

Director of Clinical Quality Improvement Research

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 Vice President, Translational Research, the Director of Clinical Quality Improvement Research will be responsible for managing and leading initiatives and collaborations in quality improvement (QI), clinical care and clinical research aligned with the TSC Alliance's strategic plan and research business plan. This role is a hands-on position that includes driving progress of multiple research collaborations, reporting on project outcomes, scheduling and planning meetings and pursuing other project management-related functions. The Director of Clinical Quality Improvement Research will interact with many TSC Alliance staff members, especially within the Science and Outreach Departments, and with dozens of external researchers and healthcare professionals. Through internal and external collaborations, this role will impact quality of care and outcomes for individuals living with TSC and accelerate the translation of discoveries into clinical trials and, eventually, improved treatments and outcomes for TSC. This will be a full-time hybrid position (three days per week in the Silver Spring office, two days working from home) for a local candidate or a fully remote position for a candidate who is not in the Washington, DC, area.

ORGANIZATIONAL STRUCTURE AND INTERFACES

Reports to:	Vice President, Translational Research (VPTR)
Primary Interfaces (internal):	VPTR; Manager, Translational Research; Chief Scientific Officer (CSO) and entire Science Department; Outreach Department (includes Government and Global Affairs, Communication, and Community Programs and Support); CEO; CFO; Senior Staff Accountant
Primary Interfaces (external):	Academic and industry researchers and healthcare providers, vendors and contract research organizations (CROs), TSC Preclinical Consortium, TSC Clinical Research Consortium, TSC Clinic Committee, Professional Advisory Board, Science and

Medical Committee of the Board of Directors, individuals with TSC and their families and caregivers

MAJOR FUNCTIONS

- Manage/lead the implementation of quality improvement initiatives working closely with TSC Clinic directors and staff, the TSC Alliance's Community Programs staff and volunteer community leaders.
- Help drive research projects to enable evidence-based recommendations for reproductive and perinatal care in TSC in collaboration with the Reproductive and Perinatal Health Task Force.
- Contribute to the success of the TSC Clinical Research Consortium (CRC) by growing and diversifying membership and managing projects prioritized by the TSC Steering Committee and company-sponsored trials.

RESPONSIBILITIES

Facilitate Quality Improvement (QI) Research leading to data-driven changes of evidence-based guidelines for TSC reproductive and perinatal health (RPH) challenges, including:

- Identify leading indicators of health disparities and gaps in clinical care through longitudinal tracking of TSC or LAM (lymphangi leiomyomatosis) pregnancies.
- Stratify risk in clinical care from preconception, pregnancy and perinatal outcomes based on data in the literature and real-world data collected from TSC community and TSC Clinics.
- Communicate findings through peer-reviewed publications, scientific and clinical meetings and community outreach through webinars and presentations.
- Manage a peer-reviewed funding processes for QI projects from TSC Alliance funds.

Expand QI Clinical Research:

- Grow research projects together with TSC Clinics, CRC, academic and industry partners and the TSC community.
- Cultivate funding for QI and clinical research by providing scientific rationale and strategy to TSC Alliance's Development team.

Clinical Research Consortium:

- Increase and maintain the diversity of clinical specialties and researchers.
- Contribute to relationship management of consortium members including clinics, researchers and TSC community members.
- Facilitate discussions and development of projects to improve clinical outcome measures defined by the steering committee.
- Participate in the cultivation of interventional and non-interventional trials with a focus on tumors and TSC-Associated Neuropsychiatric Disorders (TAND).
- Working with the consortium and other partners, facilitate development/review of project design.
- Assist in the management of clinical projects as assigned.

General Activities Across Programs:

- Partner with Vice President of Translational Research, Manager of Translational Research and the entire TSC Alliance team for cultivation of industry and academic clinical projects.
- Develop and review project descriptions, budgets and contracts, ensuring compliance with TSC Alliance procedures and policies.
- Proactively coordinate, track and monitor multiple projects with internal and external partners, including academics, industry and CROs.
- Conduct internal and external reviews of projects, providing oversight of progress reports and tracking milestones.

- Proactively identify and elevate issues; help facilitate constructive discussions regarding potential solutions and achieve project team alignment.
- Support cultivation of potential donors for clinical and QI projects through collaboration with the Development team and the Office of the President. Provide written and verbal communication supporting the rationale, project strategy, timeline and budget.
- Contribute to successful community-facing events (e.g., workshops) alongside the Community Programs team and the Office of the President.
- Elevate TSC Alliance programs and projects to the community and research partners.

Other Duties:

- Provide original articles and resource information for the TSC Alliance website, magazine (*Perspective*) and other informational brochures/handouts.
- Provide monthly activity reports to the CEO and CFO for inclusion in the monthly report to the Board of Directors.
- Help support the community programs team with clinical questions that require engagement with TSC Clinics and COEs
- Limited travel required, including nights and weekends.
- 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 degree in public health, nursing, biology or other medically related field. Advanced degree preferred, including PhD, MS, MPH/MSPH/MHA, MS in Healthcare Quality and Patient Safety or related field.
- Minimum 10 years' experience with demonstrated increasing level of responsibilities.
- Experience in research in both qualitative and quantitative projects and in managing/leading research teams.
- Experience with quality improvement projects and clinical research. Experience in reproductive and/or perinatal health (medical and/or policy) is a plus.
- Experience translating and communicating complex medical information in lay terms desired.
- Experience in building relationships and working with clinicians.
- Previous experience involving clinical research or care in TSC or related disorders desired.
- Ability to work well both in person and remotely with people at all educational levels required.
- Demonstrated ability to drive forward multiple projects simultaneously required.
- Excellent oral and written communication skills required.
- Skill to function under deadlines, strong critical thinking, organizational skills and attention to detail required.
- Proficiency in MS Office (Word, Excel, PowerPoint, Outlook) desired.
- Proficiency in statistical analysis programs (SPSS, GraphPad Prism, etc.) preferred but not required.