Head of Research Communications for 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. The research team at Solve ME/CFS is focused on two key areas, The Ramsay program: a grant program designed to bring new researchers into the field; and You + ME: a biobank and registry.

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. This is a unique opportunity to join a rapidly growing team, and to chart the course and define success for a new, but critical role: Head of Communications.

About the Role: The Head of Communications is a big, juicy role that is central to the success of the registry. We are looking for a hands-on leader who can set a holistic communications strategy for the research team, with a particular focus on the You + ME Registry.

We are looking for someone who can set ambitious but attainable communication goals to ensure the continued success and growth of the You + ME Registry, as measured by the following:

- Meeting/exceeding enrollment and engagement metrics
- Participants feel a sense of community: they feel engaged and activated.
- There is wide recognition of the value of the registry as a foundational resource that will result in transformational change among key stakeholders, including members of the ME/CFS and “longhauler” COVID communities, the scientific community and the media.

The Head of Communications will report to the Chief Scientific Officer and will liaise closely with all members of the You + ME Team. The Head of Communications is also required to collaborate with other members of the Solve ME/CFS team to ensure cohesiveness and connectivity. 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.

The specific responsibilities will be informed by the development of the strategic communications plan, which will be a crucial first step for the Head of Communications. While the programs we support are predominantly in the US, there is also a global aspect to our work, which should be reflected in communication activities.

Responsibilities may include but are not limited to:

- Develop and execute on a strategy to establish You + ME scientific staff as thought leaders and build a bench of media-trained spokespersons within and affiliated to the organization
- Create and implement a media and news bureau strategy to elevate You + ME among all key stakeholders
- Develop and execute strategies that support the registry, including to:
  - Recruit new participants for the registry that reflect a diversity in race/ethnicity, age, gender mix
- Foster short and long-term engagement with participants through multichannel communications (e.g., webinars, podcasts, social media, etc.)
- Conceptualize and develop communications materials, including message grids, news releases, Q&A documents, videos, toolkits and social posts to support key milestones/initiatives, writing copy and working with our agency support on design
- Produce and execute creative campaigns
- Coordinate with partners to ensure amplification of milestones/initiatives
- Oversee social media strategy and management of channels in partnership with digital agency
• Contribute registry specific copy to quarterly print publications (These publications are managed at the organizational level, but feature registry specific content.)
• Oversee the You + ME Website and generate innovative, engaging new content on a rolling basis. Work with our website vendor on implementation of updates.
• Summarize research findings from Ramsay grantees, communicating complex science in an easily accessible way
• Promote the Ramsay program to encourage researchers to apply for grants and for donors to contribute funding towards the program
• Develop and manage research communications budget
• Vet, hire and manage research communications budget

Specific requirements include:

• BA or BSc
• Minimum of 10 years of experience developing and implementing strategic communications plans
• Highly collaborative style and commitment to work collaboratively with all constituent groups, including staff, board members, volunteers, donors, program participants, and other supporters
• Strategic thinker with a strong track record both developing and implementing innovative communications ideas
• Entrepreneurial self-starter, able to work independently
• Experience in either a scientific or healthcare setting with proven ability to translate complex scientific concepts into accessible content
• High energy, maturity, and leadership with the ability to serve as a unifying force and to position communications discussions at both the strategic and tactical levels
• Relationship builder with the flexibility and finesse to "manage by influence"
• Excellent writing/editing and verbal communication skills
• Proven ability to manage external vendors and agencies
• Significant experience communicating to a variety of audiences. Experience with media relations.
• Significant experience in leading teams and managing staff and project operations as well as working overseas and/or on international issues.

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 your cover letter and resume to: jobs@solvecfs.org.