e.g., payments, approvals, regulatory notices) are met in case of sudden or prolonged staff absences.

Assist the Director, Research and 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 perceptions 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.

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

- A bachelor's degree with at least three years' experience working on relevant research projects is required, or an advanced degree.
- A desire to work with patients or caregivers as partners in research.
- Experience with scientific project management, clinical research coordination, and IRB processes are preferred.
- Proficiency in medical terminology preferred.
- Completion of human subjects' research protection training within two weeks of initiating job will be required.
- Excellent oral and written communication skills to a wide range of stakeholders including researchers, clinicians, patients, and the lay public.
- Excellent organizational skills and strong attention to detail, with proven ability to handle multiple tasks efficiently and effectively.
- Ability to effectively analyze project-specific data/systems to ensure accuracy and efficiency.
- Flexibility to reprioritize workload to meet changing project timelines.
- Ability to problem-solve and complete tasks with minimal oversight.
- Comfort with technology, including setting up and utilizing web meetings, teleconferences, online secure sharing of documents, and scheduling meetings across multiple time zones. Proficiency with Microsoft Word, PowerPoint, and Excel is expected.
- Ability to work well with others as part of a team, particularly a team in which accountability and responsibilities are shared with others. The successful candidate will seek to grow and learn continuously and to share his/her/their own knowledge and experience with others.
- Ability to travel occasionally within the continental United States. Trips may occur over a weekend 1-6 times per year.