

Press Release

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LONG COVID DRAMATICALLY INCREASES CASES OF MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME

On 5th Annual Advocacy Week, bipartisan legislators set to make major funding announcement.

LOS ANGELES, C.A. - As Long COVID brings renewed attention to the debilitating and chronic illness known as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), a record number of advocates are virtually gathering on Capitol Hill for Solve M.E.'s 5th Annual Advocacy Week Monday, April 19.

Organizers believe the surge in Long COVID is driving more participation. Nearly one thousand advocates signed up to attend this year's Advocacy Week – nearly tripling 2020 numbers, with registrants representing 49 states, the District of Columbia and Puerto Rico. More than 60 percent of the advocates say it's their first time ever seeking a conversation with their member of Congress.

"The significant rise in participants directly corresponds with the rapidly increasing number of people suffering from the disease, including millions now dealing with Long COVID," said Oved Amitay, President and CEO at Solve ME/CFS Initiative (Solve M.E.). "There are 2.5 million Americans (and, climbing by the day) affected by ME/CFS, yet it is at the bottom 5% of National Institutes of Health funding."

Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases, concurs the lasting effects being experienced by many COVID-19 patients are indicative of ME/CFS.

"There is no question there are a considerable number of individuals who have a post-viral syndrome that in many respects can incapacitate them for weeks and weeks following so-called recovery and clearing of the virus. [People] who really do not get back to normal," said Dr. Fauci. "They have things that are highly suggestive of myalgic encephalomyelitis/chronic fatigue syndrome: brain fog, fatigue, difficulty concentrating. This is something we really need to look at."

During Advocacy Week, that's precisely what Rep. Don Beyer (D-VA) and Rep. Jack Bergman (R-MI) aim to do with a special bi-partisan **press conference on April 21**. Media is encouraged to join the live announcement at 3:00pm ET <u>via zoom</u>.

"The issues brought to the forefront by Long COVID have a direct impact on our communities. This is why it is important we all come together to amplify our voices on Capitol Hill," said Emily Taylor, Solve M.E. Director of Advocacy and Community Relations. "Working together with these diverse groups of patient-advocates, their loved ones, scientists, clinicians and caregivers from across the country will strengthen our collective call to action. Together, in one voice, we will fight for a stronger federal investment in research, education, and care for complex, chronic illnesses."

By the numbers, according to leading experts:

- 2.5 million Americans are affected by ME/CFS
- 25–35% of COVID-19 patients experience long term effects
- 2.5 million new cases of ME/CFS will be caused by the pandemic
- \$4 trillion impact to the U.S. economy is predicted over the next decade

Solve M.E. expanded its 2021 advocacy events to include many post-infectious chronic illness communities, such as: ME/CFS, Long COVID, Postural Orthostatic Tachycardia Syndrome (POTS), other forms of dysautonomia, Ehlers-Danlos Syndrome (EDS), Hypermobility Spectrum Disorder (HSD), and Mast Cell Activation Syndrome (MCAS). The Long COVID Alliance is partnering with Solve M.E., leveraging their collective knowledge and resources to educate policymakers and accelerate research to address the emerging challenges facing those with Long COVID and related post-viral illnesses.

ME/CFS is a chronic, complex, neuroimmune disease that profoundly limits the health and productivity of patients. There is no cure, nor are there any FDA-approved drugs or treatments. Symptoms can include extreme exhaustion at the cellular level (exacerbated by activity), and neurological symptoms such as: extreme sensitivity to light and sound, cognitive impairment, and even complete organ system shutdown.

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

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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.