



The Solve ME/CFS CHRONICLE

Visit our website for the latest updates on COVID-19 and ME/CFS:
<https://solveme.org/covid>

SPRING 2021

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!

>> to page 3

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

Each board member has ME or has a family member affected by this disease

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 keystone 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 and ME/CFS Act, will give a keynote address to kick off the week of events and welcome attendees.

>> to page 3

"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

SOLVE ME/CFS ADVOCACY WEEK				
MON. APR 12	TUES. APR 13	WEDS. APR 14	THURS. APR 15	FRI. APR 16
	Congressional Meeting Training 10am PT/1pm ET	Advocacy Day Office Hours • Spoonies, Families & Friends 11am PT/2pm ET • Team Leads 4pm PT/7pm ET	Advocacy Day Office Hours • Long COVID patients & loved ones 11am PT/2pm ET • First-time Advocates 4pm PT/7pm ET	Advocates Social Happy Hour 4pm PT/7pm ET *personalized meeting schedules will be emailed by 4/16
MON. APR 19	TUES. APR 20	WEDS. APR 21	THURS. APR 22	FRI. APR 23
Advocacy Day Welcome & Virtual Keynote Address Special Guest: Representative Jamie Raskin 10am PT/1pm ET	Advocacy Day Remote Congressional Meetings (All Day) Registration Required	Social Media Action Day! (All Day)	EmPOWER M.E. Roundtable Workshop TBD	EmPOWER M.E. Office Hours TBD

Please note all events are virtual and will be accessible through a phone, tablet, or computer.



For more information about additional events, please visit www.MEAdvocacyWeek.com.

>> from page 1

Victory! Congress Heeds Call to Fund Post-Viral Research (cont'd)

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 proudest moment as an ME/CFS advocate," shared Emily Taylor, our Director of Advocacy and Community Relations. "Without a doubt this is the **single 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. ■

SOLVE ME/CFS INITIATIVE PROFESSIONAL STAFF

- Oved Amitay *President and CEO*
- Sadie Whittaker, PhD *Chief Scientific Officer*
- Emily Taylor *Director of Advocacy and Community Relations*
- Allison Ramiller, MPH *Director of Research Programs*
- Maryellen Gleason *Director of Development*
- Kira Poplowski *Head of Research Communications*

- Karman Kregloe *Communications and Media Relations Manager*
- Deborah Saady *Accounting and Operations Manager*
- Elle Seibert *Registry Data Manager*
- Jessica Brown-Clark *Engagement Coordinator*
- Jade Green *Development Assistant*
- Ani Vahradyan *Public Relations Coordinator*

- Michael Atherton, Treasurer
Arlington, VA
- Andrea Bankoski
Chapel Hill, NC
- Victoria Boies, Vice-Chair
Chicago, IL
- Stewart Gittelman
Lloyd Neck, NY
- William Hassler, Esq.
Washington, DC
- Carol Head
Los Angeles, CA
- Gurdyal Kalsi MD, MFPM (Hon)
Baltimore, MD
- Rona E. Kramer
Olney, MD
- Barbara Lubash, Secretary
Corona del Mar, CA
- John Nicols, Chair
Redwood City, CA
- Fern Oppenheim
Scarsdale, NY
- Amrit Shahzad
San Diego, CA
- Rick Sprout
Fairfax, VA
- Janice Stanton
Harrison, NY
- Karl Zeile
Westlake Village, CA

Solve M.E. This Quarter: Spring 2021

Research

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

The **RAMSAY GRANT PROGRAM 2021** is now [open through April 30, 2021](#). This is the fifth cycle of the Ramsay Program, through which Solve M.E. invests in research studies in ME/CFS or Long COVID with a particular emphasis on engaging young investigators and researchers new to the field.

In February 2021, Solve M.E. welcomed the newest member of the research department, **KIRA POPLOWSKI**, who serves as Head of Research Communications.

As part of Solve M.E.'s work with the University of California, Los Angeles (UCLA) Iris Cantor Women's Health Center to create an [ME/CFS-specific funding](#) channel through their Annual Health Pilot Program, scientists at the [UCLA NEUROMODULATION DIVISION](#) have been funded to test an investigational treatment using non-invasive brain stimulating technology. The partnership is generously supported by Solve M.E. Board Member Karl Zeile and his wife, Dian.



Research Advisory Council member Dr. Anthony L. Komaroff and Oved Amitay present at the YPO Live: COVID-19 Relief Virtual Reality Trade Show.

Advocacy

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

After three years of hard work and over 10,000 community emails to Congress, Solve M.E. successfully added ME/CFS as an eligible topic area for the **PEER REVIEWED MEDICAL RESEARCH PROGRAM (PRMRP)**. This program received \$350 million in FY 2020 and two ME/CFS research applications were funded, totaling over \$547,000 in new federal research funding.

Solve M.E. endorsed and successfully advocated for the passage of **H.R. 913, THE CLINICAL TREATMENT ACT**. Signed into law in December 2020, these new provisions will 1) make it easier for Medicaid participants to participate in clinical trials, 2) reduce the cost of clinical trials, 3) address racial and income disparities in clinical trial participation. These changes will lead to additional resources for ME/CFS clinical trials.

Solve M.E. joined Research!America's Science and Technology Action Plan (STAP), signing on to a [transition letter](#) sent to the then-incoming Biden Administration making the case for why we as a nation must lead with science and technology.

Solve M.E., along with over 100 other organizations, signed a letter in March urging President Biden to champion the \$25 billion that would be authorized by the Research Investment to Spark the Economy (RISE) Act (H.R.869/S.289).

Influence and Education

Providing trusted, up-to-date medical information, current research, and policy work on ME/CFS

Solve M.E. President and CEO **OVED AMITAY** served as a panelist for the World Health Organization (WHO) Inaugural Global Meeting "Expanding Our Understanding of the Post COVID-19 Condition."

Oved Amitay and Research Advisory Council (RAC) member **DR. ANTHONY L. KOMAROFF** presented "Learning from the Past: The Long-Term Consequences of COVID-19" at the YPO Live: COVID-19 Relief Virtual Reality Trade Show attended by CEOs from across six continents.

Oved Amitay led the discussion "Needs and Barriers to Care for Persons with ME/CFS: The Community Perspective" at the **2ND INTERAGENCY ME/CFS WORKING GROUP MEETING** hosted by the Centers for Disease Control (CDC) and the National Institutes of Health (NIH). Solve M.E. Chief Scientific Officer Dr. Sadie Whittaker presented "The Long COVID Alliance and the Creation of a Global Data Collaborative" at the same meeting.

The announcement of the formation of **THE LONG COVID ALLIANCE** (LCA) was featured in the national news outlet [Politico](#). Director of Advocacy and Community Engagement Emily Taylor was interviewed by [Health Leaders](#) for a story about the LCA. ■

Solve M.E. Spearheads The Long COVID Alliance: Joining Forces, Creating Change

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.



"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 Longhailer 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."

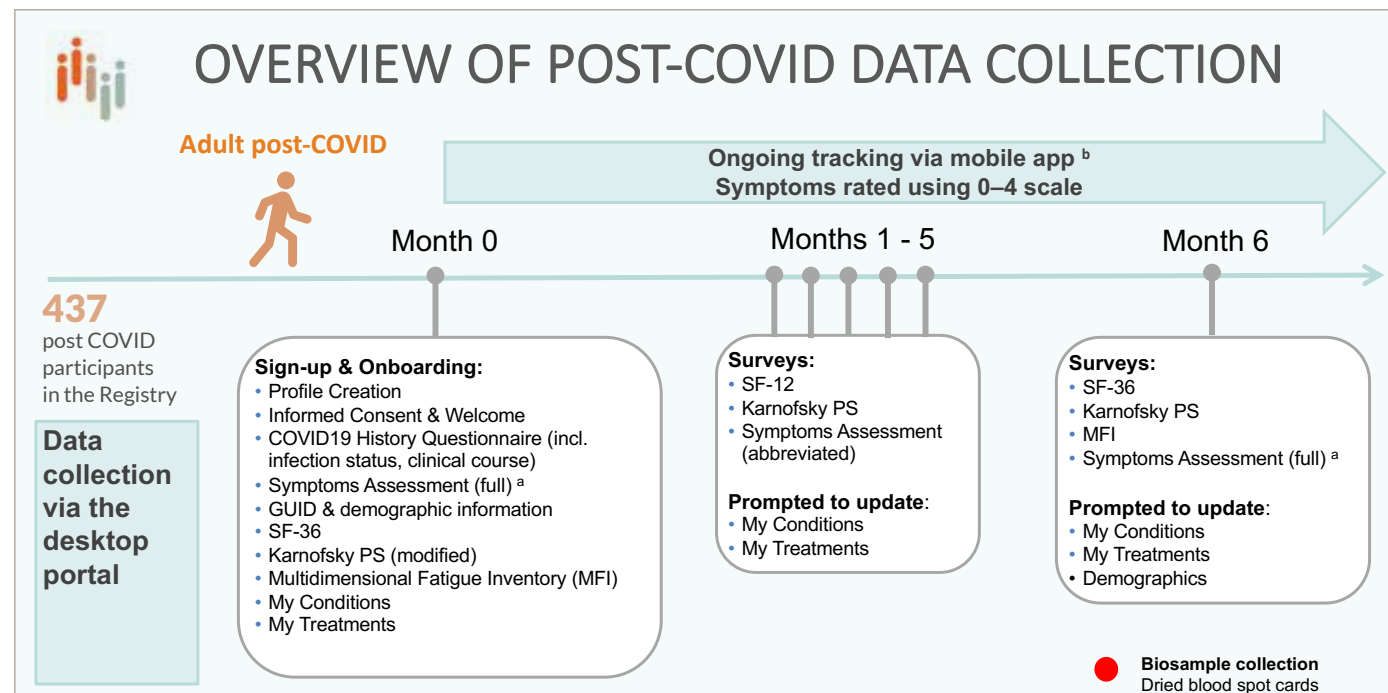
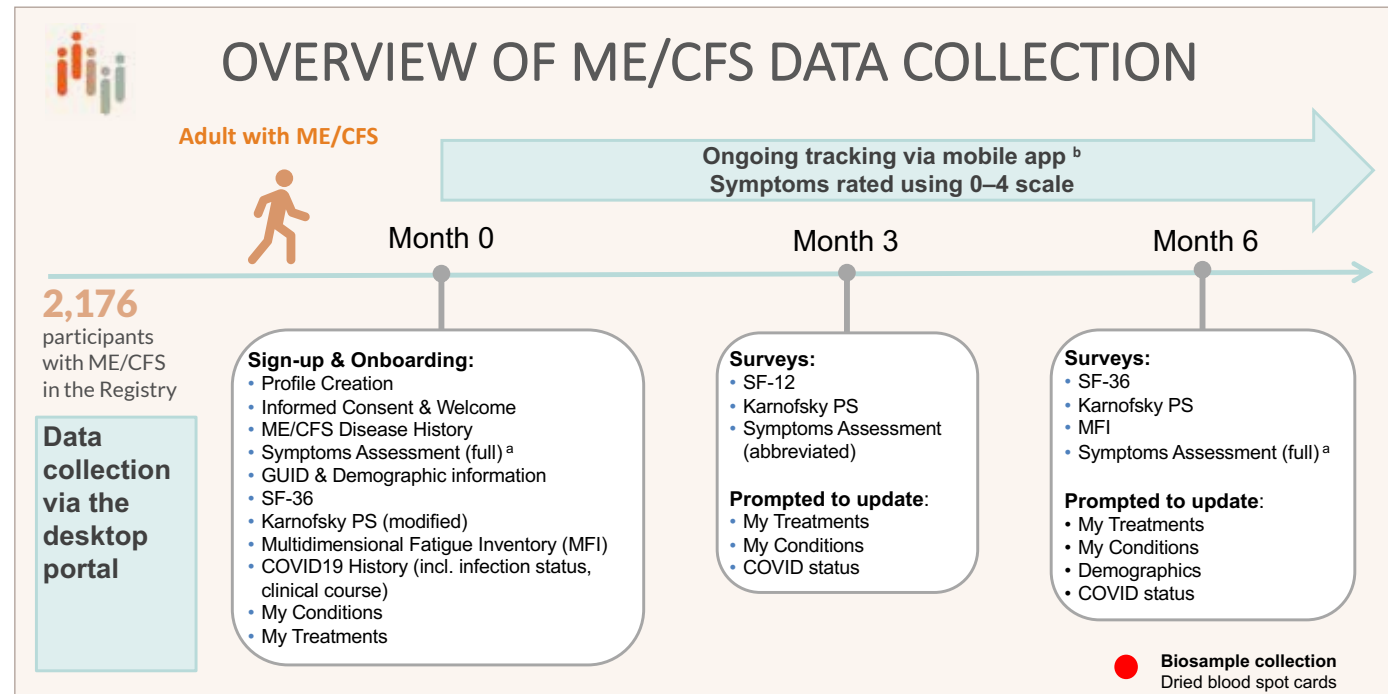
To learn more about The Long COVID Alliance, visit our website at: <https://longcovidalliance.org/>. ■

What is Long COVID?

Long COVID is the patient-preferred term for a collection of lingering symptoms devastating 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.

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.



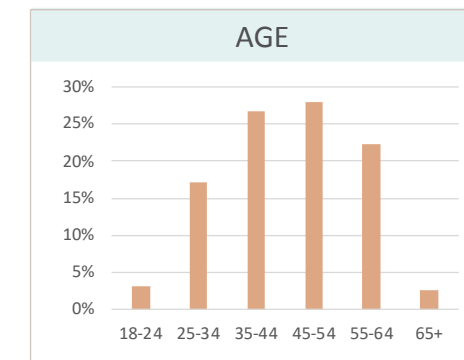
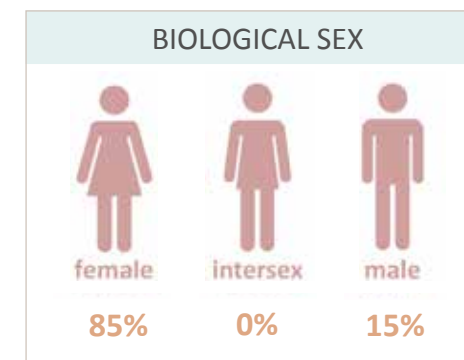
^a Maps to ME/CFS case definitions.
^b Daily, if possible. Participants can self-select additional symptoms. Additional screens are available for logging life events, medications/treatments, activity levels, and an overall rating of wellness. Data is graphed for longitudinal monitoring of individuals' symptoms.

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

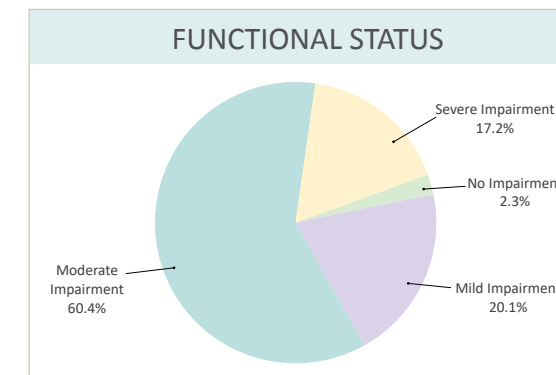
A healthy control is someone with no known significant health problems who participates in research. To understand what is different for someone with ME/CFS or Long COVID, we need to compare their biology to someone who is healthy. "I became a control to help my daughter-in-law who has ME and reached 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 youandmeregistry.com.

DEMOGRAPHICS | COVID-19 DATA



28.5% of Long COVID patients in the Registry who completed the Symptoms Assessment fulfill at least 1 case criteria for ME/CFS.



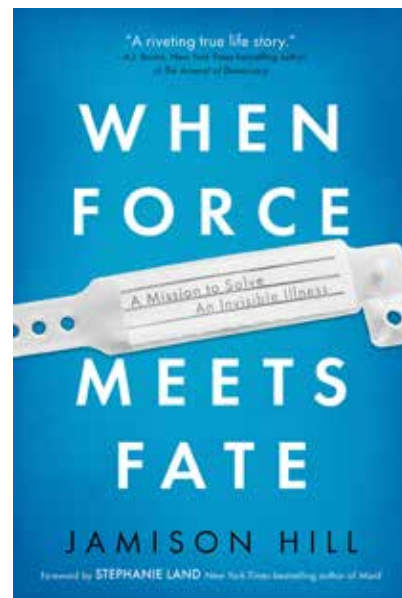
Early estimates suggest that **10%** of COVID patients will develop Long COVID which is characterized by chronic fatigue, post-exertional malaise and cognitive dysfunction, much like ME/CFS.

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.

SOLVE M.E. RESEARCH ADVISORY COUNCIL

-  Anthony Komaroff, MD
Simcox-Clifford-Higby Professor of Medicine, Harvard Medical School
-  Susan Levine, MD
Founder, Medical Office of Susan M. Levine
-  Maureen Hanson, PhD
Liberty Hyde Bailey Professor, Cornell University
-  Peter Rowe, MD
Professor of Pediatrics, Johns Hopkins University School of Medicine
-  Lucinda Bateman, MD
Founder & Chief Medical Officer, Bateman Horne Center
-  Rochelle Joslyn, PhD
Immunologist, Independent Consultant
-  Sheila Stewart, PhD
Associate Professor, Washington University School of Medicine
-  Daan Archer, MBA, MSc
Technology Entrepreneur
-  John Nicols, MBA
President & CEO, Codexis Inc.
-  Morgan Fairchild
Actress and Activist
- Ex Officio Members**
-  Oved Amitay
President & CEO, Solve M.E.
-  Sadie Whittaker, PhD
Chief Scientific Officer, Solve M.E.

PATIENT VOICES



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*.

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

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, as if I can not 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. ■



Jamison Hill has written for, among others, the *New York Times*, the *Washington Post*, *Men's Journal*, the *Los Angeles Times*, *Vox*, and *VICE*. He has been featured on Netflix, as well as WBUR's Modern Love podcast and Dax Shepard's Armchair Expert podcast. Follow Jamison on Twitter (@NotTheWhiskey), Instagram (@NotLikeTheWhiskey), and his blog (JamisonWrites.com).

Solve M.E. Answers Reader Questions



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."

Q: Why is Solve M.E. partnering with the Long COVID Alliance?

A: The Long COVID Alliance is a coalition of different complex, chronic, disease organizations who have come together to pool our resources. Each group is bringing along their expertise as well as their connections with patient advocates, disease experts, drug developers, and more.

The top three symptoms of Long COVID are the top three symptoms of ME/CFS, and many Long COVID

patients fit the diagnostic criteria for ME/CFS. At Solve M.E., we have been contacted by people diagnosed with ME/CFS after getting COVID-19. We are fighting for those new community members just as fiercely as we fight for our existing community members.

Since this issue has a direct impact on our community, it's important that our voice is heard in the rooms where Long COVID responses are discussed. As these other organizations have the same goal, we are pooling our resources to amplify that voice. If we

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://solve.me.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!



don't work together, we may risk having ME/CFS drowned out by competing priorities for funding. We see this as a way to get additional resources to study ME/CFS (by comparing to Long COVID).

We are still devoting all of our energies and resources towards ME/CFS, and we heartily support other organizations and coalitions who are in this fight with us. ■

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:



Through the **Ramsay Grant Program**, Solve M.E. invests in research studies in ME/CFS and Long COVID.

The Program has three main objectives: attract new researchers to the ME/CFS and Long COVID fields and ensure they stay engaged; facilitate applications for larger grants based on promising pilot data; and add to the cumulative scientific knowledge. Programs such as the Ramsay Grant allow us to support our quest for greater understanding of ME/CFS.

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



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 volunteer controls—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 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. With your support, we continue to be community leaders who spearhead efforts like this Alliance to ensure ME/CFS is a central focus of Long COVID research.



LCA member Melinda participating in our 2020 virtual Advocacy Day event.

This year, "**ME/CFS & Long COVID Advocacy Day**" welcomes all of our friends and partners from the complex, chronic illness community to participate in this virtual event, strengthening our advocacy with our new-found allies.

This event connects hundreds of ME/CFS advocates directly with their members of Congress using personalized online conversations. Their stories and voices can make a difference at the highest levels of government. This year, Advocacy Week is sponsored by EveryLife Foundation for Rare Diseases and an anonymous donor.

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. Bolstered by this progress, Solve M.E. convened The Long COVID Alliance, a network of patient-advocates, scientists and disease experts collaborating to share our collective knowledge to transform the 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.

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 heightens 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

Oved Amitay



The progress is undeniable. The endgame is more achievable than ever. And it all starts with the generous gifts from donors like you. Give online at www.solveme.org/donate, or call Maryellen Gleason, Director of Development, at 704-364-0016 ext. 207. Thank you for being a part of our community!

Solve ME/CFS Initiative
350 N Glendale Avenue
Suite B #368
Glendale, CA 91206

ADDRESS SERVICE REQUESTED

NONPROFIT
US POSTAGE
PAID
PERMIT #3235
LOS ANGELES, CA

STAY IN TOUCH!

Solve ME/CFS Initiative
350 N Glendale Avenue
Suite B #368
Glendale, CA 91206

Telephone: 704-364-0016

E-mail: SolveCFS@SolveCFS.org

Website: SolveME.org

Facebook: [facebook.com/
SolveME/CFSInitiative](https://www.facebook.com/SolveME/CFSInitiative)

Instagram: [Solve_CFS](https://www.instagram.com/Solve_CFS)

LinkedIn: [Solve ME/CFS Initiative](https://www.linkedin.com/company/Solve-ME-CFS-Initiative)

Twitter: [@PlzSolveCFS](https://twitter.com/PlzSolveCFS)

YouTube: [youtube.com/SolveCFS](https://www.youtube.com/SolveCFS)

Solve ME/CFS Chronicle archive:
SolveME.org/archive

Humans of ME/CFS:
HOME/CFS.SolveCFS.org

You + M.E. Registry and Biobank:
youandmeregistry.com

SUPPORT SOLVE M.E.
SolveME.org/DONATE

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.



Photo by Lina Simonian on Unsplash

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/>