The You + ME Registry: Together, We Can

As many of you know, in May of this year, we launched the You + ME Biobank and Registry. You + ME is an online clinical study of individuals with ME/CFS, post COVID-19 “long-haulers,” as well as healthy volunteer controls—all committed to identifying a cure for ME/CFS and other post-viral illnesses. Individuals provide information on their lived experience and are invited to donate biological samples for research.

We are thrilled to see so many of you enrolling in the Registry both as individuals with ME/CFS and as controls. As of early September, we have nearly 1500 members contributing their health information! A sneak peek of some of the demographic data can be found below.

One of the things that was important to us in building this resource was that we work hand in hand with the ME/CFS community to co-create an infrastructure and data collection process that was going to meet the needs of the individuals contributing their information and the researchers using that information to drive discovery. We have been amazed by how generous the community has been with their time and the creative ideas which have emerged.

We recently fielded a survey among a group of participants to better understand their experience with the registry. We are pleased to share some highlights with you.
REGISTRY SATISFACTION

Our community’s response to the Registry has been overwhelmingly positive, reinforcing our commitment to this bold endeavor. Participants from nearly every state in the U.S. are represented, and 75 percent of community members report being satisfied with the Registry.

The Net Promoter Score (NPS) is a loyalty and satisfaction measurement taken from asking users how likely they are to recommend a product or service to others on a scale of 0-10.

SATISFACTION WITH SYMPTOM TRACKING APP

- 505 (40%) Users Tracking
- 7380 Days Tracked
- On average, users logged data on 88% of the scheduled tracking days (every 3 days)
- 14% of users have been highly engaged, tracking on average 5 out of every 7 days

Nearly 80 percent of you report satisfaction with the You + ME Tracking App, available for download on Apple and Android devices.

We couldn’t be more pleased with how everything is going so far. You +ME is built on a big vision, to collect health information and biological samples from hundreds of thousands of individuals to help us identify treatments and a cure for ME/CFS. That vision is being realized, thanks to you.

So, if you’ve already joined—thank you! Please log in and check that you’ve completed all the surveys on your dashboard. If you haven’t signed up yet, join now at: www.youandmeregistry.com.

And don’t forget to ask someone in your network to join as a control.

If you have questions, comments, or suggestions, please contact Registry@SolveCFS.org.

“I am so pleased to have joined this app. I don’t feel so alone now or so out of control. By logging how I feel, I am able to make more sense of my condition. Thank you for all you are doing.”