



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 “longhailer” experience.

[You + ME](#) is enrolling three cohorts: those with ME/CFS, people with long-term symptoms of COVID-19, known as “longhailers,” 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 "longhailer" 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 external vendors or agencies to support the communications work

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.

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