

FOR IMMEDIATE RELEASE - April 18, 2023

SOLVE M.E. BRINGS ARMY OF PATIENT ADVOCATES TO CAPITOL HILL, PRESSES CONGRESS TO SUPPORT THE CARE FOR LONG COVID ACT

Advocacy Week 2023 unites Long Covid, ME/CFS communities in an effort to educate congressional representatives, marking the first in-person gathering for the event since 2019.

LOS ANGELES, CA - Today Solve M.E. kicks off its 7th annual Advocacy Week, a nationwide advocacy effort to connect people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long Covid, and associated chronic conditions; scientists; clinicians; and caregivers to share their unique stories with Congress.

Solve and its advocates are asking Congress to support the <u>CARE for Long Covid Act</u> in both chambers of Congress. This legislation seeks to increase research, educate patients and medical providers, and expand resources for those struggling with Long Covid and related conditions, including ME/CFS and other infection-associated chronic illnesses.

The CARE for Long Covid Act represents a bipartisan House effort with both Congressmen Don Beyer (D-VA) and Jack Bergman (R-MN) co-sponsoring. Senators Tim Kaine (D-VA), Ed Markey (D-MA), and Tammy Duckworth (D-IL) reintroduced the legislation on the Senate side.

To date, Senator Kaine is the only member of Congress to disclose his status as a Long Covid patient. At a recent Solve event, he remarked, "It's clear that much more needs to be done to support Americans with Long Covid—from improving research to connecting patients with resources—and the CARE for Long Covid Act does just that."

The widespread prevalence and devastating impact of Long Covid are undeniable. It's estimated that up to 30% of those who contract COVID-19 will develop Long Covid, and a recent study in *Nature* estimates that at least 65 million people worldwide have already experienced Long Covid. The <u>Brookings Institution</u> estimated in 2022 that Long Covid is keeping up to 4 million U.S. workers out of the labor force, resulting in about \$170-\$230 billion of lost earnings per year.

As the number of Long Covid cases continues to increase, so do the number of people suffering from the debilitating and chronic illness ME/CFS. Before the pandemic, experts estimated up to 1 to 2.5 million cases of ME/CFS. Due to COVID-19, those same experts now estimate between 5 and 9 million cases of ME/CFS. There are no diagnostic tests for ME/CFS, and no FDA-approved treatments or cures.



"The prevalence and impact of Long Covid have brought unprecedented attention to our cause. As a result, we have a once-in-a-lifetime opportunity to understand and address the underlying biological mechanisms of infection-associated diseases, including ME/CFS," noted Solve President and CEO Oved Amitay. "Solve is leading the charge to educate Congress. Our representatives must pass this critical legislation and address the urgent and still unmet needs of millions who suffer from these debilitating conditions."

Following the congressional trainings and meetings, Solve will host the signature EmPOWER M.E. event. The theme this year is "Navigating the World with Energy Limiting Disabilities." This special event on April 21 at 10 AM ET will feature expert ME/CFS and Long Covid advocates sharing tips for overcoming personal, professional, and medical challenges. Spanish-language interpretation will be available.

After the roundtable, we will host optional breakout sessions from 1-4PM ET featuring the following expert perspectives:

- Amy Mooney, MS OTR/L, Occupational Therapist (OT) (personal)
- Dr. Sharon Stevenson, Program Manager, CaringInfo.org (personal)
- Laura Casey, Research Editor, The Wall Street Journal (professional)
- Alison Sbrana, Patient Researcher, ME/CFS Disability Activist (professional)
- Jailyn Mercadel, RN, Registered Nurse, ME/CFS Patient Experience Advocate (medical)
- Ashanti Daniel, BSN, RN, Disabled Registered Nurse, ME/CFS Patient Expert (medical)

Advocacy Week events are open to the public and include opportunities for every energy level and ability to join.

Below are key dates and relevant links to help you stay engaged:

April 17: Advocacy Month Kickoff and In-Person Congressional Meeting Training

April 18: US Senate Congressional Meetings

April 19: Social Media Action Day (use this link to get involved)

April 20: US House of Representatives Congressional Meetings

April 21: EmPOWER M.E.roundtable event "Navigating the World with Energy Limiting

Disabilities" (register online here)

Pre-registration is required for some events. Visit StopTheLongHaul.org to learn more about the full calendar of Advocacy Week events.

To learn more about the Solve, visit <u>www.solveme.org</u>.



Follow Solve M.E. on <u>Facebook</u>, <u>Instagram</u>, or <u>Twitter</u>.

About Solve M.E

Solve M.E. is a non-profit organization that serves as a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long Covid, and other post-infection diseases. Our work with the scientific, medical, and pharmaceutical communities, advocacy with government agencies, and alliances with patient groups around the world are laying the foundation for breakthroughs that can improve the lives of millions who suffer from various "long haul" diseases.

MEDIA INQUIRIES ONLY CONTACT:

Karman Kregloe Solve M.E.

Direct: 323-828-1655

Email: kkregloe@solvecfs.org