

# Solve M.E. This Quarter: Fall 2020

**RESEARCH:** *Engaging the entire ME/CFS community and accelerating the discovery of safe and effective treatments*

Solve M.E. Chief Scientific Officer **DR. SADIE WHITTAKER** presented “Understanding Susceptibility or Resilience to Chronic Effects of COVID-19 and Deepening Our Understanding of ME/CFS” at the first virtual meeting of the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME).

Solve M.E. participated in the first meeting of the Interagency **ME/CFS WORKING GROUP**, represented by Chief Executive Officer Oved Amitay and Dr. Sadie Whittaker. Led by the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC), the Group coordinates efforts to further research, treatment, and prevention of ME/CFS, as well as facilitate stakeholder input and community participation.

To better understand the reasons why COVID-19 “long haulers” are suffering with persistent symptoms, our **YOU + ME REGISTRY AND BIOBANK** is collecting data and biological samples from individuals with and without persistent symptoms. We will compare these data to information from people with myalgic encephalomyelitis (also known as chronic fatigue syndrome or ME/CFS), to characterize similarities and differences between the two groups. Learn more at [www.youandmeregistry.com](http://www.youandmeregistry.com).

**ADVOCACY:** *Bringing government support, funding and public awareness to ME/CFS*

Solve M.E. led the charge for and endorsed H.R. 7057, The Understanding COVID-19 Subsets and ME/CFS Act, the first-ever legislation specifically for ME/CFS research funding. Introduced by **REP. JAMIE RASKIN** (MD-08), the bill will authorize a \$60M program expansion for ME/CFS research at the National Institutes of Health (NIH) and an expansion of public and medical education ME/CFS initiatives. Read more about H.R. 7057 on page 2.

**EMILY TAYLOR**, Director of Advocacy and Engagement for Solve M.E., hosted the virtual “H.R. 7057 Legislative Café Chat” to answer community questions about this historic piece of ME/CFS legislation.



Solve M.E., The Headache & Migraine Alliance, and Miles for Migraine partnered with the Bipartisan Women’s Caucus to host “Women’s Chronic Illness During a Pandemic: A Virtual Congressional Briefing” concerning **THE IMPACT OF COVID-19 ON CHRONIC ILLNESS**. This virtual educational roundtable featured panelists included Caucus Vice-Chair Representative Madeline Dean, Dr. Nancy Klimas, Jamie Sanders, Dawn Buse (PhD), Ashanti Daniel (BSN, RN), and Joanna Kempner (PhD).

**INFLUENCE AND EDUCATION:** *Providing trusted, up-to-date medical information, current research, & policy work on ME/CFS*

Solve M.E. Research Advisory Council Member **DR. ANTHONY L. KOMAROFF** presented the webinar “Will COVID-19 Lead to ME/CFS in Some People?” addressing the connection between COVID-19 and ME/CFS and the research efforts forming in response. Immediately following the webinar, Dr. Komaroff, Dr. Sadie Whittaker, Emily Taylor, Oved Amitay, and Sue Levine, M.D., held a press event on that same topic, answering journalists’ questions about the connections between ME/CFS and COVID-19.

Oved Amitay and Dr. Sadie Whittaker presented the **WEBINAR**, “You + ME: A Registry for the Whole ME/CFS Community,” which took an interactive tour of the Registry and offered a closer look at how users can make the most of their You + ME experience. Read more about You + ME on page 6.

**SOLVE M.E.** provided public comments on three significant policies: COVID-19 Vaccine Distribution Priorities, Strategic Priorities for the Office of Women’s Health, and Proposed Data Collection for the CDC’s Multi-site Clinical Assessment of ME/CFS (MCAM).

Dr. Komaroff and Oved Amitay co-authored an **OP-ED ON COVID-19 LONG HAULERS** in the Guardian. Read it at <https://rb.gy/wzmkbn> ■