FOR IMMEDIATE RELEASE – April 21, 2020

AS AN URGENT COVID-19 RESPONSE, ADVOCATES IMPLORE CONGRESS TO SUPPORT RESEARCH FUNDING FOR POST-VIRAL DISEASES—SPECIFICALLY MYALGIC ENCEPHALOMYELITIS (ME)

Hundreds to Participate in Virtual Takeover of Capitol Hill

LOS ANGELES, Calif. (April 21, 2020) – Nearly 350 advocates—people with Myalgic Encephalomyelitis (ME), their loved ones, scientists, clinicians, and caregivers from around the world will virtually storm Capitol Hill today for the fourth annual ME/CFS Advocacy Day, a national event to educate congress about the neuroimmune disease. Patients and supporters can go to Solve ME/CFS Advocacy to get the most current information about this event and others, along with instructions about how to participate.

The ME/CFS advocates, led by The Solve ME/CFS Initiative (Solve M.E.), will share their personal experiences with ME/CFS and urge Congress to help combat the disease, ME (formerly known as Chronic Fatigue Syndrome or CFS), by increasing federal research funding by $60M.

Nearly 35% of COVID-19 patients are experiencing ME/CFS and neurological symptoms and since the onset of ME/CFS usually follows a viral infection, experts estimate up to 3,570,000 new ME/CFS cases following the COVID-19 pandemic. This would more than double the existing cases of ME/CFS in the United States in just 36 months.

“ME/CFS is an urgent public health crisis based on what is happening in our country right now,” says Emily Taylor, Director of Advocacy and Community Relations at Solve M.E. “Evidence suggests that a virus as serious and widespread as COVID-19 could ignite rapid and significant growth in the ME/CFS population in just 36 months. This is a very real, science-based concern, adding an even stronger sense of urgency to take action today. We must get the attention of our country’s leaders.”

Advocates will call on Congress to provide relief in the form of a ramped up biomedical research program targeting COVID-19 patients who develop ME/CFS. Hopefully, early identification and analysis will lead to diagnostic markers and treatment that could protect the health of millions. Those outcomes directly align with the Solve ME/CFS Initiative’s established goals of expanding and accelerating research investments, expediting governmental response to the ME/CFS public health crisis, increasing the quality and accessibility of clinical care and patient support, raising global awareness, and expanding the knowledge of the disease.
As many as 2.5M Americans and nearly 20M people worldwide are estimated to suffer from ME/CFS, but its causes are still unknown. There is no cure for ME/CFS nor are there any FDA-approved drugs or treatments. Because ME/CFS epidemics have historically followed viral outbreaks similar to COVID-19 and our nation’s frontline responders are not equipped to identify and diagnose post-viral neuroimmune diseases, the Solve ME/CFS initiative and their supporters will be imploring Congress to immediately and proactively fund important research.

ME/CFS is a chronic, complex, neuroimmune disease that profoundly limits the health and productivity of patients. Symptoms can include extreme exhaustion at the cellular level, exacerbated by activity), and neurological symptoms like: extreme sensitivity to light and sound, cognitive impairment, and even complete organ system shutdown.

In 2019, the Senate unanimously passed a resolution to raise awareness about ME/CFS and sixty-three members of the House and Senate, 11% of the members and a record-breaking number, mobilized to sign appropriations requests in favor of ME/CFS.

This national effort precedes the upcoming launch of You + M.E., Solve M.E.’s global, big data ME/CFS registry and biobank. The Solve ME/CFS Initiative hopes to convince congress to join the National Institutes of Health (NIH) in delegating funds towards ME/CFS research; doing so would solidify 2020 as a monumental year of progress for the entirely donor-funded organization towards their mission to make ME/CFS understood, diagnosable, and treatable, especially in light of the new and urgent concerns brought about and compounded by COVID-19.

To learn more about the Solve ME/CFS Initiative, visit www.solvecfs.org. Follow Solve M.E. on Facebook, Instagram, or Twitter.

About Solve M.E.

The Solve ME/CFS Initiative (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. is the largest US provider of private competitive research funding exclusively for ME/CFS working to accelerate the discovery of safe and effective treatments, strives for an aggressive expansion of funding for research that will lead to a cure, and seeks to engage the entire ME/CFS community.

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1 Link to Covid-19/CFS/ME White Paper