SOLVE M.E. PRESENTS

LEGISLATIVE CAFE CHAT

Join us for the first Solve M.E. Legislative Cafe of 2021!

Emily Taylor

Director of Advocacy and Community Relations

Solve ME/CFS Initiative

January 21, 2021
10:00 AM PT/1:00 PM ET

www.SolveME.org
H.R. 7057 Made History

- 51 Cosponsors: 45 Democrat, 6 Republican
- Over 4000 congressional messages were sent from the community in support of the legislation
- Ping-ponged between Appropriations and Health committees, but neither had authority.
- Representative Anna Eshoo’s office agreed to work with us to repackage H.R. 7057 as a supplemental appropriations request in the 2020 COVID-19 Economic Relief Bill
ME/CFS ADVOCACY FEDERAL BUDGET REPORT

A Summary of Solve M.E. Advocacy Results in the FY21 Federal Budget and COVID Relief Package

$1.15 Billion to the NIH
Congress approved $1.15 billion to the National Institutes of Health (NIH) as a set-aside specifically for research and clinical trials related to long-term studies of COVID-19.

$100 Million to the NIH
Congress also approved an additional $100 million specifically set aside for the Rapid Acceleration of Diagnostics. The funds will remain available to the NIH until September 30, 2024.

$500k from the DOD
The Department of Defense announced its first-ever funding of ME/CFS research projects. Two research awards have been announced totaling $47,000 for the next two years.

$5.4 Million for the CDC
Despite the administration's recommendation to defund the program, $5.4 million will be funded for the Chronic Fatigue Syndrome program at CDC.

Potential to Unlock $370 Million from PRMRP
ME/CFS will return to FY21 Defense research programs. The Peer-Reviewed Medical Research Program (PRMRP) will once again accept applications from ME/CFS researchers who can compete for a slice of $370 million.
Advocacy Day 2020 – educate about Long COVID and ME/CFS connection

HR 7057 converted to 2020 COVID Relief appropriations request submitted by Senator Markey in the Senate and Reps. Eshoo & Lofgren in the House

Pushed key members to request a briefing about Long COVID from NIH

Solve M.E. also appealed to key champions, specifically asking for funding for the “rapid acceleration of diagnostics”

Led Dec 4 leadership letter w/ 21 orgs

$1.15 Billion to the NIH

Congress approved $1.15 billion to the National Institutes of Health (NIH) as a set-aside specifically for “research and clinical trials related to long-term studies of COVID-19”

$100 Million to the NIH

Congress also approved an additional $100 million specifically set aside for the Rapid Acceleration of Diagnostics. The funds will remain available to the National Institutes of Health (NIH) until September 30, 2024
OUR GOALS

Secure Research Funding at the NIH

Ensure this $1.25 billion is spent on quality research

Leverage NIH resources to create a public-private post-viral research infrastructure

Ensure continued growth and sustainability of research infrastructure, beyond pandemic response

Translate research results into diagnostics, treatments, and cures for millions

Address critical needs in medical education, access, and patient outcomes

CDC:
- Clinical Care Guidance
- Medical Education
- Public Awareness Campaigns
- Epidemiology Studies
- Natural History Report

AHRQ
- Treatment Efficacy recommendation
- Disparity and Health Equity reports
- Medical Education effectiveness analysis
- Morality and comorbidity research

PCORI (Patient-Centered Outcomes Research Institute)
- Comparative Clinical Effectiveness Research
- Patient-led research
- Healthcare Delivery and Disparities Studies
- Recommendations for post-viral research infrastructure

Creation of a Long COVID Federal Advisory Committee
SAVE THE DATE: **Tuesday, April 20**

9:00am – 4:00pm ET  |  Digital Capitol Hill Day!

A Special Thank You to our 2021 sponsors and other generous donors
Be at the Center of the Solution

Register for future webinars:
http://solvecfs.org/webinar

Stay informed with the latest COVID-19 updates:
http://solvecfs.org/covid

Join the You + ME Registry and Biobank
https://youandmeregistry.com/

Drive research and fund progress:
https://solvecfs.org/donate

Follow us on twitter @PlzSolveCFS

Subscribe to youtube SolveCFS

Follow us on Instagram @solve_CFS

Like us on Facebook SolveMECFSInitiative

Follow us on Linked-In SolveMECFSInitiative

www.SolveME.org

You + ME Registry & Biobank

A Registry for the ME/CFS and long-COVID Communities

https://youandmecovid.com/

https://youandmeregistry.com/
To ask a question or make a comment

- Click on the **Participants** button

- Click the **raise hand** icon. Click the icon again to remove it.

- You can also use the **chat** box to type your question.

- We will answer questions in the order that we receive them.
- We will let you know when you are next in the queue.
- When it is your turn, we will unmute you, or ask you to unmute yourself