



Project Manager Registry and Biobank at Solve ME/CFS

Background

Solve ME/CFS is a non-profit organization, established in 1987, whose purpose is to make ME/CFS understood, diagnosable, and treatable.

About ME/CFS: Affecting 20 million people worldwide, Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME / CFS) is a life-altering and complex multi-system disease that can present as an array of different symptoms that may change over time and differ from patient to patient. The most common symptoms of ME/CFS are post-exertional malaise, unrefreshing sleep, profound fatigue, cognitive impairment, orthostatic intolerance, and pain. The cause of ME/CFS is currently unknown, but both genetic and environmental factors appear to be relevant. There are also no diagnostic tests or approved treatments available.

About You + ME: Registries are a fundamental step towards translational research and are foundational in increasing our understanding of chronic illnesses. The research team at Solve ME/CFS developed and launched the You + ME Registry. The Registry went live at the end of May 2020 and has more than 1500 participants and growing. The Registry provides a unique opportunity to transform our understanding of ME/CFS and the “longhauler” experience.

[You + ME](#) is enrolling three cohorts: those with ME/CFS, people with long-term symptoms of COVID-19, known as “longhaulers,” and controls. Participants collectively provide the research community with critical insight into their lived experience by entering health data and completing quality-of-life surveys online as well as by tracking and reporting their symptoms through an app. Participants are also subsequently invited to provide biological samples for the You + ME Biobank.

We are guided by three key principles:

- **Collaboration and coalition building** – we work with others in the community to harmonize data collection and share insights. We allow open access to our digital infrastructure to enable other organizations to implement similar programs.
- **Co-creation with the community** – our Registry was co-created with individuals with ME/CFS as well as clinicians and researchers to ensure it meets the needs of the community.
- **Empowerment through information** – we are committed to ensuring that individuals with ME/CFS or long-COVID can use the data they are recording about their experience to better manage their condition and inform their healthcare team.



About the Research Team: We are small but mighty. We work hard but have fun, and we are driven by the impact we're making for the millions of patients around the world suffering with ME/CFS and long-COVID. We foster a collaborative and supportive team environment.

Registry Project Manager Role (Full Time)

The Registry Project Manager is responsible for the smooth and efficient day-to-day operation of the You + ME Registry. The Registry Project Manager will report to the [Chief Scientific Officer](#) and will work closely with all members of the You + ME Team, and other members of Solve ME. The team is located in Los Angeles, CA, but we are open to a remote candidate. We offer a competitive salary and benefits package and are committed to ongoing professional development.

This is a unique opportunity to join a rapidly growing team, and to learn and grow through this new, dynamic position of Registry Project Manager.

Responsibilities:

The Registry Project Manager supports the Research Team and coordinates all aspects of You + ME Registry operations to ensure the continued success and growth.

Tasks will include but not limited to:

Project management

- Establishes work plans for projects and manages overall project plan for Registry
- Plans, directs and coordinates activities to ensure goals are met within prescribed timeframe; creates and manage timelines
- Provide solutions to project-related issues
- Tracks and manages budget
- Coordinates grant submissions in collaboration with our consultant grant writer
- Coordinates with external vendors to ensure timely deliverables
- Leads biobanking coordination to include liaison with biobank vendor, shipping and coordination of sample kits
- Interacts with Registry participants by email or phone
- Supports getting feedback from the Registry community; synthesizes feedback into reports

Team and stakeholder management

- Organizes and leads team meetings; sets agenda and records minutes; ensures action items are completed in a timely fashion
- Liaises with external and internal partners to establish meetings and ensure timely follow up
- Manages board communication and updates related to Registry progress
- Manages the Registry Innovation Council, an advisory group of patient experts, clinicians, researchers, data scientists and technology innovators
- Creates slide decks and other communication materials as needed
- Assists in facilitating workshops, webinars, meetings or conferences; coordinates logistics, scheduling and participant communications



Specific requirements include:

- Bachelor's degree and at least 5 years of project management or operations experience
- Highly collaborative style and experience in an environment requiring one to foster collaboration and work effectively on cross-functional teams
- Exemplary verbal and written communication skills; strong interpersonal skills with the ability to effectively interface with lot of different stakeholder groups including patients, family members, clinicians, researchers, and others
- Experience utilizing critical thinking and problem resolving skills to achieve results
- Experience applying standard project management tools, and practices
- Well-developed organizational and time-management skills
- Self-starter who is goal-oriented; able to prioritize projects and meet deadlines
- Team-oriented philosophy with the ability to handle multiple projects at once
- Proficiency with Microsoft Office and database management
- Experience with patient registries highly desirable

Solve M.E. is an equal opportunity employer who recruits, employs, trains, compensates, and promotes regardless of race, religion, color, national origin, gender, gender identity, sexual orientation, disability, age, veteran status, and any other protected status as required by applicable law.

To apply, please submit a cover letter and resume to: jobs@solvecfs.org.