



The Solve ME/CFS CHRONICLE

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<https://solvecfs.org/covid-19-and-the-me-cfs-community/>

FALL 2020

CEO Oved Amitay Ushers in the Next Chapter for Solve M.E.

By Ani Vahradyan, Solve M.E. Public Relations Coordinator

OVED AMITAY has always been interested in scientific discovery.

Long before his days of working at various biotechnology companies, Oved could be found distilling chemicals in a makeshift lab at his parents' home—the remnants of failed experiments still decorating the ceiling.

Oved now leads Solve M.E. as President and CEO, joining in June 2020 during a period of transition both within the organization, and across the country as the world grappled with the devastating coronavirus pandemic.

Oved pursued an education in pharmacy after receiving acceptances from both pharmacy and medical schools. He spent several years working at Cambridge Neuroscience—his first career in the pharmaceutical industry after completing his graduate studies in Pharmacology—before moving back to Israel and working for Genzyme, a biotechnology company dedicated to developing treatments for rare or specialized diseases.

It was at Genzyme that Oved found his passion for orphan diseases—diseases that are documented to affect fewer than 200,000 people—and for rare hereditary diseases in particular. Oved noted that ME/CFS has very similar disease characteristics to orphan diseases: lack of awareness, difficulty in diagnosing, shifting disease definition, insufficient funding for research and no industry interest. However, ME/CFS is not a rare disease, and it is estimated that there might be as many as

2.5 million people in the U.S. affected by it.

“When developing therapies for rare diseases, which often involve small populations, we work closely with the patient community,” Oved said. “I have been privileged to work with a number of patient advocacy groups over the years—something I’ve really cherished. These patient communities are all very different from one another; each has its own character.”

Oved is personally invested in advancing a cure for ME/CFS and helping individuals avoid what he called a “diagnostic odyssey” when it comes to understanding



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H.R. 7057: Historic Legislation for the ME/CFS Community

“We cannot let the number of ME/CFS cases rise due to a lack of research and understanding. As we battle the coronavirus, this critical legislation will help us respond to this ME/CFS hidden health crisis.”

— Rep. Jamie Raskin (D-MD)



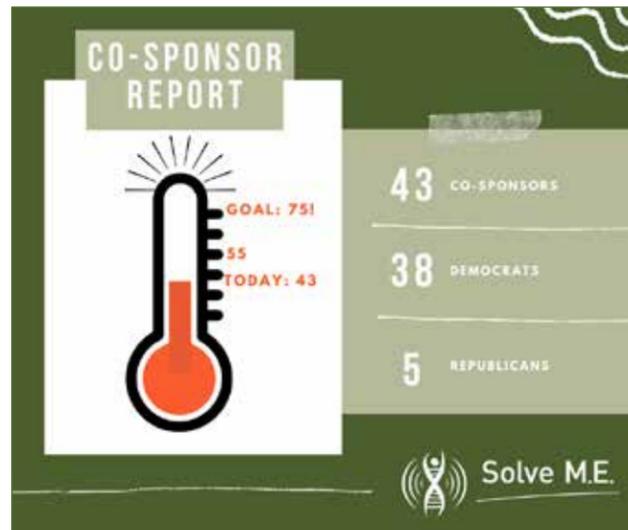
Emerging evidence indicates that growing numbers of COVID-19 “long haulers” are experiencing persistent, ME/CFS-like symptoms, including extreme fatigue, prolonged pain, and headaches, among other symptoms. In May 2020, longtime ME/CFS champion Representative Jamie Raskin introduced landmark legislation for ME/CFS research as part of congressional efforts to respond to the rising number of COVID-19 cases. It’s important to note that Raskin’s 8th Congressional district is also home to the National Institutes of Health (NIH).

H.R. 7057, The Understanding COVID-19 Subsets and ME/CFS Act, will authorize \$60 million over the next four years to expand NIH research into ME/CFS and post-viral impacts of COVID-19. The bill also empowers the Department of Health and Human Services (HHS) to provide for public awareness and medical education campaigns to increase understanding of ME/CFS.

As early as February 2020, Representative Raskin and his team recognized and shared our concerns about post-COVID ME/CFS and quickly worked through the

details for the final version of H.R. 7057. Raskin is an incredibly effective legislator and his leadership has been essential to the bill’s success so far.

Community advocacy will play a crucial role in getting H.R. 7057 across the finish line, and we have until December 2020 to make that happen. ■



“With so many unknowns still surrounding the long-term effects of COVID-19, researching any potential patterns that may be surfacing is crucial. We are grateful for the work of Representative Raskin and our partners at the NIH in taking these first necessary steps. Given the emerging relationship between COVID-19 and post-viral fatiguing diseases, especially ME/CFS, the time to invest in researching potential links is now.”

— Oved Amitay, Solve ME/CFS President and CEO

WHAT WOULD H.R. 7057 MEAN IN THE FIGHT AGAINST ME/CFS?

\$15 MILLION FOR 4 YEARS TOWARD DESPERATELY-NEEDED RESEARCH

This money would be appropriated toward research at the National Institutes of Health to address post-viral chronic neuroimmune diseases, including Chronic Fatigue Syndrome (ME/CFS).

IMPROVED RESEARCH AND DATA

The legislation would allow the NIH to support data collection on ME/CFS to better understand how best to diagnose and treat these patients, as well as possible risk factors. The bill also allows NIH to establish or expand collaborative research centers for ME/CFS.

EDUCATION AND AWARENESS

The bill highlights the importance of public awareness and education campaigns to increase understanding with emphasis on early diagnosis.

PROGRESS REPORT

Within 24 months of enactment of H.R. 7057, NIH must submit a report to Congress on the progress made in gathering data and expanding research regarding the onset and clinical care of COVID-19 survivors with ME/CFS.

To read more about H.R. 7057 visit:

<https://www.congress.gov/bill/116th-congress/house-bill/7057>

www.SolveCFS.org

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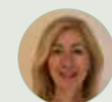
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CEO Oved Amitay Ushers in the Next Chapter for Solve M.E. (cont'd)

their illness. Oved recalled a close family member who exhibited symptoms of ME/CFS for many years before they were able to achieve a diagnosis.

His dedication to working with poorly understood diseases has led him to two important takeaways.

First, to understand the disease better, you must collect data broadly and systematically. This year, Solve M.E. launched the You + ME Biobank and Registry, a patient-led data-capturing program designed to connect patients and researchers. As COVID-19 curtails many research capabilities, this registry will help to advance understanding, develop diagnostic criteria, and ultimately find therapies for ME/CFS, Oved said.

Second, an invested patient community is essential. Patients often know more about their disease, and their experience with that disease, than anyone else, Oved explained. It is important to get community members involved in research and advocacy efforts, and keep them updated during outreach for funding and industry involvement.

"The community has incredible power," Oved said.

As the reported numbers of "long haulers," or people continuing to experience symptoms after contracting COVID-19, rise across the globe, Oved recognizes that this is a critical time for Solve M.E. He hopes that with the expertise Solve M.E. has about post-viral diseases and ME/CFS, they can serve as a resource to this emerging community and its pressing questions. Acknowledging the tremendous tragedy of the pandemic, Oved also said that this may be a period of transformation in post-viral disease research.

"For the first time in history, we may be in a position to follow patients who contract COVID-19 and go through their journey with them," Oved said. "From a research and scientific perspective, we can begin to understand why some people do not recover, become 'long haulers,' or eventually reach an ME/CFS diagnosis."

ME/CFS is a field-wide challenge, according to Oved. As such, he believes it's an issue no single organization can solve alone. He sees Solve M.E.'s role as being an integrating force—a convener that can leverage its research and advocacy capabilities to this end. Oved said it is the responsibility of Solve M.E. and other organizations and agencies to amplify their complementary efforts to create the most powerful coalition possible. ■

Connect with Oved on LinkedIn at <https://www.linkedin.com/in/oved-amitay-1158201b2/>



Oved and his wife, Dalia, at the summit of Mount Kilimanjaro, March 2020

Solve M.E. This Quarter: Fall 2020

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

Solve M.E. Chief Scientific Officer **DR. SADIE WHITTAKER** presented "Understanding Susceptibility or Resilience to Chronic Effects of COVID-19 and Deepening Our Understanding of ME/CFS" at the first virtual meeting of the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME).

Solve M.E. participated in the first meeting of the Interagency **ME/CFS WORKING GROUP**, represented by Chief Executive Officer Oved Amitay and Dr. Sadie Whittaker. Led by the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC), the Group coordinates efforts to further research, treatment, and prevention of ME/CFS, as well as facilitate stakeholder input and community participation.

To better understand the reasons why COVID-19 "long haulers" are suffering with persistent symptoms, our **YOU + ME REGISTRY AND BIOBANK** is collecting data and biological samples from individuals with and without persistent symptoms. We will compare these data to information from people with myalgic encephalomyelitis (also known as chronic fatigue syndrome or ME/CFS), to characterize similarities and differences between the two groups. Learn more at www.youandmeregistry.com.

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

Solve M.E. led the charge for and endorsed H.R. 7057, The Understanding COVID-19 Subsets and ME/CFS Act, the first-ever legislation specifically for ME/CFS research funding. Introduced by **REP. JAMIE RASKIN** (MD-08), the bill will authorize a \$60M program expansion for ME/CFS research at the National Institutes of Health (NIH) and an expansion of public and medical education ME/CFS initiatives. Read more about H.R. 7057 on page 2.

EMILY TAYLOR, Director of Advocacy and Engagement for Solve M.E., hosted the virtual "H.R. 7057 Legislative Café Chat" to answer community questions about this historic piece of ME/CFS legislation.



Solve M.E., The Headache & Migraine Alliance, and Miles for Migraine partnered with the Bipartisan Women's Caucus to host "Women's Chronic Illness During a Pandemic: A Virtual Congressional Briefing" concerning **THE IMPACT OF COVID-19 ON CHRONIC ILLNESS**. This virtual educational roundtable featured panelists included Caucus Vice-Chair Representative Madeline Dean, Dr. Nancy Klimas, Jamie Sanders, Dawn Buse (PhD), Ashanti Daniel (BSN, RN), and Joanna Kempner (PhD).

INFLUENCE AND EDUCATION: Providing trusted, up-to-date medical information, current research, & policy work on ME/CFS

Solve M.E. Research Advisory Council Member **DR. ANTHONY L. KOMAROFF** presented the webinar "Will COVID-19 Lead to ME/CFS in Some People?" addressing the connection between COVID-19 and ME/CFS and the research efforts forming in response. Immediately following the webinar, Dr. Komaroff, Dr. Sadie Whittaker, Emily Taylor, Oved Amitay, and Sue Levine, M.D., held a press event on that same topic, answering journalists' questions about the connections between ME/CFS and COVID-19.

Oved Amitay and Dr. Sadie Whittaker presented the **WEBINAR**, "You + ME: A Registry for the Whole ME/CFS Community," which took an interactive tour of the Registry and offered a closer look at how users can make the most of their You + ME experience. Read more about You + ME on page 6.

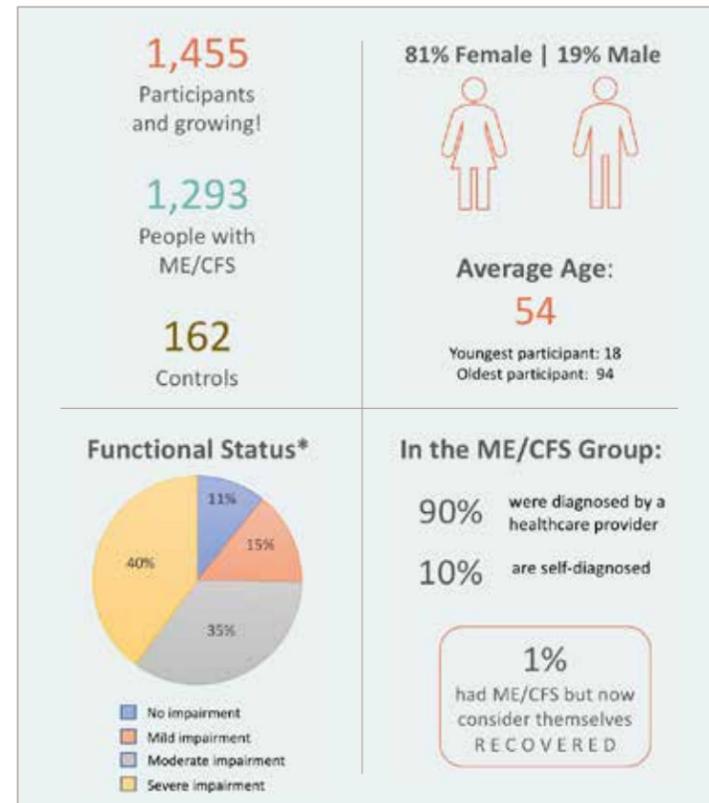
SOLVE M.E. provided public comments on three significant policies: COVID-19 Vaccine Distribution Priorities, Strategic Priorities for the Office of Women's Health, and Proposed Data Collection for the CDC's Multi-site Clinical Assessment of ME/CFS (MCAM).

Dr. Komaroff and Oved Amitay co-authored an **OP-ED ON COVID-19 LONG HAULERS** in the Guardian. Read it at <https://rb.gy/wzmkbn> ■

The You + ME Registry: Together, We Can

As many of you know, in May of this year, we launched the You + ME Biobank and Registry. You + ME 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. Individuals provide information on their lived experience and are invited to donate biological samples for research.

We are thrilled to see so many of you enrolling in the Registry both as individuals with ME/CFS and as controls. As of early September, we have nearly 1500 members contributing their health information! A sneak peek of some of the demographic data can be found below.



One of the things that was important to us in building this resource was that we work hand in hand with the ME/CFS community to co-create an infrastructure and data collection process that was going to meet the needs of the individuals contributing their information and the researchers using that information to drive discovery. We have been amazed by how generous the community has been with their time and the creative ideas which have emerged.

We recently fielded a survey among a group of participants to better understand their experience with the registry. We are pleased to share some highlights with you.

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

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Technology Entrepreneur

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Morgan Fairchild
Actress and Activist

Ex Officio Members

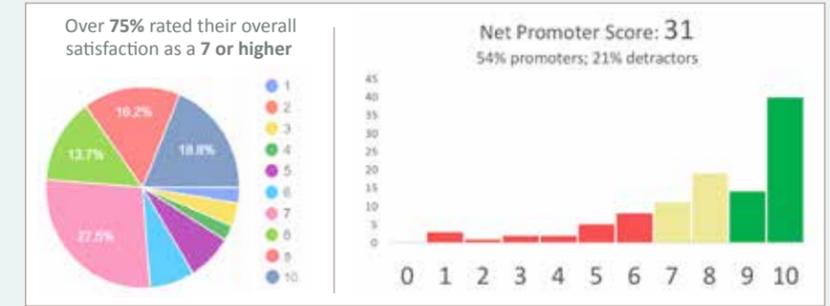
Oved Amitay
President & CEO, Solve M.E.

Sadie Whittaker, PhD
Chief Scientific Officer, Solve M.E.

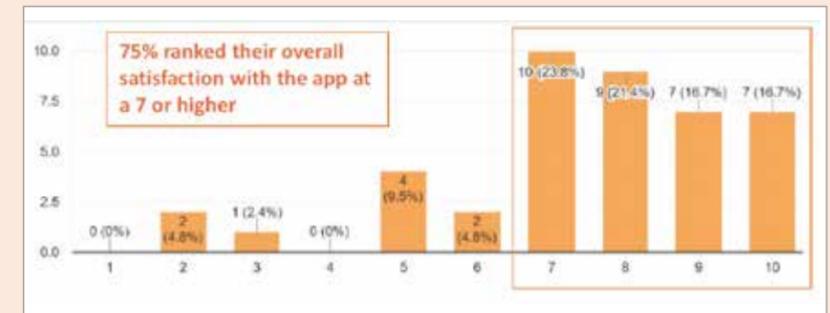
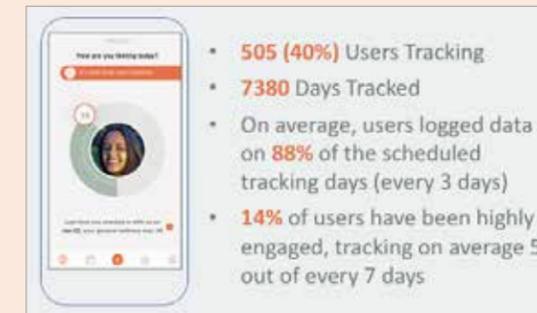
REGISTRY SATISFACTION

Our community’s response to the Registry has been overwhelmingly positive, reinforcing our commitment to this bold endeavor. Participants from nearly every state in the U.S. are represented, and 75 percent of community members report being satisfied with the Registry.

The Net Promoter Score (NPS) is a loyalty and satisfaction measurement taken from asking users how likely they are to recommend a product or service to others on a scale of 0-10.



SATISFACTION WITH SYMPTOM TRACKING APP



Nearly 80 percent of you report satisfaction with the You + ME Tracking App, available for download on Apple and Android devices.

We couldn’t be more pleased with how everything is going so far. You +ME is built on a big vision, to collect health information and biological samples from hundreds of thousands of individuals to help us identify treatments and a cure for ME/CFS. That vision is being realized, thanks to you.

So, if you’ve already joined—thank you! Please log in and check that you’ve completed all the surveys on your dashboard. If you haven’t signed up yet, join now at: www.youandmeregistry.com.

And don’t forget to ask someone in your network to join as a control.

If you have questions, comments, or suggestions, please contact Registry@SolveCFS.org.

“I am so pleased to have joined this app. I don’t feel so alone now or so out of control. By logging how I feel, I am able to make more sense of my condition. Thank you for all you are doing.”

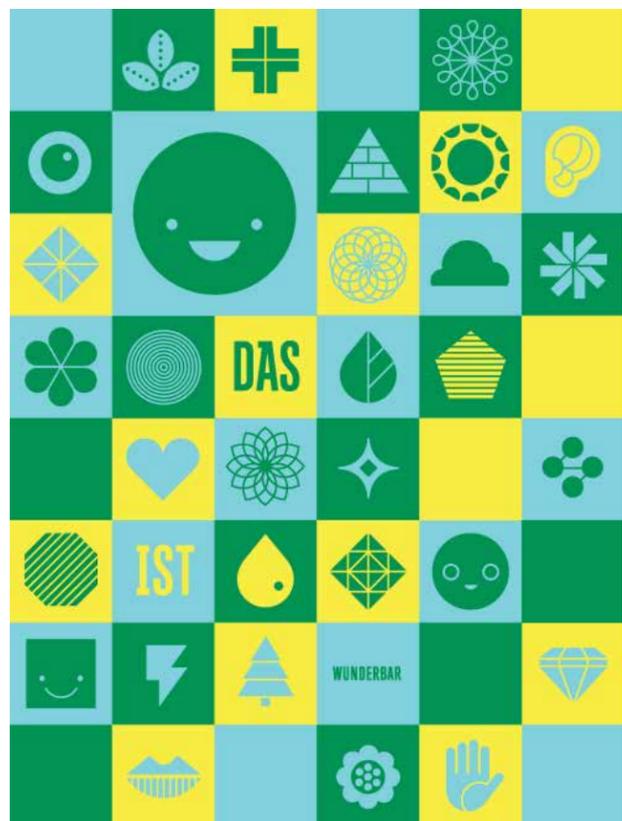
PATIENT VOICES

Every quarter, the *Solve M.E. Chronicle* features the creativity and talent of the ME/CFS community. In this edition, we are exploring the dynamic art of Jeffrey Bucholtz.



Jeffrey Bucholtz studied graphic and interactive communication at Ringling College of Art and Design in Sarasota, where he met his wife Laura. After graduation, a move to California brought Jeffrey to the San Francisco design studio Hatch, where he developed brand identities, point of sale materials, and packaging systems for global brands such as Apple, Condé Nast Publications, Fanta, Target, MTV, and Sprite. Jeffrey's design work has been featured in several design publications and has received many top recognition awards. ME/CFS brought Jeffrey and Laura back to Sarasota, where they continue to live a creative life and enjoy their ten-year-old son.

See more of his work at www.jeffreybucholtz.com.



The Solve ME/CFS Chronicle

Solve M.E. Answers Reader Questions



Q: I want to join the You+ME Registry but I'm concerned about the privacy of my data. Is the Registry secure?

A: Yes! We take privacy seriously and follow strict security protocols and processes to protect participant information. We will never sell, rent or lease any information about you.

Participant data is encrypted and stored in a secure database managed by Solve M.E. research staff who are certified in Human Subjects Research and our partners.

Personal identifiers, including your name and anything else that can be used to easily identify you, are removed from the dataset, and the "anonymized" health information is made available on a secure platform for research. We require investigators seeking access to

anonymized data in You + ME to submit an application to Solve M.E. and the You + ME Innovation Council, a group of patient, research, and data experts. We track the activity of researchers who use the platform.

Biosamples are only collected with additional consent from participants. The biosamples are labeled with a coded number to protect their privacy and confidentiality. The use of biosamples by researchers includes an additional level of approval and vetting.

Q: Are we able to download/export our tracking data from the You + ME app so it can be shared with our doctors? Many patients would significantly benefit from the ability to share this data with their physicians. It would document the significant downward spiral of the ability to function in even basic daily activities that comes with PEM (Post-Exertional Malaise).

A: The You + ME tracking app allows you to record symptoms, life events, and activity on an ongoing basis. This "moving picture" provides researchers with more detailed information on how your health changes over time. But it was also important to create a way for people to get insight into their own illness and provide tools to communicate the day-to-day impact with loved ones or a healthcare team.

While the app does not currently have an export data feature, this is a priority for development! We're currently working with community members on the best way to bring



this feature to the app and it should be ready soon.

In the meantime, you can use the app's "Insights" screen to pick up to 5 symptoms to graph over a custom date range. You can also view select self-reported life events and your general wellness score over the same time period.

LEARN MORE
about the Registry and
SIGN UP at
YOUANDMEREISTRY.COM



IT STARTS WITH YOU.

You are the foundation for Solve M.E. 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 helps us build a community to propel research, advocacy, and education so we can live in a world without ME/CFS. Here, your voice is heard and you will spark real change. We couldn't do it without you.



When you make your gift today, we immediately pour it into actionable, powerful tools for change. Right now, you can join other donors in funding:



YOU + ME REGISTRY AND BIOBANK

Your gift and involvement help us harness the power of big data to unlock causes and treatments for ME/CFS! Both a registry and a biobank, You + ME captures insights from community members just like you to help fill the gaps in ME/CFS data and accelerate ME research.

Participants can record their daily symptoms, medical histories, and activities, and donate biological samples. This information is shared with researchers around the world who are eager to learn from their real-life experiences

In other words, **your gift helps You + ME use insight—from actual people with ME/CFS—to uncover disease causes and identify treatments.**



SUPPORT FOR H.R. 7057

The passionate support of our community has enabled Solve M.E. to endorse the first-ever legislation for ME/CFS research—H.R. 7057.

U.S. Representative Jamie Raskin's bill will authorize funding from the National Institutes of Health (NIH) to address the growing health crisis due to ME/CFS.

COVID-19 has given momentum to our movement. Some survivors who continue to feel chronic, debilitating symptoms—"long haulers"—are experiencing post-viral ME/CFS. The entire world is watching COVID-19 and the medical community can no longer overlook the effects of ME/CFS on long haulers and the millions of other patients who have suffered from this disease prior to the pandemic.

People with ME/CFS have often felt overlooked or abandoned by their doctors. Your gift to Solve M.E. helps us fight for our community, which grows bigger, stronger, and louder. **The more voices we have, the more power we have to bolster federal funding and research for ME/CFS.**



The progress is undeniable. The end-game is more achievable than ever. And it all starts with the generous gifts from donors like you.

Give online at www.solvecfs.org/donate, or call Maryellen Gleason, Director of Development, at 704-364-0016 ext. 207.

Thank you for being a part of our community!

Reflections from our President Oved Amitay

Dear friends,

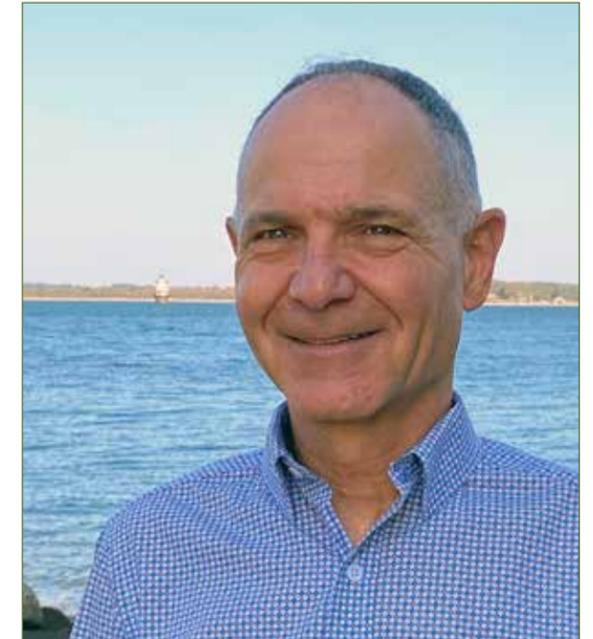
Joining Solve M.E. during a national health crisis has been the challenge and honor of my career. This critical moment demonstrates the absolute necessity of a committed space for ME/CFS research and advocacy through a dedicated organization like Solve M.E.

It's been my privilege to lead the foremost national disease organization dedicated to the ME/CFS community. As we continue our fight to find a cure, we are thrilled with the progress we've made on all fronts of our organization.

In the past few months since I joined the incredible team at Solve M.E., our organization has made tremendous strides:

- We launched the **You + ME Biobank & Registry**, reaffirming our commitment to driving research forward despite the physical limitations COVID-19 presented.
- We're now accepting applications for our 2020 **Ramsay Grant Program**, which supports investigative research into the underlying causes of ME/CFS. With many labs closed due to COVID-19, we're focused on leveraging our Ramsay research network to collaborate on existing datasets and using the You + ME Registry to generate new hypotheses in an effort to adapt to COVID-era science.
- We led **webinars** providing an expert perspective on the growing concern about the connection between COVID-19, long haulers, and ME/CFS.
- We endorsed **H.R. 7057, The Understanding COVID-19 and ME/CFS Subsets Act**, paving the way for the National Institutes of Health to make concrete investments in ME/CFS research, data collection, and education.

Now, as experts warn that ME/CFS cases will explode in the next two years in the U.S. following the COVID-19 pandemic, we recognize the enormity of our responsibility to this growing community.



We know that our work is made possible by the generosity of our patient advocates and community members, who continue to do above and beyond in demonstrating their partnership with Solve M.E.

Thank you.

While we continue working through these tumultuous times, we remain unwavering in our commitment to the ME/CFS community. Every moment we spend researching, advocating, educating, and planning is done in service of finding a cure for the millions of people who suffer from this disease. Now more than ever, our team at Solve M.E. is working tirelessly with our community members, and using every resource and tool at our disposal, to create a future that is free of ME/CFS.

Onward, with sincere gratitude and eternal hope,

Oved Amitay

Oved Amitay

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Humans of ME/CFS:
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You + M.E. Registry and Biobank:
youandmeregistry.com

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FALL 2020

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.

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**Join the You + ME Registry and Biobank and help bring
the big data revolution to ME/CFS!**

Sign up here: <https://youandmeregistry.com/>



Photo by Alisa Anton on Unsplash