Background

About ME/CFS: Affecting an estimated 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 cause of ME/CFS is currently unknown, but a combination of genetic and environmental factors appear to be relevant. There are also no diagnostic tests or approved treatments available.

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

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 a biobank and registry in May 2020, named You + ME. We are enrolling three cohorts: those with ME/CFS, people with long-term symptoms of COVID-19, known as “Long COVID”, and controls. You + ME has more than 3,000 participants (and growing!). Participants collectively provide the research community with critical insight into their lived experience by entering health data and completing quality-of-life surveys online, and by tracking and reporting their symptoms through an app. Participants are also subsequently invited to provide biological samples for the You + ME Biobank. Read more about how we got started: Our CSO Sadie on the driving force behind You + ME and its potential to transform our understanding of ME/CFS and Long COVID.

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 Our Team: We are small but mighty. We work hard but have fun, and 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: Director of Product Management & Operations

About the Role

We’re looking for our first in-house product manager who will work with and guide our external software development partners/agency. They’ll also implement and manage the overall operations related to the You + ME Registry and Biobank.

Nearly one year after launch, You + ME has enrolled thousands of individuals and we’ve collected over 1 million data points. We got here with a lot of effort and co-development with the community, but there is so much more work and creative iteration to be done so we can continue to build this resource and realize its potential for research. And what we do next, together, will ultimately determine our success. That’s where you come in! We need someone with a range of skills, including user research, database design, UI development, and forward-looking vision. You will play a key role in taking the You + ME technology infrastructure and capabilities to the next level and bring continued success and growth of the registry.

Product management needs:
- Manage the product roadmap and backlog for all digital products; including: a cloud-based registry database, user interfaces, and mobile app
- Oversee and manage user research, requirements discovery, solution design, feature development, and user acceptance testing that adheres to inclusive design principles
- Partner with the You + ME research team to identify key capabilities needed, identify potential issues, and ensure alignment on feature development and prioritization
- Partner with our external developers to manage the roadmap and backlog to ensure that they deliver all capabilities on time and per expectation
- Monitor and evaluate product performance to ensure constant product iteration and improvements
- Develop approaches to increase Registry participant engagement, including conversion of mobile app non-users to users / encourage frequent use of the app
- Strategic growth of platform to include: creative approaches for data harmonization with other research groups, use of innovative technologies like blockchain to consolidate databases, integration of wearables and other data types
- Work with the communications team to develop messaging and to help recruit new subjects

Registry operations needs:
• Handle regulatory and legal requirements (e.g. filing study protocols with our research oversight board)
• Supervise biobanking processes (e.g. developing procedures for collection and tracking of samples)
• Work with partners, including to facilitate API integration with other systems, licensing and ongoing management of the product for partner research projects, devising ways to share and aggregate data between our registry and other databases
• Manage vendor relationships, including external developers, designers or other contractors, and biosample collection and biorepository services

You’ll be working as a one-person product management and operations team, so you should be able to self-direct your priorities, juggle multiple tasks, and manage your own timelines as well as the external development agency’s timelines. It’s not a requirement, but we’d be excited to find someone who has experience with biobanking and health research software + operations.

Desired Qualifications and skill set
• 5+ years’ experience in digital product management or similar; experience with mobile app development a plus
• Ability to effectively communicate requirements and manage external developers to deliver ongoing product excellence; direct knowledge of programming language(s) and usability and customer-focused design experience a plus
• Strong analytical, prioritization, and negotiating skills
• Passionate about building great products and leveraging technology to solve complex problems; experience managing a Registry or with large datasets a plus
• Ability to manage vendor relationships
• Partnership management experience
• Desire to make a difference for a community in need
• Detail-oriented and able to address immediate priorities and needs, but able to see the bigger picture and shape strategic vision for the product
• Entrepreneurial and doesn’t shy away from doing big, ambitious projects

The Director of Product Management + Operations will report to the Chief Science Officer and will liaise closely with all members of the You + ME Team. The team is located in Los Angeles, CA, but we are open to someone working remotely. We value work-life balance and offer flexible working hours. The position is full-time, but we would consider a part-time schedule for the right candidate. We offer a competitive salary and benefits package, and are committed to ongoing professional development.

How to Apply for this Role
Please submit
• CV
• Cover letter
To Drew Ramsey at dramsey@valorpartners.com