

Help make our public service announcement go viral! SolveLongCovid.org

**FALL 2022** 

### New Ramsay Grant Researchers Push the Envelope with Innovative ME/CFS & Long Covid Studies

We're excited to announce the newest class of Ramsay Researchers! Since 2016, Solve's Ramsay Research Grant Program has been successful in attracting new scientists to the field of ME/CFS, and now to Long Covid. These "seed" grants provide much-needed financial support for researchers to make advances and build pilot data for innovative research studies. Ramsay researchers have gone on to earn \$8 million in follow-on funding, much of it from the National Institutes of Health (NIH). That's a 8x return on our investment in preeminent scientists and researchers driving toward treatments.

This year, one study will explore an animal model of ME/CFS which, if successful, could expedite the discovery of ME/CFS disease mechanisms and treatments. Three others are clinical trials exploring new treatments in ME/CFS and Long Covid.

"The Ramsay Grants this year reflect an intentional focus on research that gets us closer to diagnostics and treatments for ME/CFS and Long Covid. I am thrilled that we are at a point where we can support trials that deploy therapeutic interventions and study if they can meaningfully reduce symptoms in people with ME/CFS," says Solve M.E. CEO Oved Amitay. "I am also encouraged to see how ME/CFS can benefit from progress in Long Covid, as well as the potential to develop animal models, which can help translate basic research into drug development. We look forward to learning more about the progress of these exciting studies in the coming months."





- 4 Milestone: First You + ME Registry Peer-Reviewed Paper Published
- 5 Solve's Summer Advocacy Roadshow
- 6 Community Support Resource Guide
- 7 Solve M.E. Spearheads the First Nationwide Long Covid PSA Campaign
- 8 Ryan Prior On The Long Haul and How Patients Can Change the World
- 9 Solve Experts Educate Millions About ME/CFS and Long Covid in National Media Tour
- O The Transformative Power of Monthly Giving
- 11 Reflections from President and CEO Oved Amitay

INSIDE

# New Ramsay Grant Researchers Push the Envelope with Innovative ME/CFS & Long Covid Studies (cont'd)

### Meet the Researchers

Deborah Duricka, PhD | Effect of Stellate Ganglion Block on ME/CFS Symptoms and Plasma Metabolites



Dr. Deborah Duricka's study will follow up on the work of her colleague Dr. Luke Liu, MD, who discovered that blocking nerves at the stellate ganglion with regional anesthesia reduced symptoms of Long Covid. They will apply these findings to investigate the effect of the stellate ganglion block on ME/CFS symp-

toms and physiology. Sympathetic signals routed through the stellate ganglion from the brainstem modulate cerebral blood flow, which is associated with the severity of brain fog and fatigue in ME/CFS and POTS. The block also reduces markers of inflammation and affects metabolic control.

If the block is successful in reducing symptoms and biomarkers, this study could illuminate the physiology underlying ME/CFS and ultimately lead to a potentially effective treatment.

Avik Roy, PhD Targeting ATG13 in an Animal Model for ME/CFS

Dr. Avik Roy and his team are developing an animal model to explore the molecular mechanism of ME/CFS. Dr. Roy will investigate how impaired autophagy — the natural degradation of the cell that removes

unnecessary or dysfunctional components — contributes to the pathogenesis of ME/CFS. His group will study if the genetic ablation of early autophagy protein ATG13 gene might display post-exertional malaise (PEM) pathology in mice.

If the study is successful, it will help to establish the link between autophagy impairment and ME/CFS pathogenesis. The animal model could identify the molecular mechanism of PEM in ME/CFS, and also has potential as an important tool for drug discovery.

Katharine Seton, PhD | Immunosenescence, Premature Aging of the Immune System in ME/CFS and the Response to Fecal Microbe Transplantation



Premature immune aging could explain immune dysfunction in ME/CFS. Dr. Katharine Seton will use Ramsay funding to investigate the link between microbial dysbiosis and immune aging and Natural Killer (NK) cells senescence in ME/CFS. This clinical trial will assess the efficacy

of fecal microbe transplantation (FMT) – the transfer of stool microbes from a person with healthy colon flora to another individual for therapeutic purposes – to determine whether FMT is able to restore immune function in ME/CFS patients and whether this affects symptoms.

This is important both for understanding the role of the immune system in ME/CFS as well as a mechanism by which FMT could improve quality of life for people with ME/CFS.

Rob Wüst, PhD | Micro-clots, Skeletal Muscle Pain and Post-Exertional Malaise in Patients with Long Covid: from Pathophysiology to Treatment

Dr. Rob Wüst and his team will study the mechanism underlying the development of post-exertional malaise (PEM), and the relationship with the development of microclots to provide a deeper molecular understanding of skeletal muscle adaptations. The pri-



mary aim of this study is to unravel the origins of muscle pain, extreme muscle fatigue and PEM in patients with Long Covid.

In its observations of PEM —the hallmark symptom of ME/CFS—this study may have direct implications to ME/CFS, including therapeutic options such as anticoagulants.

### Dana Yelin, MD MPH | Enhanced External Counterpulsation (EECP), Non-invasive Approach to Treat Long Covid Fatigue

Dr. Dana Yelin and her team will study the effects of enhanced external counter-pulsation (EECP) on Long Covid patients suffering from fatigue. EECP is a non-invasive outpatient therapy that uses external inflatable cuffs that are applied around the lower legs, upper legs and buttocks. It has been shown to improve functional status and quality of life in some groups of patients with impaired blood flow and other vascular problems.



This study builds on the use of EECP for cardiac conditions that require improved blood flow to the upper body. A similar mechanism has been documented in some people with ME/CFS. This study in Long Covid could provide additional proof of concept for ME/CFS as well.



66 THANK YOU! Your support and investment are absolutely essential. Without private funding, ME/CFS research would be limited to just a few projects. Solve M.E.'s work to fund promising leads is the only way to discover treatments and cures."

— Deborah Duricka, PhD 2022 Ramsay Grant Recipient

**SOLVE M.E.** IS **PROUD TO FUND STUDIES** that directly impact the lives of patients and caregivers who desperately need solutions. Innovative research is costly, and since 2016 our Ramsay research program generated more than \$8 million in follow-up grants. But there are so many more promising studies that we could have supported if only we had the means.

With your support, we could underwrite more studies, and one of those scientists could make the breakthrough discovery that changes everything.

You can help!

Please consider supporting our Ramsay Research Grant program today.



Together, we can make breakthroughs possible.

#### 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

# 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
Biotechnology Industry
Advisor
CEO, Codexis Inc. ('12-'22)



Morgan Fairchild Actress and Activist

Ex Officio Members



Oved Amitay President & CEO, Solve M.E.

## Milestone: First You + ME Registry Peer-Reviewed Paper Published

It's been more than two years since we launched the You + ME Registry and we're thrilled to have nearly 7,000 people contributing data to the community. We also have a new milestone to celebrate — our first peer-reviewed paper based on the Registry has just been published! The article, "The Facilitation of Clinical and Therapeutic Discoveries in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and Related Diseases: Protocol for the You + ME Registry Research Platform," is published in the August 2022 edition of the *Journal of Medical Internet Research*, a publication focused on digital medicine and health care in the internet age.

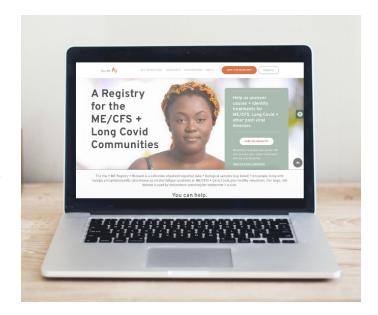
The paper outlines the reasons we set up the Registry, the methods and surveys we're using, and how data are collected. An underlying principle behind creating the Registry was to amplify the impact through collaboration, both with others collecting data on ME/CFS and Long Covid, and researchers who are trying to understand these illnesses.

A protocol paper like this one increases transparency, builds greater awareness about the resource, and fuels future collaborations. It also allows others to replicate our data collection methods, thereby creating opportunities to share data in the future.

The You + ME Registry was designed to create a powerful dataset made up of a large, diverse group of people with ME/CFS, Long Covid, and control volunteers. Our goal was to build a resource that would inspire scientists to apply creative thinking, generate new insights, and rapidly share results.

We want to use what we learn to enhance translational research, speed the development of new therapies, and increase access to care and support for everyone. We believe, now more than ever, in the potential of the Registry to help accomplish these goals.

We have already begun to see the impact the Registry has on research. Two of our Ramsay researchers are using the data to analyze patterns in symptoms and other characteristics in people with ME/CFS and Long Covid. The Registry, in partnership with Hyperion Biotechnology, now serves as a resource



to research a salivary biomarker for fatigue. Registry data has contributed new information to critical research questions, like whether people with joint hypermobility make up a ME/CFS disease subgroup. Additional projects with other researchers in the biotech industry and in academia are now under development.

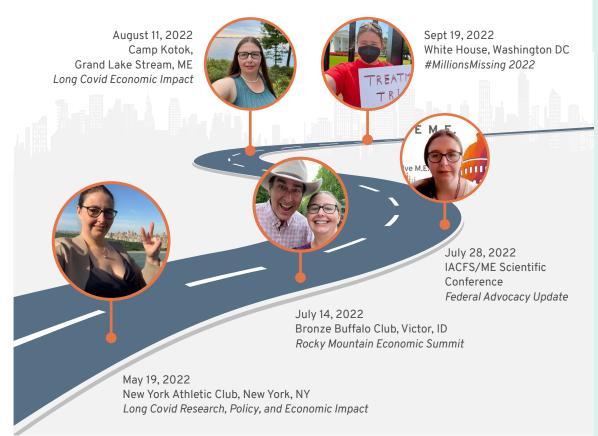
So, what's next?

We're working on ways to enroll more participants, with a focus on expanding the diversity of the You + ME community. We'd like to enhance the user experience so people continue to stay engaged over the long term. We're also looking at how we can further improve the quality and usefulness of the data for Registry participants and researchers.

But for now, we wanted to extend our thanks to you, the You + ME community. So many people have registered and contributed their data, energy, and ideas. Thank you for all you've done and continue to do with us. The work isn't done yet, and we can't wait to keep doing research with you. If you haven't signed up yet, please do so! And if you can encourage a control volunteer to join you, all the better.

To join the You + ME Registry, go to youandmeregistry.com.

Solve's Summer Advocacy Roadshow



Emily Taylor, Solve M.E. Vice President of Advocacy and Engagement, had a busy summer.

Between ongoing meetings with elected officials, advocacy cafe chats with community members, and planning for next year's advocacy agenda, Emily's taken her expertise in ME/CFS and Long Covid policy on the road. Her various speaking engagements at events like the IACFS/ME conference, Camp Kotok, #MillionsMissing, and others, demonstrate her continued commitment to educating and inspiring influential individuals to join our charge to make post-infection diseases better understood, diagnosable, and treatable.



SAVE THE DATE for our upcoming Advocacy Week! Stay tuned for more information on the events from April 16-22, 2023.

### Community Support Resource Guide Clip and save this page for easy reference!



•	• •		
What Do You Need Help With?	Program	Contact Information	Eligibility Notes
Activities of daily living	Disability Information and Access Line	1-888-677-1199 www.acl.gov/DIAL Email: DIAL@usaginganddisability.org	
Local referrals, peer counseling, transportation, and more	Centers for Independent Living	www.acl.gov/node/2636	
Caregiving support, food, legal assistance, and more	National Caregiver Family Support Program: Eldercare Locator	1-800-677-1116 www.ElderCare.acl.gov	Older adults, caregivers for older adults, and individuals of any age with Alzheimer's disease and related disorders
Primary health care	Federally Qualified Health Centers	1-877-464-4772 www.FindAHealthCenter.hrsa.gov	People with lower incomes, uninsured
Health insurance, paying for health care	Health Insurance Navigator and Assister	1-800-318-2596 www.healthcare.gov/find-assistance	
Medicare	State Health Insurance Assistance Program	1-877-839-2675 www.ShipHelp.org	Medicare beneficiaries
Health insurance and benefits issues after losing your job	Employee Benefits Security Administration	1-866-444-3272 www.askebsa.dol.gov	
Disability benefits	Social Security Disability Insurance and Supplemental Security Income	1-800-772-1213 www.ssa.gov/benefits/disability www.ssa.gov/benefits/ssi	Require applications and approval
Cash assistance	Temporary Assistance for Needy Families	https://www.acf.hhs.gov/ofa/map/about/ help-families	Varies by state
Food	Emergency Food Assistance Program	www.fns.usda.gov/fns-contacts	Varies by state
Your house	Homeowner Assistance Fund	202-624-7710 www.ncsha.org/homeowner-assistance- fund	Varies by state
Rent	Emergency Rental Assistance Program	1-800-569-4287 https://www.consumerfinance.gov/ coronavirus/mortgage-and-housing- assistance/renter-protections/	Varies by state
Utilities	Low Income Home Energy Assistance Program	1-866-674-6327 www.EnergyHelp.us Email: energyassistance@ncat.org	
Transportation	National Aging and Disability Transportation Center	1-866-983-3222 www.nadtc.org	
Child with Long Covid	Family-to-Family Health Information Centers	1-888-835-5669 www.FamilyVoices.org	Families caring for children with special health care needs
Education	Parent Training and Information Centers	973-642-8100 www.ParentCenterHub.org	Parents and caregivers of children with disabilities
Accomodations at work	Job Accommodations Network	1-800-526-7234 www.AskJan.org	
Legal Issues	Protection and Advocacy Systems	202-408-9514 www.ndrn.org/about/ndrn-member- agencies/	Varies by state
Information about your rights	Americans with Disabilities Act National Network	1-800-949-4232 www.adata.org	

# Solve M.E. Spearheads the First Nationwide Long Covid PSA Campaign

In August, Solve M.E. launched the first of its kind national TV and radio Public Service Announcement (PSA) campaign about Long Covid, entitled "How Long?"

The goal of the campaign is to broaden awareness of Long Covid, ME/CFS and other post-infection diseases, create empathy for those who suffer, and highlight the need for research to better help patients. The campaign features:60,:30 and:15 TV and radio ads in English and in Spanish. You can view the TV PSA on our YouTube page at youtube.com/SolveME.

As of this month, the PSA has reached a combined TV & radio audience of over 305 million, airing over 57,000 times nationwide.

We created this campaign in collaboration with the Entertainment Industry Foundation (EIF), a unique non-profit that leverages the powerful voice of the entertainment industry to develop and enhance programs on the local, national and global level that facilitate positive social change. Through this partnership the campaign is expected to be supported by over \$20 million in donated airtime over the next six months. The EIF has been instrumental in developing and promoting many important healthcare initiatives, such as Stand Up to Cancer.

While these first ads focus on Long Covid, the "How Long?" campaign is an umbrella effort that includes ME/CFS and related diseases. We want "How Long?" to become a battle cry that focuses attention on the urgent need for research into all of these little understood and under-funded illnesses.



To the extent that we can extend the reach of this campaign, we will be helping patients, caregivers, clinicians and researchers in their quest to find answers that can help end the devastating impact of these diseases. Together we can help alleviate the suffering of so many.

Journalist Cort Johnson wrote a feature about the PSA and our efforts in the Long Covid space for his outlet, <u>Health Rising</u>, and our contacts at key government agencies praised our efforts and committed to spreading the message.

Like you, we are dedicated to finding diagnostics, treatments and cures for post-infection diseases like ME/CFS and Long Covid. To that end, we encourage you to amplify the message of this campaign — that there is an urgent need for research now. By posting this PSA on your social media platforms and distributing it within your communities, you can help us make "How Long?" go viral. Visit SolveLongCovid.org to get involved and help spread the word!



The road to the end of ME/CFS in large part lies through what we learn about Long Covid ... Hence the value of a PSA that dramatically and succinctly points out the major symptoms of Long Covid. Please share it widely – it will benefit us all.



Cort Johnson

Health Rising

Founder and Director

# Ryan Prior On *The Long Haul* and How Patients Can Change the World

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. In this edition of "Patient Voices," we share an excerpt from Ryan Prior's new book, *The Long Haul*.

RYAN PRIOR

On March 11, 2020, I left the CNN World Headquarters for the last time with a sinking feeling.

I opened my car door just after the *Anderson Cooper 360* show finished broadcasting President Trump's primetime Oval Office address about the novel coronavirus outbreak. Knowing that I'm immune compromised with a post-viral condition, I worried that the lives of millions of others might be irreparably harmed if this outbreak got out of control.

As a science features writer, I knew my role would be to highlight the human heart at the center of the greatest moment of upheaval of the 21st century. And I knew that simply writing articles wouldn't be enough.

After writing profiles of Covid long haulers throughout 2020, I received a book deal to tell the story with all the emotional pathos, historical perspective, and futuristic vision this topic deserves. And as my natural killer cells failed in the face of Covid, I too fell ill with Long Covid. I fought against the clock – and my own biology – to hit the publisher's deadline.

The resulting book "tells the story of Long Covid as it should be told, centering the experiences of people who predicted the condition, endured it, named it, and researched it," according to Ed Yong, the Pulitzer Prize-winning science writer for *The Atlantic*, our most brilliant chronicler of the Covid pandemic. "Long-haulers are the heroes of their own story, and this important book beautifully captures their struggle and their courage"

The Long Haul is the culmination of my own decade-long story, in which I set off in 2013 to travel the country directing and producing a film called *Forgotten Plague*, profiling patients and top ME/CFS experts. That journey led me to working for

the next six years as a CNN journalist while also serving as a Stanford Medicine X ePatient Scholar, soaking up the wisdom of patient innovators from across healthcare, from brain cancer to diabetes.

For years, I've known in my bones that patients are the experts in their own healthcare and patient-led research can change how our institutions view post-viral conditions. *The Long Haul* 

gives us that roadmap.

This book also tells the story of how Solve M.E.and the wider ME/CFS community – sprung to action to help long haulers baffled by their new disease, and leveraged long-standing relationships on Capitol Hill to build political coalitions that might turn this crisis into a once-in-alifetime opportunity to fund the right kind of scientific research.

We're at a tipping point in history, and advocacy efforts are blossoming with multiple bills in Congress that can deliver change. The Long Haulers Act, the CARE for Long Covid Act, and the TREAT Long Covid Act could together mark a more patient-centered future.

I hope that every member of Congress might read *The Long Haul*, and that it might be the catalyst for this story, our story, to change hearts, change minds, and change the world.



Ryan Prior covered health and science during the Covid-19 pandemic as a features writer for CNN. He directed the documentary film Forgotten Plague, and has also written for The Daily Beast, USA Today, Business Insider, and STAT News.

# Solve Experts Educate Millions About ME/CFS and Long Covid in National Media Tour

In October, Solve conducted a satellite media tour to raise awareness about Long Covid, ME/CFS and other post-infection diseases — an extension of the #HowLong? public service announcement campaign we launched in August.



ME/CFS expert Dr. Peter Rowe and patient advocate Cynthia Adinig

ME/CFS and Long Covid expert Dr. Peter Rowe and Long Covid patient expert Cynthia Adinig were interviewed by 27 news stations from around the U.S. and spoke to the devastating personal and economic impact of Long Covid, and how more research for Long Covid cures and treatment will also benefit ME/CFS and associated disease communities. Their segments have aired over 400 times and have already reached over 7 million viewers.

Dr. Rowe is a member of Solve's
Research Advisory Council and Director
of the Chronic Fatigue Clinic at Johns
Hopkins Children's Center, as well as
Professor of Pediatrics at Johns Hopkins
Children's Center. His clinic at Johns
Hopkins is one of the country's leading
centers for ME/CFS, and he has treated
Long Covid patients at his practice, many
of whom meet the criteria for ME/CFS.
Dr. Rowe was the first to describe the
relationship between ME/CFS and treatable orthostatic intolerance syndromes,

as well as the association between Ehlers-Danlos syndrome and ME/CFS.

In each interview, Dr. Rowe explained the complexities of diagnosing and treating Long Covid, emphasizing that it's not a "new" problem, but just the latest in a long line of post-infection diseases, such as ME/CFS.

Dr. Rowe told journalists that we must connect the dots and link Long Covid to other post-viral illnesses like ME/CFS in order to apply learnings from prior research. He emphasized the real need to include ME/CFS and other post-infection disease patients in all studies of Long Covid, such as the National Institutes of Health \$1 billion Researching COVID to Enhance Recovery (RECOVER) project.

"We have not paid enough attention in the past to chronic symptoms after other post-infectious illness, such as ME/CFS. There were very few specialty clinics spread around the country, maybe 8-10 clinics for over 2 million people. So when the pandemic came along, we were caught completely unprepared."

- Dr. Peter Rowe

Solve board member Cynthia Adinig is a patient advocate for both ME/CFS and Long Covid, and has been featured in a multitude of national news media and asked to speak at international conferences in this capacity. In addition to her work as a marketing specialist and equity policy advisor, she also created a digital guide for medical care for longhaulers of color.

Adinig, who contracted COVID-19 in March, 2020, shared her own journey as a Long Covid and ME/CFS patient advocate. In her tour interviews, she detailed how misdiagnosis and racial bias by medical providers led her to connect with an online patient community that provided crucial health information and resources.

"Because I lacked proper medical advice or treatments, the advice and experience of seasoned ME/CFS patient advocates are the only reasons I have any quality of life today. Without them, I would still be severely disabled to the point of needing a caretaker."

Cynthia Adinig

In the interviews, Adinig recounted how she and other patient-advocates organized and, together with more experienced organizations like Solve M.E., successfully fought for government-funded research. Adinig also shared her experience as parent of a child with Long Covid, and the devastating impact the disease has had on her family. She underscored the paucity of experienced post-viral pediatric specialists like Dr. Rowe, and shared her fears for the long-term health of her sevenyear-old son, Aiden.

The tour was designed to highlight the urgent need for research and resources, and direct viewers to the <u>SolveLong-Covid.org</u> page to learn more and get involved.

Visit the Solve M.E. website for more information on satellite media tour coverage.

## The Transformative Power of Monthly Giving

Recurring donations – donations that come in monthly, quarterly, or otherwise repeatedly – are the lifeblood of nonprofit organizations such as Solve M.E. These gifts sustain our efforts through and over time, bolstering Solve through various evolutions and expansions while we work to advance our mission.

Recurring donations provide our organization with a steady source of funding, which provides stability for our programs. Not only do these monthly gifts support our hallmark projects and initiatives, but they also drive innovation at our organization, emboldening us to chart ever-new paths forward in the fight against post-infection diseases.

"Monthly givers in particular are a great foundation for our work," says Joe Komsky, Solve M.E. Director of Development. "They are often the most dedicated donors to the organization, because they make continued gifts consistently, building our infrastructure. The more people that give monthly, the more we can plan effective projects and initiatives."

These types of recurring gifts also allow donors to give more by spreading payments out over time, maximizing their impact.

Remarkably, we have donors in our Solve network who have been giving to us regularly for **over 30 years** — since our days as the CFIDS Association. We are honored by their dedication and trust, and have since committed their generous contributions to supporting more research breakthroughs through our Ramsay Research Grant Program, as well as conducting more effective and ongoing federal advocacy.

It is a tremendous benefit to us to know that you, our community, are giving year after year. To learn more about how you can expand your giving, contact <a href="mailto:development@solvecfs.org">development@solvecfs.org</a> or go to <a href="mailto:solvecfs.org/donate">solvecfs.org</a>/donate and sign up for monthly giving.



### **Donor Spotlight: Fara Leonard**



Fara Leonard was working full time as a staff nurse when she became ill, over two decades ago. When she could no longer get through her shifts and had to quit her job, she was devastated. Her world became confined to her home, and Fara revealed to us that these first years were difficult — particularly as she felt those around her didn't accept her ME/CFS diagnosis.

In time, she found Solve M.E. Our organization was a great source of validation, information about the illness, support services and possible treatments for symptoms, Fara shared, inspiring her to begin her giving journey. Today, Fara has been donating to Solve for **24 consecutive years**.

"Throughout the years, Solve has provided a vital sense of community, of not feeling alone. And, now, it is a source of great hope in the research studies it encourages and funds, and in its great lobbying efforts, especially in Washington, D.C."

Fara attributes her philanthropic efforts to her parents, who taught her the importance of humility and generosity. As a donor and community member, she is especially interested in understanding why certain people get so sick with ME/CFS, and how understanding the disease pathology could lead to possible treatments — questions that Solve is seeking to answer through our Ramsay Research Grant Program, which has given Fara hope for a diagnostic test and treatments.

"This is why I give something to Solve ME/CFS every month,"
Fara says. "I set up my checking account to send a small check
every month so I don't even think about it. I only wish I was a
billionaire so that I could give millions!"

Fara has also encouraged her loved ones to support our work. This year, in lieu of gifts, Fara requested that her family and friends donate to Solve M.E. for her birthday.

A tremendous thank you to Fara for her support and dedication over the years. We're honored to work on your behalf to create research breakthroughs and ease the suffering of millions.

### An Evolving Landscape: Long Covid's Impact on ME/CFS

It's hard to believe that we're well into the third year of the COVID-19 pandemic, which coincidentally overlaps with my time as Solve M.E.'s President and CEO.

In this time of great transformation — in the broader society, the healthcare space, and even our own organization — I continue to see the once-in-a-lifetime opportunity that COVID-19 presents to understand and address the underlying biological mechanisms of infection-associated diseases, including ME/CFS.

Today, I see Long Covid's impact, not only on the research front, but also on public awareness, legislative opportunities, interest from pharmaceutical companies, and potential therapeutics.

Biotechnology company AIM ImmunoTech recently announced that the U.S. Food and Drug Administration (FDA) gave a green light to study Ampligen (rintatolimod) for the treatment of post-Covid conditions. This rare second chance comes a decade after the FDA did not approve Ampligen for the treatment of ME/CFS. Building on years of advocacy from the ME/CFS community, the unfortunate emergence of Long Covid reopened the opportunity to study this therapy again. If results are positive, it could bring the drug to people who had COVID-19 and experience symptoms such as fatigue and cognitive dysfunction, which could lead to its use as a potential therapy for ME/CFS.

Solve is committed to working with drug developers, representing the community's needs, and helping design and execute clinical studies that address them.

Long Covid is already informing Solve's investment in research. This year's recipients of our Ramsay Research Grants demonstrate the importance of applying learnings from both ME/CFS and Long Covid to benefit all individuals suffering from shared hallmark symptoms, such as fatigue, brain fog, and post-exertional malaise (PEM). In one study, Dr. Deborah Duricka applies observations from a successful use of a therapeutic procedure that involves blocking specific nerves (stellate ganglion) using a localized injection to reduce symptoms of Long Covid. Their team will apply these findings to investigate the effect of this treatment on ME/CFS symptoms and physiology.

In another research program, Dr. Rob Wüst will study the mechanism underlying the development of PEM and skeletal muscle pain in people with Long Covid, investigating the role of small blood clots. The findings about PEM could have direct implications to ME/CFS, including therapeutic options such as anticoagulants.

At every turn, we are connecting ME/CFS and Long Covid for national and international audiences. By forging new connections with other patient communities and advocacy organizations, we multiply our cumulative strength and influence.

While the unmet needs continue to grow, I believe that we're on the cusp of a new era of intensified research towards therapies. We work everyday to make this hope a reality.

Oved Amilog

Oved Amitay, President and CEO





Oved Amitay
President and CEO

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

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 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

Instagram: Solve\_CFS

LinkedIn: Solve ME/CFS Initiative

Twitter: @PIzSolveCFS

YouTube: youtube.com/SolveME

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

Humans of ME/CFS:

HOMECFS.SolveCFS.org

You + M.E. Registry: youandmeregistry.com

**SUPPORT SOLVE M.E.** SolveME.org/DONATE

### **FALL 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: <a href="youandmeregistry.com">youandmeregistry.com</a>

#### IN THIS ISSUE

- Meet the 2022 Class of Ramsay Researchers
- The First You + ME Registry Publication
- Solve M.E. Launches National Awareness Campaign

