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Solve M.E. Announces Launch of You + M.E. Registry and Biobank to Transform the Study of ME/CFS and Post-viral, Chronic Illnesses Likely Impacted by COVID-19

New disease registry brings big data revolution to disease affecting nearly 20 million people worldwide and collects critical information on “long haulers”¹ experiencing persistent post-COVID-19 symptoms

LOS ANGELES, CA – The Solve ME/CFS Initiative (Solve M.E.) today announced the official launch of the You + M.E. Registry and Biobank, a resource of clinical information, patient-reported symptoms, and bio samples that can be used by researchers to better understand Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS) or ME/CFS.

ME/CFS is a chronic, complex, multi-systemic disease that profoundly limits the health and productivity of patients with symptoms that can include: extreme exhaustion without an attributable cause (exacerbated by activity), severe headache and debilitating pain, diminished ability to concentrate and process information, extreme sensitivity to light and sound, cognitive impairment, neurological abnormalities, and complete organ system shutdown.

As many as 2.5 million Americans and nearly 20 million people worldwide are estimated to suffer from ME/CFS. About 80% of reported ME/CFS cases follow an acute infection, particularly viral infections (possibly such as COVID-19). There is no known cure for ME/CFS nor are there any FDA-approved drugs or treatments.

“ME/CFS is one of the few remaining, highly prevalent diseases about which much is still unknown,” said Dr. Sadie Whittaker, Solve M.E. Chief Scientific Officer. “The You + M.E. Registry and Biobank allows us to leverage the power of big data, which I firmly believe will transform our understanding of this disease, helping the scientific and medical communities identify causes and treatments.”

There is emerging evidence that many individuals who contract COVID-19 are suffering with persistent symptoms that are reminiscent of ME/CFS. To better understand the reasons behind this, the You + M.E. Registry and Biobank is designed to gather valuable data from individuals with persistent post-COVID-19 effects alongside those diagnosed with ME/CFS and healthy controls.

“Because of the large number of COVID-19 cases occurring simultaneously, we have a unique scientific window and a huge responsibility to investigate any long-term consequences and disabilities that COVID-19 survivors may face. Doing so will provide clues and potential treatment candidates for the millions of Americans already diagnosed with ME/CFS,” said Mady Hornig, MA, MD, Associate Professor of Epidemiology at the Columbia University Mailman School of Public Health. “This intensive, prospective look after SARS-CoV-2 infection may also inform strategies that prevent additional cases of ME/CFS from ever developing. The You + M.E. Registry and Biobank is an evidence-based resource that

¹ Individuals experiencing symptoms of COVID-19 for more than 100 days.

allows us to effectively collect data and biological samples, in a serial, ongoing fashion, from COVID-19 survivors.”

The You + M.E. Registry and Biobank was co-created with the ME/CFS community—those living with the disease, care partners, researchers, and clinicians. It was generously underwritten by the National Institutes of Health (NIH), The Mason Foundation, and numerous individual donors.

A groundbreaking feature of You + M.E. is the integration of a symptom tracking app to facilitate ongoing data collection. This will allow individuals to track how their symptoms fluctuate over time and provide researchers with a more complete picture of what it’s like to live with ME/CFS.

“Until recently, doctors studying patients with a particular disease had no practical way of regularly checking in with these individuals. Smart devices solve that problem, said Anthony Komaroff, M.D., Simcox-Clifford-Higby Professor of Medicine at Harvard Medical School; Senior Physician at Brigham and Women’s Hospital; Solve M.E. Research Advisory Council member. “People can, in real time, report symptoms and life events that may affect their symptoms (like exercise and diet). The information is transmitted electronically and readily available for research teams. In my opinion, the You + M.E. app will transform and deepen our understanding of this disease.”

Global You + M.E. partners include: the CureME UK ME Biobank (UKMEB) at London School of Hygiene and Tropical Medicine, EmERGE Australia, and La Trobe University in Australia, the National Institutes of Health Collaborative Center for Solutions at Columbia University.

To learn more about You + M.E. and to sign up, visit <https://youandmeregistry.com/>

To learn more about HR 7057, the “Understanding COVID-19 Subsets and ME/CFS Act,” visit: <https://solvecfs.org/together-were-sponsoring-an-historic-me-cfs-legislation/>

ABOUT THE ORGANIZATION: Solve M.E. is the leading, national non-profit organization solely dedicated to solving ME/CFS. We are committed to making ME/CFS understood, diagnosable, and treatable. Solve M.E. works to accelerate the discovery of safe and effective treatments and strives for an aggressive expansion of funding for research that will lead to a cure.

To learn more, visit our website at www.solveCFS.org

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