## FOR IMMEDIATE RELEASE

CONTACT: Chris Smiley, Communications and Engagement Coordinator PHONE: (704) 364-0016 ext. 210 E-MAIL: CSmiley@SolveCFS.org DATE OF RELEASE: May 8, 2017

## Solve ME/CFS Initiative and #MEAction Assemble 'ME/CFS Advocacy Week' in D.C.

Washington D.C. - Solve ME/CFS Initiative (SMCI) and #MEAction rally patients and their loved ones to D.C. in a week of action to save federal programs for disease research. This week of action, beginning May 15<sup>th</sup>, will be preceded by a week of local advocacy meetings as supporters will meet with congressional representatives across the country starting May 8th.

Proposed reductions to scientific programs (such as the elimination of the Prevention and Public Health Fund or the proposed \$6 billion NIH budget cut in FY 2018), threaten critical medical research, especially in regards to ME/CFS. ME/CFS has historically been in the bottom 4% of diseases funded by the NIH, which is alarming as ME/CFS affects more people than HIV/AIDS and Multiple Sclerosis combined. The mission of ME/CFS advocacy week is to raise awareness about ME/CFS, garner support to find a cure, and fight to preserve and grow the few federal ME/CFS research programs still in existence.

SMCI and #MEAction will hold a <u>congressional briefing MAY 18<sup>th</sup></u> Speakers-

**Jennifer Brea**: Director of award-winning <u>Unrest</u>, TED Fellow and #MEAction Co-founder **Carol Head**: MBA Stanford University, CEO of the Solve ME/CFS Initiative **Dr. Zaher Nahle**: PhD, MPA, Harvard University, Chief Scientific Officer and VP For Research of the Solve ME/CFS Initiative:

> Noon to 1:30 pm Capitol Visitors Center Room SVC-201

The symptoms of ME/CFS include unrelenting physical and mental fatigue, post-exertional malaise, debilitating pain, cognitive and sleep dysfunction and severe immune abnormalities. The economic impact of ME/CFS is catastrophic. The costs due to job loss, disability, medications and medical services for as many as 2.5 American million patients and their families is estimated to cost society \$17 to 24 billion annually. Without funding for research, diagnosis and effective treatment, these costs have a significant, long-term impact in the U.S.

Patients and leaders, including filmmaker Jennifer Brea and Solve ME/CFS Initiative CEO Carol Head, will be available on Capitol Hill on Wednesday May 17<sup>th</sup> to take interviews and questions:

421 Cannon House Office Building 27 Independence Ave SE Washington DC, 20003

## ABOUT THE ORGANIZATIONS:

The **Solve ME/CFS Initiative** is the leading national organization exclusively dedicated to biomedical research and federal policy work for ME/CFS. SMCI envisions a world free of ME/CFS and works steadfastly to make this disease understood, diagnosable, and treatable. SMCI is the only ME/CFS organization with a 4-star rating from Charity Navigator, America's largest independent charity evaluator.

**#MEAction** is an international network of patients empowering each other to fight for health equality for Myalgic Encephalomyelitis aka ME/CFS. #MEAction is a grassroots organization and platform designed to empower patients advocates and organizations, wherever they might be, with the technological tools and training to do what they are already doing – better.