Victory! Congress Heeds Call to Fund Post-Viral Research

In December 2020, Solve M.E. helped secure one of the biggest congressional investments in post-infectious disease research ever—a whopping $1.15 billion for Long COVID research, diagnostics, and clinical trials at the National Institutes of Health (NIH).

One of our main focuses every year is increasing the federal spending dollars dedicated to research for myalgic encephalomyelitis, otherwise known as chronic fatigue syndrome, or ME/CFS. Early scientific evidence made clear that ME/CFS and Post-Acute Sequelae of SARS-COV-2 infection (PASC) or “Post or Long COVID-19 syndrome” have a lot in common, including symptoms, patient experience, and poor medical education. People with “Long COVID” (the patient-preferred terminology) need help and have turned to the ME/CFS community to find answers. Our federal affairs team quickly recognized that the ME/CFS community and the Long COVID community can work together to call for more federal funding for overlapping areas of research.

Despite the many challenges COVID-19 presented, we continued to push Congress for a monetary commitment. In December 2020, Solve M.E. led the charge for federal action. We authored a letter, joined by 20 leading chronic disease and health equity stakeholders, and met with dozens of congressional offices to discuss these federal funding needs.

In the letter, we warned of the “second wave” of post-viral symptoms following COVID-19 and identified the gaps in medical and research infrastructures to address this growing public health crisis. We urged Congress to prioritize Long COVID and post-viral disease funding in the 2020 Congressional COVID-19 relief packages.

And that’s exactly what Congress did!

INSIDE
2 Solve M.E. Forges New Partnerships for 2021 ME/CFS & Long COVID Advocacy Week
4 Solve M.E. This Quarter: Spring 2021
5 Solve M.E. Convenes The Long Covid Alliance: Joining Forces, Creating Change
6 You + ME Registry Marks Milestone
8 Patient Voices
9 Solve M.E. Answers Reader Questions
10 It Starts with You
11 Reflections from President and CEO Oved Amitay
Solve M.E. Forges New Partnerships for 2021 ME/CFS & Long COVID Advocacy Week

The 5th Annual ME/CFS Advocacy Week will take place from Sunday, April 18, 2021 to Saturday, April 24, 2021 with this year’s keynote event “Advocacy Day” taking place on Tuesday, April 20.

WHAT’S NEW THIS YEAR?
• 100% FROM HOME, including virtual meetings with members of Congress
• Welcoming new partners from Long COVID and complex, chronic illness communities
• Learn more at www.MEAdvocacyWeek.com

This year, “ME/CFS & Long COVID Advocacy Day” welcomes all of our friends and partners from the complex, chronic illness community to participate FROM HOME in this virtual event.

We connect hundreds of people (just like you!) directly with their members of Congress. This year, meetings are going DIGITAL using personalized Zoom and phone conversations through our new Advocacy Associates online event platform.

In addition to our special day educating Congress, Solve ME/CFS Advocacy Week offers many events and workshops for those navigating a life with chronic illness. On Monday, April 19, Representative Jamie Raskin (D-MD), who introduced historic legislation in 2020 with H.R. 7057, The Understanding COVID–19 Subsets Act, will give a keynote address to kick off the week of events and welcome attendees.

“This year, Advocacy Week is going to be very special because we are joined by three amazing groups: The Long COVID Alliance, Advocacy Associates, and the Everylife Foundation for Rare Diseases. Together, we will fight for a stronger federal investment in research, education, and care for complex, chronic illnesses.”

— Emily Taylor, Solve M.E. Director of Advocacy and Community Relations

Congress approved $1.15 billion to the NIH specifically for “research and clinical trials related to long-term studies of COVID–19” with 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. Congress clearly communicated that these funds are "prescribed" exclusively for Long COVID.

“This has definitely been my proud moment as an ME/CFS advocate,” shared Emily Taylor, our Director of Advocacy and Community Relations.

"Without a doubt this is the largest investment opportunity for ME/CFS we’ve seen since the disease was first recognized in 1985. Our work with Congress enabled us to seize this opportunity and forge 50 new partnerships! We succeeded in one of the most difficult political environments in history. But, that’s only half the story. Our strong relationships and advocacy at NIH were and will continue to be essential. The NIH now has the resources, the will, and the support of Congress to transform and expand the ME/CFS scientific landscape permanently."

While we celebrate these monumental wins for ME/CFS research, we know the fight is far from over. We still have more to do. We must ensure continued growth, equity, and sustainability of the complex chronic illness research infrastructure, beyond the immediate pandemic response.

See page 5 for information on how we are working with our new partners at The Long COVID Alliance on these important goals.
In 2020, Solve M.E. convened 21 science, post-viral disease, and patient advocacy organizations to call for urgent government investment for Long COVID research. Together, we submitted recommendations to Congress for Long COVID research investment in the 2020 COVID-19 Economic Relief Bill and helped secure $1.15 billion for Long COVID research, diagnostics, and clinical trials at the National Institutes of Health (NIH).

This successful effort laid the foundations for the formation of the Long COVID Alliance, formally launched in February 2021. The Long COVID Alliance, now boasting 234 members, is a network of patient-advocates, scientists, disease and public health experts, and drug developers, who have joined together to leverage our collective knowledge and resources to educate policy makers and accelerate research to transform our understanding of post-infectious illness.

**What is Long COVID?**

Long COVID is the patient-preferred term for a collection of lingering symptoms devasting the lives of many COVID-19 survivors. These symptoms persist in an estimated 25-35% of COVID-19 patients, regardless of infection severity. Preliminary reports and data about Long COVID symptoms and patient experiences contain many similarities to other chronic illnesses known to be associated with viral triggers, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS), other forms of dysautonomia, and mast cell activation syndrome (MCAS), just to name a few.

"The Long COVID Alliance is a critical collaboration based on the current reality that doctors and researchers are reporting that millions of COVID-19 patients continue to experience chronic and often debilitating post-viral symptoms," said Oved Amitay, Solve M.E. President and CEO. "This state of extended illness is presently labeled Long COVID. Even though tests might reveal that no virus remains in the body, COVID-19 ‘long haulers’ continue to struggle, often alone.”

In addition to our early congressional victories, the Alliance has also shared research process recommendations and best practices with the NIH.

In the coming months, the Alliance members will generate research recommendations, host webinars, attend congressional meetings, and will partner with Solve M.E. for our annual Advocacy Week event in the pursuit of legislative solutions to the unique problems faced by people with ME/CFS and Long COVID.

"Many long haulers are now approaching a full year post-infection. We have lost jobs, lost significant quality of life, and lost pieces of who we once were," said Karyn Bishof, founder of the COVID-19 Longhauler Advocacy Project and founding member of the LCA. “Many of us have ME/CFS symptoms and some of us have been diagnosed with ME/CFS. It’s been a long road with an uncertain future and we’ve finally found hope. With the help of our partners, we will ensure that long haulers are not left out in the cold. The Long COVID Alliance will fight with us for awareness, answers, and ensure that patient voices are included at every step of solving this ‘second wave’ Long COVID health crisis.”

To learn more about The Long COVID Alliance, visit our website at: [https://longcovidalliance.org/](https://longcovidalliance.org/).
You + ME Registry Marks Milestone

We’re pleased to share that the You + ME Registry recently hit another milestone—we now have more than 3,000 participants! The Registry becomes a richer resource as our numbers continue to grow and we are grateful to everyone who has joined the effort so far. The infographics on these pages provide a snapshot of the Registry and a call for healthy controls—those without ME/CFS and those who experienced a COVID-19 infection and did not develop long-term symptoms.

Ongoing tracking via mobile app:
- Symptoms rated using 0–4 scale

Data collection via the desktop portal:
- Sign-up & Onboarding:
  - Profile Creation
  - Informed Consent & Welcome
  - ME/CFS Disease History
  - Symptoms Assessment (full) *
  - GLID & Demographic information
  - SF-36
  - Karnofsky PS (modified)
  - Multidimensional Fatigue Inventory (MFI)
  - COVID19 History (incl. infection status, clinical course)
  - My Conditions
  - My Treatments
- Surveys:
  - SF-12
  - Karnofsky PS
  - Symptoms Assessment (abbreviated)

Promoted to update:
- My Conditions
- My Treatments
- Demographics
- COVID status

Biosample collection:
- Dried blood spot cards

### You + ME Registry Marks Milestone

#### Healthy Participants Are Critical to the Success of You + ME!

A healthy control is someone with no known significant health problems who participates in research. To understand what is different for someone with ME/CFS or Long COVID, we need to compare their biology to someone who is healthy. “I became a control to help my daughter-in-law who has ME and reached out to friends and cousins to join too. It’s such a quick, easy, and no-cost way for supporters to provide huge value to the fight to cure ME,” said Board Member Barbara Lubash, Emily Taylor, our Director of Advocacy and Community Relations, added. “My mom has ME/CFS so I know first-hand about the importance of being a healthy control. By volunteering to provide health data and a blood sample, I know I am helping researchers uncover what has gone wrong with my mom’s biology. This is a small sacrifice for me but could have a major impact for individuals affected by ME/CFS.”

To join the Registry as a healthy control, please visit youmanderegistry.com.

### DEMOGRAPHICS | COVID-19 DATA

#### BIOLOGICAL SEX

- Female: 85%
- Intersex: 0%
- Male: 15%

#### AGE

- 18-24: 20%
- 25-34: 25%
- 35-44: 30%
- 45-54: 20%
- 55-64: 10%
- 65+: 5%

#### FUNCTIONAL STATUS

- No Impairment: 25.0%
- Mild Impairment: 20.0%
- Moderate Impairment: 20.0%
- Severe Impairment: 57.0%

#### Early estimates suggest that 10% of COVID patients will develop Long COVID which is characterized by chronic fatigue, post-exertional malaise and cognitive dysfunction, much like ME/CFS.

Long COVID research may yield insights on ME/CFS and our knowledge of ME/CFS could enhance our understanding of Long COVID. The You + ME Registry offers researchers a rich dataset on both illnesses.
It’s been more than two weeks since I got sick, and my health hasn’t improved. Pain, weakness, and nausea are the most persistent symptoms, but the others aren’t much better. My skin is clammy, and I frequently have chills. At least a couple times a day, I feel like I’m either going to puke or pass out. That’s usually when I get short of breath, dizzy, disoriented, and my heart rate soars.

Dr. Gretchen, my general practitioner, a short, middle-aged woman with dark hair and remarkably straight posture, has yet to figure out why any of this has happened. I went to see her, but she didn’t have a conclusive answer for my poor health, and she expressed some skepticism about my symptoms. It probably didn’t help that I told her I sometimes have flashbacks and imagine car crashes while I’m driving. Now she seems to think that whatever is afflicting me is psychological, that my mind has created my illness, if I can’t only imagine car accidents but also entire illnesses. I don’t think it’s caused by my imagination though. I think it’s caused by something pathogenic, something sophisticated and complex, something that’s going to take lab tests to detect. It feels like I have a virus or bacterial illness, not something that my mind triggered.

When I mentioned this to Dr. Gretchen, she wavered a bit, but like the urgent care doctor, she still suggested that my symptoms could be caused by anxiety and depression from the car accident. I told her that I don’t have depression but I do get anxiety, though working out usually makes me feel better. I also told the doctor that, in the year and a half since that fateful day on the Napa River Bridge, I’ve seen a therapist and participated in a support group. The trauma from the car accident is something I still struggle with, but I don’t think my illness was caused by it. My current symptoms feel different than the anxiety I’ve experienced. I have never had a panic attack or flashback that has caused such profound weakness or made the lymph nodes on my neck tender to the touch and swollen to the size of large marbles. Anxiety has never given me a persistent fever and a strawberry-like rash covering my tongue.

I told Dr. Gretchen about these physical symptoms, but she seemed unconcerned. Her solution was to prescribe me an antidepressant medication, which she said works for anxiety too. She did do a blood draw and urine test to check for viruses, bacterial infections, and other physical illnesses, but I won’t get the results for a couple weeks. I also told Dr. Gretchen that my heart rate feels especially abnormal during exercise, so she let me borrow a wearable EKG device called a Holter monitor. I’m going to use it during my next workout, in case exercise is triggering my illness.

CHAPTER 10 • The Only One Rattled • December 15, 2010

The Solve M.E. Chronicle regularly features the creativity and talent of the ME/CFS community. In this edition, we share an excerpt from Jamison Hill’s new memoir, When Force Meets Fate.

Q: I have ME/CFS. Should I get the COVID-19 vaccine?

A: Because the health needs of each person with ME/CFS vary, it’s a decision you should make with the assistance of your medical care provider. Dr. Lucinda Bateman of the Bateman Horne Center tells us, “We [the world] certainly need COVID-19 vaccines desperately and everyone who is healthy enough for the vaccine should get vaccinated, starting with those at highest risk of COVID exposure. This includes healthy family members of vulnerable people...In general, the people who should be most cautious are those who have previously had allergic reactions to vaccines or are prone to severe allergic reactions in general. If you decide to get the vaccine, be rested and stable prior to the vaccine, and plan on resting/relaxing for at least 72 hours afterward. Supportive care will include anything you usually do for flu symptoms, PEM, allergy flares, worsened orthostatic intolerance, etc. If anything, including a vaccine, makes you sick enough that you are unable to maintain adequate fluids and nutrition, or results in fluid and electrolyte losses (sweating, diarrhea, etc.), it is always appropriate to seek IV fluids as a primary intervention.”

Dr. Nancy Klimas of the Institute for Neuro Immune Medicine recommends, “While there certainly is a risk of an ME relapse with these hyper reactive vaccines (the first wave to be released), you have to weigh the possibility of an ME relapse against the risk of death from COVID-19. You can mitigate the risk in a number of ways—just the way you do when you feel a relapse coming on.”

You can find more recommendations from ME/CFS medical experts on our COVID 19 webpage: https://solveme.org/the-me-cfs-community-and-covid-19/ (scroll down to “Should I take the COVID-19 vaccine when it becomes available?”).

The You + ME Registry is surveying participants to gather data on vaccination status and experiences with the vaccines.

As we learn more about the vaccine for people with ME/CFS, we’ll keep you informed!
It Starts with You

Whether you or someone you love bravely fights ME/CFS, or if you are simply passionate about supporting people with ME/CFS more effectively, your involvement with Solve M.E. is crucial to our success! Your generosity can spark real change. When you make your gift today, we immediately pour it into actionable, powerful tools for change. This is what you have already made happen:

The You + ME Registry and Biobank is an online clinical study of individuals with ME/CFS, post COVID-19 "long haulers," as well as healthy volunteers—all committed to identifying a cure for ME/CFS and other post-viral illnesses. These volunteers collectively provide the research community with critical insight into the lived experience and genetics of ME/CFS and post-viral illnesses. Accessing the power of big-data will help us unlock causes and treatments for ME/CFS by filling gaps in ME/CFS data, accelerating research. Your gift helps You + ME tap into the collective knowledge of the ME/CFS community and empower them to take an active role in furthering understanding of their disease.

The Long COVID Alliance, launched by Solve M.E., is a network of patient-advocates, scientists, disease experts, and drug developers who have joined together to leverage our collective knowledge and resources to educate policy makers and accelerate research to transform our understanding of post-viral illness and other chronic conditions. Joining forces with long haulers and other stakeholders will enable us to leverage all of our resources for progress in the fight against ME/CFS.

This year, we are including Long COVID research and providing a rich longitudinal data set via the You + ME Registry.

Reflections from President and CEO Oved Amitay

Dear friends,

A lot has happened since our last Chronicle edition in the fall of 2020. We continue to face immense national health and economic crises, with tragic consequences for so many people.

Yet, I am encouraged by the power of the human spirit and by seeing the results of what can be accomplished when we all come together around shared goals.

In December 2020, less than a year since the start of the pandemic, the 1st vaccine in the U.S. was administered outside of clinical trials and by June this year, it’s expected that there will be enough vaccines available for the entire U.S. adult population. And while there has been a lot of focus on the vaccines’ efficacy in preventing people from getting infected by SARS-CoV-2, it is probably more important to recognize that vaccination is turning COVID-19 into a manageable disease.

Real-world evidence is now telling us that there is a 94% fall in symptomatic infections among those who were vaccinated and a 92% fall in the rate of those who were seriously ill with COVID-19, and nearly no deaths. These achievements are outstanding, almost miraculous, giving us a renewed hope for returning to some normalcy in the near future. Furthermore, they reinforce the trust in the power of science, and in what purposeful, determined research can do to transform peoples’ lives.

Even among those “long haulers” who contracted COVID-19 and have yet to fully recover, there is reason to be hopeful. Our advocating voices have been heard, and in the last days of 2020 Congress approved $1.15 billion for Long COVID research and clinical trials. More and more evidence is indicating that some people with Long COVID meet the diagnostic criteria for ME/CFS, and the National Institute of Neurological Disorders and Stroke (NINDS) has formally acknowledged the overlap between symptoms of Long COVID and ME/CFS.

As part of this effort, we continue to grow the You + ME Registry and Biobank as a unifying research platform that now includes ME/CFS, Long COVID and control cohorts. With more than 3,000 people now in the registry, we know that each participant makes an invaluable contribution to our study of ME/CFS and Long COVID.

Knowing that our ranks are likely to grow exponentially due to this global pandemic highlights our sense of urgency to solve the challenges of ME/CFS. Our collective efforts would not be possible without your help. You inspire every aspect of our work, and your generosity fuels our action.

Onward, with sincere gratitude and hope,

Oved Amitay
SPRING 2021

Solve ME/CFS Initiative (Solve M.E.) is the leading disease organization solely dedicated to solving the devastating disease Myalgic Encephalomyelitis (M.E.). Solve M.E. is unrelenting in our drive to make the disease widely understood, diagnosable and treatable.

IN THIS ISSUE

• Monumental wins for ME/CFS research
• Solve M.E. and The Long COVID Alliance partner for 2021 Advocacy Week
• A milestone for The You + ME Registry
• An excerpt from the new book by ME/CFS community member Jamison Hill
• Your COVID-19 vaccine questions answered

Join the You + ME Registry and Biobank and help bring the big data revolution to ME/CFS!
Sign up here: https://youandmeregistry.com/