

Press Release

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Nearly \$100M in Long COVID Funding Introduced in Congress

Historic bipartisan act focuses on research, treatment, disparities of debilitating diseases affecting millions of Americans

LOS ANGELES, C.A. –Rep. Don Beyer (D-VA) and Rep. Jack Bergman (R-MI) have introduced the historic COVID-19 Long Haulers Act (H.R. 2754)—bipartisan legislation authorizing and funding research and education initiatives benefiting so-called "long haulers," an estimated 25–35% of COVID-19 patients who experience long-term effects of the virus.

Solve M.E. and members of the Long COVID Alliance worked closely with Representative Beyer's office to help craft data-driven policy solutions that meet the diverse needs of ALL long haulers and post-infectious illness patients.

"The incredible partnership with Solve M.E. and the Long COVID Alliance has been instrumental in getting us to this critical juncture," said Representative Don Beyer (D-VA). "Their ongoing dedication to research, advocacy work and overall understanding of post-viral diseases helped shape HR 2754 into a piece of much-needed, time-sensitive legislation that will help millions of patients that either are currently suffering or will become afflicted with Long COVID symptoms in the future."

While 2.5 million Americans currently suffer from Myalgic Encephalomyelitis, Chronic Fatigue Syndrome (ME/CFS) and Long COVID, experts estimate two-fold growth as a result of the pandemic.

"Over the course of one year, [we will see] at least double the number of Americans suffering from ME/CFS...a remarkable event in the history of a chronic illness," said Dr. Anthony Komaroff, Harvard University. "The direct and indirect cost to the US economy from just the chronic illnesses that follow COVID are going to range over \$4 trillion in the next decade."

The COVID-19 Long Haulers Act was introduced following the 5th Annual ME/CFS Advocacy Week hosted by the Solve M.E. During the weeklong event, three members of Congress and a record number of participants held nearly 350 congressional meetings—pushing for more funding and support.

The COVID-19 Long Haulers Act (H.R. 2754) would authorize:

- \$30 million for research and development of centralized patient registries and biobanks through the Patient-Centered Outcomes Research Institute (PCORI)
- \$33 million for the Agency of Healthcare Quality and Research (AHRQ) and Centers for Medicare & Medicaid Services (CMS) to research and provide recommendations to improve the health care system's response to long-term symptoms of COVID–19

• \$30 million for the Centers for Disease Control and Prevention (CDC) to develop and disseminate information for medical providers and the general public about common symptoms, treatment, and other post-viral illnesses

Solve M.E. embraces and supports 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 and its co-founder Solve M.E. are 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.

"Long COVID presents an extreme threat to our ability to fully recover from this pandemic," said Rep. Jack Bergman (R-MI). "The COVID-19 Long Haulers Act will give us the tools that we need to understand, identify, and treat the long-term symptoms of COVID-19. I'm proud to help introduce this bill and I'm thankful for the work at the Long COVID Alliance and Solve M.E. and all they've done bringing this issue to the forefront."

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.

"We are so grateful to the Congressmen for their continued commitment to this critical issue affecting an estimated 5.8 million Americans with ME/CFS and Long COVID," said Oved Amitay, President and CEO at Solve ME/CFS Initiative (Solve M.E.). "This is how we solve problems—by harnessing the power of private and public sectors—joining forces for a common cause."

To learn more about the Solve M.E., visit www.solvecfs.org. Follow Solve M.E. on <u>Facebook</u>, <u>Instagram</u>, or <u>Twitter</u>.

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MEDIA INQUIRIES ONLY CONTACT

Stephanie Worrell Sedulo Communications on behalf of Solve M.E. Direct: 208.484.9470 Email: stephworrell@thinksedulo.com

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.

About the Long COVID Alliance

The Long COVID Alliance is a network of patient-advocates, scientists, disease experts, and drug developers who have joined together to leverage their collective knowledge and resources to educate policy makers and accelerate research to transform our understanding of post-viral illness.