



The Solve M.E. CHRONICLE

Your data makes a difference. Join the You + ME Registry!
youandmeregistry.com

SUMMER 2022



LONG HAUL VOICES

Amplifying the voices of patients sharing their health journeys is one of the most critical ways we can increase understanding of debilitating diseases such as ME/CFS and Long Covid.

On May 12, World ME Day, we launched the first episode of *Long Haul Voices: Living with Long Covid and ME/CFS*, a mini-series that amplifies the experiences of individuals with Long Covid and ME/CFS, the experts devoted to improving their care, and the challenges surrounding these largely invisible, poorly-understood diseases that affect a rapidly growing population.

The mini-series, created in partnership with Unfixed Media Productions, is directed by award-winning filmmaker Kimberly Warner and edited by Emmy Award winner Michael Wolcott, both of whom live with chronic disease.

Long Haul Voices has amassed thousands of views online and is currently streaming on The Disorder Channel. Visit <https://rb.gy/efrcal> to learn more and watch all three episodes!



INSIDE

- | | | | |
|---|--|----|--|
| 2 | ME/CFS and Long Covid: Seizing the Moment | 8 | Ramsay Grants Empower Researchers |
| 4 | Creating Change: Local & State Advocacy | 9 | A Family Tackles ME/CFS |
| 5 | CDMRP Announces \$1.6M for ME/CFS Research | 10 | Meet Development Director Joe Komsky |
| 6 | A Whirlwind Advocacy Month | 11 | Reflections from President and CEO Oved Amitay |
| 7 | ME/CFS ICD Tracking Victory | | |

ME/CFS and Long Covid: Seizing the Moment

The tragic public health emergency of Long Covid has created a once-in-a-lifetime opportunity to address decades of neglect, raise awareness about ME/CFS, and make unprecedented progress in our search for treatments and cures for post-infection diseases. Additionally, the ME/CFS community has much wisdom and experience to offer those suffering from Long Covid, particularly the large number who have or will be diagnosed with ME/CFS. With the Solve Long Covid Initiative, we are seizing this moment.

The Solve Long Covid Initiative

The Solve Long Covid Initiative represents a collection of new and expanded programs in research, advocacy, and education that will improve outcomes for the millions suffering from post-infection diseases. Based on more than 30 years of research and advocacy experience advancing the understanding of post-infection diseases, the Solve Long Covid Initiative takes a strategic approach to integrating pre-pandemic and post-pandemic knowledge and community insights. Our work in the post-infection disease space has allowed us to create connections and build partnerships with researchers, clinicians, patients, government, and industry leaders.



This initiative will allow us to continue to expand capacity and investment in programs such as the You + ME Registry, our federal advocacy, the Ramsay Research Grant Program, and more – strengthening our response to this emerging crisis while ensuring that progress made will benefit everyone with a “long haul” disease.

Solve M.E.: Leading the Way on Long Covid

The Solve Long Covid Initiative launched a new whitepaper, *Long Covid’s Impact on Adult Americans: Early Indicators Estimating Prevalence and Cost*, estimating the magnitude of the Long Covid public health crisis, which mirrors that of ME/CFS. Our previous experience shows how important it is to quantify the burden of “invisible” chronic diseases so that they are not ignored as ME/CFS was for many years.

The most prevalent Long Covid symptoms – crippling fatigue, post-exertional malaise, and cognitive dysfunction – mirror those of ME/CFS and can have profound implications for the lives of those affected. Using mathematical models, publicly available data,

Solve M.E. Strides in the Long Covid Space

	Secured \$1.25 Billion from Congress
	Co-founded and Aggregated Alliance with Over 1,000 Voices in the Long Covid Space
	Registered Over 1,200 Participants in Long Covid Registry
	Awarded Funding for Early-Career Long Covid Researchers

and patient-led research, Solve M.E. estimated the prevalence and cost of Long Covid on adult Americans with a specific emphasis on the impacts of this mass disabling event on American labor markets and labor shortages.

In our whitepaper, we report that Long Covid affects an estimated 10-30% of people infected with SARS-CoV-2, including those who were asymptomatic, and that:

- 22 million U.S. adults are living with Long Covid (LC) – close to 7% of the population.
- 7 million are experiencing Disabling Long Covid (DLC) – 2.3% of the population.
- As of January 2022, the cumulative cost of LC is estimated at more than \$386 billion.

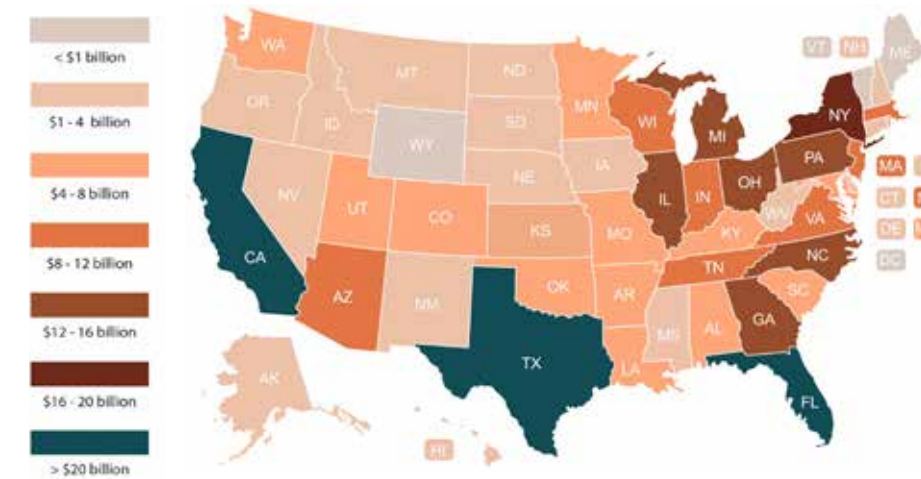
(This estimate includes lost wages, lost savings and medical expenses incurred by individuals. It does not include costs incurred by businesses or government agencies.)

This paper generated coverage in prestigious publications such as *The New York Times*, *Bloomberg Law*, and *Fortune*, helping to increase awareness of this urgent crisis.

It is critical that we prepare for the tsunami of disabling cases of Long Covid, not only by scaling up programs to compensate victims of DLC, but by reforming the disability system to make a return to work – full-time or part-time – the preferred outcome. Employers, as well as government program administrators, will need to make real efforts to accommodate the needs of their workers. In many cases, this will require a change in workplace culture that may ultimately prove widely beneficial and be embraced by workers and employers alike. Creating a path to work for individuals with disabilities and chronic illness could be part of the solution to the broader demographic problem of long-term decline in labor force participation, and certain inequalities.

We hope others will build on this data to better understand the impact of Long Covid, ME/CFS, and other post-infection diseases, so the true scope of these devastating diseases can be addressed and lead to better policies and improved outcomes.

Prevalence and Economic Impact of Long Covid



C-19 LAP (2021). Mathematical Breakdown and Formulas for Long COVID Calculations. COVID-19 Long-Hauler Advocacy Project. CDC Case Task Force (2022). United States COVID-19 Cases and Deaths by State over Time [Dataset]. Centers for Disease Control and Prevention. Whitaker, M. et al. (2021). Persistent symptoms following SARS-CoV-2 infection in a random community sample of 508,707 people. MedRxiv [Preprint].

SOLVE M.E. BOARD OF DIRECTORS

Each board member has a personal connection to post-infection diseases. They either themselves live with these diseases, have a loved one who suffers, or care for people who are impacted.

Cynthia Adinig
Alexandria, VA

Michael Atherton, Treasurer
Arlington, VA

Joseph Barerra
Newport, CA

Kenya Beckman
Los Angeles, CA

Victoria Boies
Chicago, IL

Stewart Gittelman
Lloyd Neck, NY

William Hassler, Esq.
Washington, DC

Carol Head
Los Angeles, CA

Hunter Howard
Dallas, TX

Gurdyal Kalsi, MD, MFPM (Hon)
Baltimore, MD

Rona E. Kramer
Olney, MD

Barbara Lubash, Vice-Chair
Corona Del Mar, CA

John Nicols, Chair
Redwood City, CA

Fern Oppenheim
Scarsdale, NY

Amrit Shahzad
San Diego, CA

Rick Sprout, Secretary
Fairfax, VA

Janice Stanton
Harrison, NY

Karl Zeile
Westlake Village, CA

Creating Change at Every Level: Local & State Advocacy

Each year during Advocacy Month, we host our hallmark EmPOWER M.E. roundtable, during which patient advocates, professionals, and scientists share their expertise on topics relevant to the quality of life for people with ME/CFS, Long Covid, and their caregivers.

This year, a panel of veteran state advocates discussed the importance of local and state advocacy and shared tips for starting projects in your neck of the woods. Participants included:

- **Melinda Lipscomb** - Co-founder and Co-chair, #MEAction Maryland State Chapter
- **Art Mirin** - Chair, #MEAction California State Chapter
- **Charmian Proskauer** - Former President, Massachusetts ME/CFS & FM Association and Chair, US Action Working Group
- **Laura Bucholtz** - Florida State Lead
- **Suzanne Wheeler** - Co-founder and President, Minnesota ME/CFS Alliance
- **Charonda Johnson** - Strategic Partnerships Manager, Covid Survivors for Change
- **Terri Wilder** - Co-Leader, #MEAction New York State Chapter

Though this collection of advocates had varying strategies, energy levels, and connections to these diseases, each panelist demonstrated an unwavering commitment to creating positive impact for individuals with ME/CFS, Long Covid, and other post-infection diseases.

Several panelists stressed the importance of medical education, raising awareness, and clinical care – much of which can happen at a local state health department, or even your very own doctor’s office. Every conversation, Suzanne said, should be treated like a partnership.

Melinda echoed this notion, encouraging advocates to ensure their representatives are aware of them, their expertise, and



know they can be called upon with questions. She also cautioned individuals to use their energy wisely.

Our panelists acknowledged the importance of advocating at all levels, while emphasizing that smaller, more local governments may have greater capacity to address your issue.

“Getting things done at the federal level takes a lot more red tape, and it takes a lot of bipartisan support,” Charonda shared, making it easier – and faster – to get things done at the local level.

For individuals just getting started, our advocates had three main bits of advice. Laura spoke to the importance of advocating with others. “Find your people,” she shared. Charonda suggested developing your story – your “elevator pitch” – which can be shared easily with others. If you’re unsure of where to get started, Art recommended contacting your local or state organizations.

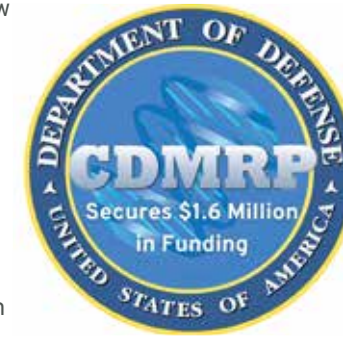
Thank you to all our panelists for sharing their time and expertise with us!

To watch the full conversation, visit our YouTube page at [YouTube.com/SolveME](https://www.youtube.com/SolveME).

CDMRP Program at DOD Announces \$1.6M Grant for ME/CFS Research

At Solve M.E., our advocacy team is dedicated to opening new funding avenues for ME/CFS, Long Covid, and post-infection disease research and care.

We’re excited to share that our efforts at the Department of Defense (DoD) have continued to yield big results! We recently learned that Ronald W. Davis, PhD, Director of Open Medicine Foundation (OMF) and Chair of the OMF Scientific Advisory Board received an incredible \$1.6 million grant from the DoD to study manganese and its role in ME/CFS.



Congressionally Directed Medical Research Programs provide funding to support therapeutic research related to medical threats, and treatments for Service Members in current and future battlefield settings. In recent years ME/CFS has been included within the ‘Peer-Reviewed Medical Research Programs.’ Funds included in this account are shared with many medical research programs at the discretion of the Department. In April, Solve M.E. hosted a webinar about PRMRP and the application process. Watch the webinar at youtu.be/v94xgmue0nQ.

Congratulations to OMF and Dr. Davis for this incredible win for ME/CFS research! Solve M.E. is celebrating another big research win from the CDMRP program this year.



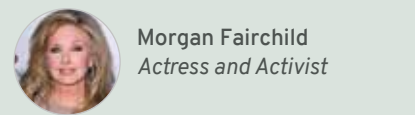
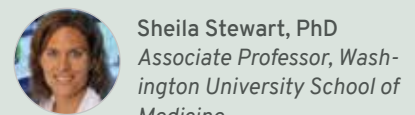
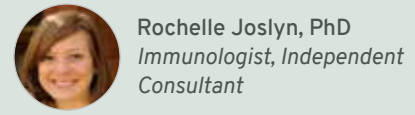
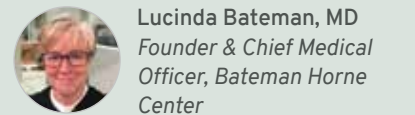
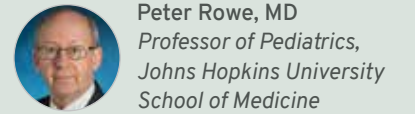
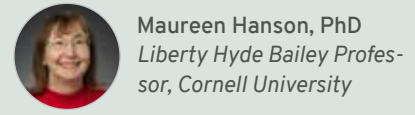
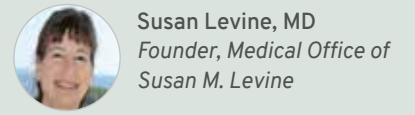
Draft Defense Appropriations Bill Includes Language for ME/CFS and Long Covid Research

A draft of the FY23 Department of Defense Appropriations Bill from the House of Representatives includes language addressing ME/CFS and Long Covid. This separate callout was fought for by our team at Solve M.E. and advocates during Advocacy Month! The report reads:

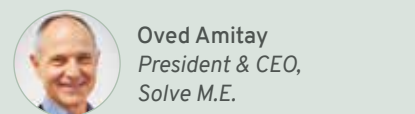
“LONG COVID AND MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME: The Committee urges the Secretary of Defense, in conjunction with the Service Surgeons General, to address research projects related to diagnostic testing, cures, and treatments for post-viral illness, specifically Long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). The Committee recommends that the Assistant Secretary of Defense for Health Affairs conduct research on Long COVID and ME/CFS with a focus on issues related to military populations.”

Read the full bill at <https://rb.gy/dujjrw>.

SOLVE M.E. RESEARCH ADVISORY COUNCIL



Ex Officio Members



A Whirlwind Advocacy Month!



For the first time ever, we dedicated an entire month to our annual advocacy event, and your steadfast participation throughout May made this year a success!

Thank you to the 325 advocates that participated in 254 virtual meetings with members of Congress and their staff. We are already starting to see more names added to the lists of co-sponsors for the TREAT Long Covid Act and CARE for Long Covid Act.

With these bills, we aim to:

- Expand resources for those struggling with Long Covid and related post-viral illnesses (CARE for Long COVID Act - S. 3726 / H.R. 2754)
- Direct HHS to provide dedicated grant resources for the expansion of Long Covid clinics (Cosponsoring the TREAT Long COVID Act -S. 4015/ H.R. 7482)

During our annual advocacy events, we connect people with ME/CFS, Long Covid, and other chronic illnesses; scientists; clinicians, and caregivers to share their unique stories with Congress. Social media posts, emails, and phone calls are also facilitated to allow actions for every energy level and ability to join.

These meetings and actions are great opportunities to connect with and educate your legislators, raise the issues most vital to our community, and lay the foundation for a better future for people with ME/CFS, Long Covid, and other chronic diseases.

During Advocacy Month 2022, we also premiered a new series spotlighting the voices of several standout members of our community as they inspired us with their stories, advocated for change, and answered your questions. This series – Advocacy Cafe – became a community favorite, and we’re excited to announce that we will continue hosting more through the end of the year! Join us the last Friday of the month through 2022 as we bring you more stories, inspiration, and conversations.



“We gained five new co-sponsors for the CARE for Long COVID Act, thanks to the passionate participation during Advocacy Month. This brings us another step closer to the passage of legislation that will fund comprehensive access to resources and education for all post-viral diseases, including Long Covid and ME/CFS.”

– Emily Taylor
Solve M.E. VP of Advocacy and Engagement

Tracking of ME/CFS Cases in the Revised U.S. ICD-10-CM

Thanks to your advocacy, ME/CFS tracking in the U.S. is being transformed! With the upcoming release of the 2023 ICD-10-CM (the *International Classification of Diseases*), Americans diagnosed with ME/CFS, including any new cases following COVID-19 infections, will no longer be invisible.

Last year, under **Mary Dimmock’s** expert and dedicated leadership, we proudly joined six other organizations, including IACFS/ME, The #MEAction Network, Open Medicine Foundation, Massachusetts ME/CFS & FM Association, Minnesota ME/CFS Alliance, and Pandora Org, in submitting nearly 3,200 signatures in support of our joint proposal to the National Center of Health Statistics (NCHS) to fix the coding of ME/CFS in the U.S. ICD-10-CM.

“Fixing ICD tracking is a major step toward improving understanding and visibility of this disease,” said Emily Taylor, Solve M.E. Vice President of Advocacy and Engagement. “We’re grateful for the

leadership and partnership of our allies in the ME/CFS disease community space – this united front was crucial in making sure our voices were heard.”

Since 2015, virtually all U.S. cases of ME/CFS have been effectively lost in a bucket of unspecified chronic fatigue due to any cause. This impacts tracking of ME/CFS disease mortality and morbidity and assessment of its disease burden and healthcare utilization and cost. It impacts insurance billing and reimbursement. And it also impacts research using electronic health records, including plans by NIH and CDC to undertake such research to understand Long Covid and its sequelae.

To fix this coding problem in the ICD-10-CM, the term ME/CFS has been added and the term “postviral fatigue syndrome” expanded to “postviral and related fatigue syndromes” to account for non-viral infections and other causes. “Chronic fatigue syndrome” has been moved back to the neurological chapter

and the term “systemic exertion intolerance disease” added because some U.S. healthcare providers use this term. Importantly, a note has been added to also code post-COVID condition (U09.9) when ME/CFS is associated with COVID.

The success of this campaign will help us ensure that ME/CFS is correctly tracked and identified in electronic health records. Proper disease coding will not only enable greater research into this disease, but also increase its visibility to doctors, researchers, and policymakers.



Highlights From Our Long Covid: Research, Policy and Economic Impact Conference

As part of our work via the Solve Long Covid Initiative, we partnered with the Global Interdependence Center on a year-long webinar and conference series exploring the pandemic’s long-term healthcare, policy, and economic impact.

In May, we co-hosted in New York City our signature event, Long Covid: Research, Policy, and Economic Impact. An outstanding array of thought-leaders, researchers, and practitioners explored critical insights into defining, diagnosing, and optimizing treatments and healthcare policies for Long Covid and post-infection diseases based on analyses of their impact on the U.S. and global labor markets.

Presentation sessions included scientific research, industry-specific implications, economic impact and labor market challenges, the human experience, and a standout keynote presentation from 2022 Nobel Peace Prize nominees Dr. Peter Hotez and Dr. Maria Elena Bottazzi, for their work to develop and distribute a low-cost COVID-19 vaccine to people of the world without patent limitation.

To read a summary of the event, or to watch the conference sessions, scan the QR code.



Solve M.E. Ramsay Research Grants Empower Researchers

Solve M.E. invests in innovative scientific studies to address knowledge gaps in ME/CFS, Long Covid and other post-infection diseases. Through our Ramsay Grant Program, we assist early-career researchers and fund a portfolio of research projects at some of the most prestigious medical centers and research laboratories in the United States and abroad.

Our 6th annual Ramsay Grant application cycle recently closed, and in the coming months we'll announce the next round of grant winners. Since 2016, Solve M.E. has invested over **\$1 million in Ramsay Grants** and built an extensive network of 80 scientists engaged in ME/CFS research, with a growing number of them making meaningful scientific contributions.

Ramsay Researcher Dr. Bhupesh Prusty is a passionate molecular biologist committed to patient-oriented research. He recently published a study in *Nature* funded by our Ramsay program.



With your donations and support, our Ramsay Research Grants have helped scientists like Dr. Prusty secure *millions more* in research funding. To date, Ramsay researchers have gone on to receive a total of over \$7,700,000 in additional research funding—nearly 8x the return on the investment.

Ramsay Grants have had huge success in attracting new researchers to the ME/CFS and Long Covid fields and in ensuring they stay engaged, while also facilitating applications for larger grants based on promising pilot data.

In 2021, Solve expanded the Ramsay Program by launching the Stupski Awards to fund projects that analyze You + ME

Registry data. These new grants honor the memory of Joyce Stupski, whose generous support of research and dedication to Solve M.E. will be sorely missed.

As part of our educational webinar series, several Ramsay researchers have joined us this summer to provide updates on their ongoing research. Some have become leaders in the post-infection disease space; researchers like Dr. Jarred Younger, who was one of the first researchers to receive a Ramsay grant in 2016. Since then, he has received an R01 grant from the NIH for a neuroimaging study (\$3M over five years) and a Department of Defense grant for another neuroimaging study (nearly \$400K over two years).

To watch webinars featuring Ramsay researchers, visit our YouTube page at [YouTube.com/SolveME](https://www.youtube.com/SolveME).

“

This study in particular is very interesting as it was never supported by any major research grant. The Ramsay Research Grant from Solve M.E. was very crucial as it helped us to continue our work at a very delicate stage of research and to take the project forward.

— Bhupesh Prusty, PhD, 2016 Ramsay Awardee, Scientist/Principal Investigator, Institute for Virology and Immunobiology, University of Wuerzburg



Larry & Nicole Baldwin: A Father-Daughter Duo Tackling ME/CFS

Every so often, a story from one of our donors will re-energize our team at Solve M.E. and remind us of the profound impact our work inspires, and likewise, our donors create through their contributions. The strides we stand to gain, we gain together.

Larry Baldwin and his family are longtime supporters of Solve M.E. — not only through generous contributions, but also through connections with our network of scientists and researchers. Larry, a former practicing surgeon, has suffered with ME/CFS for nearly three decades. His daughter, Nicole, a neurology resident, has conducted ME/CFS research with Dr. Lucinda Bateman (Bateman Horne Center), published this research in a peer-reviewed journal and presented her research at the IACFS/ME (International Association for ME/CFS) international meeting.



“We have been donating to Solve for many years, since it was the CFIDS Assn. of America. ME/CFS causes many patients to lose their ‘voice,’ their voice to advocate for themselves. Changing this situation requires patient groups, like Solve ME/CFS Initiative, to research this disease to find biomarkers and its cause. Research funding requires donations. We donate to Solve to give back to patients their voice.”

— Larry Baldwin

“My wife is the person who helps me get through this disease by encouragement, wise advice, patience putting up with this disease, helping me figure out what medical event is happening at certain times when there is no doctor in town or region who knows about the disease,” Larry shared about his wife, family practitioner Jan Linse Baldwin, MD.

The Baldwins demonstrate the family-wide commitment that is often necessary to help care for a loved one who is sick with ME/CFS, but also show us the strides we can take together when we are in lockstep about what is needed to improve outcomes and quality of life — greater research, inquisitive and supported scientists, and understanding medical practitioners.

Solve M.E. is proud to be part of the fight for Larry and everyone with post-infection diseases. With the Baldwins' and others' donations, Solve continues to support research and advocate for patients' rights and more resources to find diagnoses, treatments, and a cure.

New Faces at Solve M.E.



Ilise Friedman has joined us as major gifts officer to provide her over two-decades long development experience and help us grow our capacity efforts.



Dr. David Hardy, an infectious disease specialist, has joined us as a medical advisor, providing scientific and medical expertise. In addition to caring for patients, his work has focused on developing novel vaccines, cures, and remission strategies for human viral diseases.



TaKeisha S. Walker has joined us as chief operating officer. In this newly-created role, TaKeisha will lead Solve's communications, finance, and development strategies and manage cross-functional operations.

Learn more about the Solve M.E. team at solvecfs.org/about-us/staff/

Meet Solve M.E. Director of Development Joe Komsky



My name is Joe Komsky, and though I only joined Solve M.E. as Director of Development in October, my journey with nonprofits began three decades ago.

I arrived in the nonprofit space when my father was diagnosed with ALS in January of 1992. Through becoming his caretaker, I learned the joy of helping someone in trials and triumph; keeping stride with a person through their most difficult days. Even after my father passed away, at age 50, I continued to work in nonprofit, raising money for charities ranging from the Starlight Children's Foundation to the ALS Association to City of Hope cancer hospital.

Telling people I work in fundraising often solicits a flurry of skeptical responses: "Yikes, I could never ask people for money," "Do you just cold-call people all day long?" My real day-to-day experience working in fundraising couldn't be further from the car salesperson pitches and constant hang-ups they imagine.

My philosophy is simple – I have the unique opportunity to connect people interested in our cause and demonstrate how they can change the world through our work at Solve M.E. There are countless ways to support our organization, and we want you to help us in a way that is most meaningful to you. My goal is to get everyone as engaged as possible with our organization's vision and efforts so that when you do give, you know what you're supporting and how that donation is changing lives.

Your donations are the fuel that power our breakthroughs in research and efforts in advocacy. You are changing the world, bringing us closer to a day when we have ways to diagnose, treat, and cure post-infection diseases.

Today, I'm honored to be working for this great organization and in such a vibrant, dedicated community of you, our supporters. I look forward to working with you and I thank you for everything that you do for us.

WHAT YOUR GIFT TODAY CAN DO!

\$1,000 supports expanding our Ramsay Research Grants to studies that enable drug development.

\$500 will help outreach and collaboration with underserved communities to increase engagement through You + ME.

\$250 will enable Solve M.E. representatives to advocate virtually with members of Congress and other federal agencies for increased funding for research.

\$120 will support Solve M.E. hosting webinars featuring thought leaders.

\$50 will support the enrollment of a patient or a control in our You + ME Registry.

SOLVEME.ORG/DONATE



Reflections from President and CEO Oved Amitay

We are well into the third year of the COVID-19 pandemic, and the entire world seems to be in flux in unprecedented ways. The SARS-CoV-2 virus continues to mutate and becomes more transmissible, making solutions seem farther than they might actually be. Even so, I continue to see more and more glimpses of hope for our community, as the entire medical and scientific world has been studying COVID-19 and its aftermath. Especially encouraging is the growing recognition of the similarities between ME/CFS and Long Covid.

Research in Long Covid supporting previous ideas about the potential underlying causes begins to emerge. Inflammation in certain areas of the brain, a misdirected immune response against our own body (autoimmunity) and continuing reaction to viral remnants or a reactivated virus, all were previously described in ME/CFS. Recent studies in Long Covid now confirm these observations and open up possibilities for therapeutic options. However, we know that these connections and their implications are not commonly recognized by the broader medical and scientific community to the extent needed. It is crucial to keep connecting the dots to drive research forward toward treatments. At Solve M.E., we are taking on this challenge.

Bringing decades of experience in representing the needs of the ME/CFS community, we are meeting the moment defined by the Long Covid public

health crisis. We continue to advocate Congress to appropriate more funding for research, including through more targeted programs such as those funded by the Department of Defense. However, we recognize that further action is needed, and we must catalyze a change to develop diagnostics and treatments faster.

In the coming months, we'll increase our focus on connecting ME/CFS and Long Covid research through our Ramsay grant program, and by engaging the biopharmaceutical industry to enter this space. We're working to create a robust dialogue among patients, researchers, drug developers, and regulators to drive development aggressively.

I am certain that bridging the gaps in ME/CFS and Long Covid research will lead us closer to more accurate diagnostic tools, therapeutic interventions and improved outcomes. Intensifying our engagement will ensure that our community members will benefit from strides made in the post-infection disease space.

You and other members of our growing community drive and inspire all of our efforts. Thank you for your continued generosity, partnership, and trust.

Onward, with sincere hope,

Oved Amitay



SOLVE M.E. TEAM

Oved Amitay
President and CEO

Jessica Brown-Clark
Advocacy and Engagement
Manager

Ilise Friedman
Major Gifts Officer

David Hardy, MD
Medical Advisor

Jacqueline Kellogg
Operations Coordinator

Joe Komsky
Director of Development

Karman Kregloe
Associate Director of
Communications

Kate Mudie
Registry Research Manager

Leslie Phillips
You + ME Registry Lead

Elle Seibert
Registry Data Manager

Emily Taylor
Vice President of Advocacy
and Engagement

Ani Vahradyan
Social Media and Marketing
Manager

Jason Van Over
Database Administrator

TaKeisha S. Walker
Chief Operating Officer

Solve M.E. board chair John Nicols recently announced his retirement from the CEO position at Codexis, a leading enzyme engineering company enabling the promise of synthetic biology. After ten years of leading the transformation and growth of Codexis, John stated in a press release that this transition will allow him to, "step back and provide the needed focus and support to my wife who has suffered for years from a debilitating post-viral infection disorder, and dedicate more time to make a difference for her and the many others who face similar challenges through the non-profit that I chair." John has served on our board since 2015, and his enduring commitment to his wife, Marcie, and the millions of others who suffer from ME/CFS, is one of the many reasons we celebrate his insights and service to our organization.



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/
SolveMECFSInitiative](https://facebook.com/SolveMECFSInitiative)

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/SolveME

Solve M.E. Chronicle archive:
SolveME.org/news-and-insights

Humans of ME/CFS:
HOMECS.SolveCFS.org

You + M.E. Registry:
youandmeregistry.com

SUPPORT SOLVE M.E.
SolveME.org/DONATE

SUMMER 2022

Solve ME/CFS Initiative (Solve M.E.) is a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long Covid and other post-infection diseases. Our work lays the foundation for breakthroughs that can improve the lives of millions who suffer from various “long haul” diseases.



The You + ME Registry is an online disease registry designed to help researchers and clinicians better understand ME/CFS and Long Covid, uncover patterns in these diseases, identify treatments, and improve quality of life.

The power of You + ME comes from people like you!
Sign up today: youandmeregistry.com

IN THIS ISSUE

- *Long Haul Voices* spotlights the patient perspective
- Solve M.E. leads the way on Long Covid
- Tracking ME/CFS in the U.S. healthcare coding system

