

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

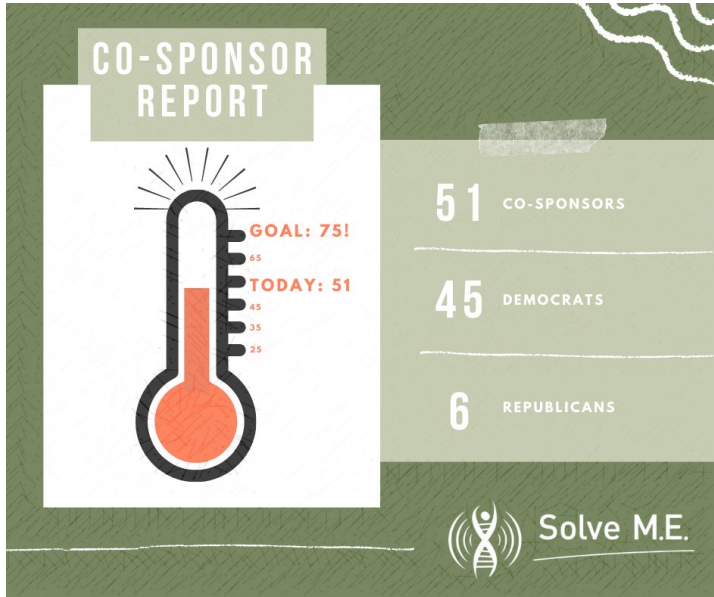
10:00 AM PT/1:00 PM ET



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# H.R. 7057 Made History



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First Ever Legislation for  
ME/CFS Research Funding,

H.R. 7057,  
The Understanding  
COVID-19 Subsets and ME/CFS Act

UNITED STATES CONGRESSMAN  
**JAMIE RASKIN**  
Representing Maryland's 8th District

- 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



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# 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 National Institutes of Health (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 \$547,000 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.



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- 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



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# 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



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**SAVE THE DATE: Tuesday, April 20**

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

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online community!



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Follow us on Instagram  
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**SolveMECFSInitiative**



Follow us on Linked-In  
**SolveMECFSInitiative**

## 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>

[www.SolveME.org](http://www.SolveME.org)

# You + ME Registry & Biobank

The screenshot shows the top navigation bar with 'You + ME' logo and links for 'ABOUT', 'M.E. IMPACT TOOL', 'COMMUNITY', and 'FOR RESEARCHERS'. A 'JOIN THE REGISTRY' button is on the right. Below the navigation is a banner with the text 'How we're leveraging the You + ME Registry to Study COVID-19' and a 'LEARN MORE' link. The main content area features a woman's portrait and the headline 'A Registry for the ME/CFS and long-COVID Communities'. To the right, a text box says 'Together we can uncover causes and identify treatments for ME/CFS and post-viral illnesses' with a 'JOIN THE REGISTRY' button. Below this, a privacy statement reads: 'We promise to protect your privacy. We will not share your contact information with any outside parties. Read Full Privacy Statement'.




COVID-19 STUDY

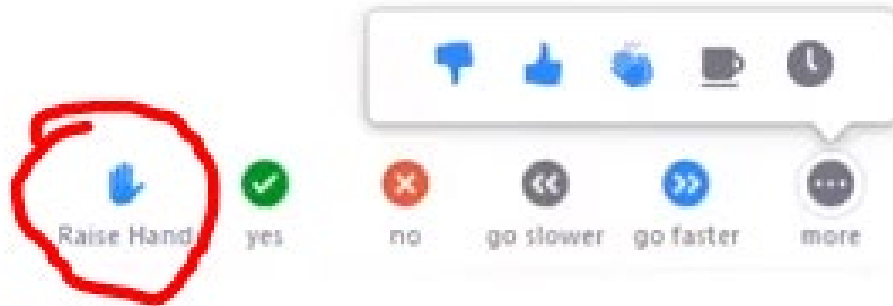
<https://youandmecovid.com/>



<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

