



SOLVE M.E.

# RESEARCH 1<sup>st</sup>

You + ME Registry **TAKEOVER EDITION** WINTER 2020

When we last checked in with you in the spring, the You + ME Registry and Biobank had just opened for enrollment. In this second Registry takeover edition of *Research 1<sup>st</sup>*, we're excited to bring you an update on the enthusiastic community response so far to You + ME.

Over 1,800 of you have registered! The success of this registry is dependent on the generous support of our community members—individuals with ME/CFS, as well as healthy “controls” to create a large, rich data set from thousands of volunteers. This information will create insights into the disease, inform and influence further research, and help us identify causes and treatments. You + ME is a way to connect patients to researchers; giving patients a platform to share what they know about their disease and inform and influence research.

## #BYOC: BRING YOUR OWN CONTROL

Someone who participates in research but does not have the health condition being studied is called a “control.” Control volunteers in You + ME play a key role by providing researchers with health information that can be compared with health information from people with ME/CFS. And we need your help to recruit more of them!

Friends and family are much more likely to join the You + ME community than those who have no association with ME/CFS, so don't delay! Reach out today and ask your loved ones to join us. If every person currently enrolled in the registry brought just 3 others along, we would have data on more than 5,000 individuals!

Joining is easy, and takes less than an hour. Pass along the link in your next text message or email.



*“My cousin is affected by this disease, and I want to do everything I can to help him. It's hard to see someone go through this condition and not want to help. Being a part of the Registry and Biobank is one easy way to do that.”*

*—Gabe, a healthy control*

## HOW TO JOIN

1. Go to <https://youandmeportal.com/home>
2. Click the “Join” button and create your profile
3. Provide information about you and your health through surveys
4. You're done!

Well, not quite done—every 90 days we'll email you to check in and ask you to provide information through brief follow-up surveys. We might also ask you to participate in new research studies or provide a biological sample (like saliva or blood). If you can't participate in everything, that's ok! But the more you can contribute to You + ME, the more data we'll have to uncover causes and treatments.

## LEVERAGING YOU + ME TO UNDERSTAND LONG-COVID

Another new development has been the launch of our long-COVID cohort. It's become evident that many people who get COVID-19 are not fully recovering. To better understand why, we have expanded our registry community to include those with long-COVID. This is also an opportunity to understand the similarities and differences between ME/CFS and long-COVID, and to learn why some people are susceptible to long term effects after a viral infection.

**If you or someone you know has had COVID-19, please encourage them to sign up at [youandmeCOVID.com](https://youandmeCOVID.com).** We are looking for individuals who do and do not have long term effects.

None of this would be possible without the support of you, our community. Thank you for all you have done to make this registry a reality. In early 2021, we will begin to report out some early findings from the registry, so stay tuned to learn more.

## ABOUT YOU + ME

You + ME is an online clinical study of individuals committed to identifying a cure for ME/CFS and other post-viral illnesses. The community is made up of people with ME/CFS, people with long-term symptoms of COVID-19 (“long-haulers”), and control volunteers collectively providing the research community with critical insight into the lived experience and genetics of ME/CFS and post-viral illnesses.

Learn more at [youandmeregistry.com](https://youandmeregistry.com)

Follow us on Twitter, Facebook, and Instagram @youmeregistry



## STAY IN TOUCH!

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