



# The Solve ME/CFS CHRONICLE

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

SPRING 2020

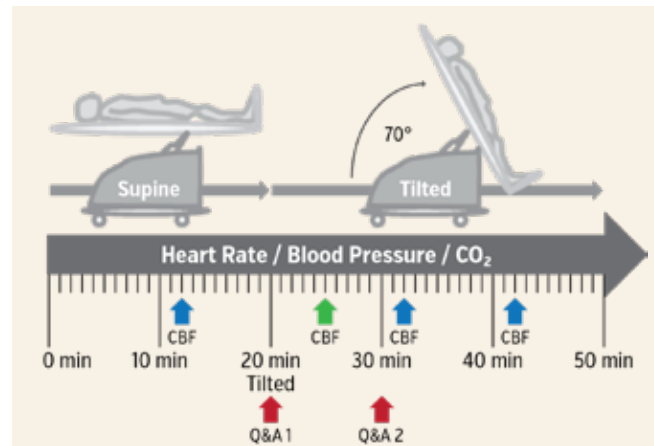
## Could Improved Testing for Orthostatic Intolerance Lead to Better Clinical Care for People with ME/CFS?

By Kathryn Boorer, PhD

**THE ME/CFS COMMUNITY** has become very familiar with the term “orthostatic intolerance” (OI), but what exactly does this mean, and what do the most recent data tell us about this condition? When they stand up, people with OI report symptoms such as dizziness, changes in vision, headaches, nausea, and fainting as well as cognitive impairment, attention disorders, depression, and problems with spatial relationships (sensing where your body is in space). OI can also lead to release of the fight-or-flight hormone adrenaline into the bloodstream, increasing heart rate and blood pressure, among other symptoms. Orthostatic symptoms with a sustained increase in heart rate of at least 30 beats per minute (40 beats in adolescents) within 10 minutes without a decrease in blood pressure is termed postural tachycardia syndrome or POTS.

Diagnosis of OI in people with ME/CFS can be made by performing the head-up tilt test. During the test, a patient lies on a bed, which is then tilted at 70 degrees while blood pressure, heart rate, and other functions are monitored using a finger sensor that measures changes to blood flow. A reduction in blood flow to the brain, also known as a reduction in cerebral blood flow (CBF), is assumed to play a role in the symptoms of OI. A technique called Doppler imaging (a type of ultrasound test) can be performed during the tilt test to measure CBF, potentially allowing more accurate diagnosis of OI.

A new study published by Linda van Campen, MD, Frans Visser, MD, and colleagues sheds light on why so many people with ME/CFS are unable to maintain an upright standing position. The authors used extracranial Doppler imaging to measure whether orthostatic symptoms in people with ME/CFS are associated with



### Head-up tilt test with extracranial Doppler imaging.

Patients were laid flat on a bed for 20 minutes and were then tilted head-up to 70 degrees for a maximum of 30 minutes. Heart rate and blood pressure were continuously recorded. Cerebral blood flow (CBF) measurements were made about 8 minutes before the patient was tilted and 12 minutes (mid-tilt) and 22 minutes (end-tilt) after the patient was tilted (blue arrows). Patients with POTS had additional images collected 5 minutes after they were tilted (green arrow). Patients were asked yes/no questions about 15 symptoms of OI. Questions were asked immediately after reaching the upright position and 10 minutes after being in the upright position (red arrows).

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# Solve M.E. This Quarter: Spring 2020

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

Solve M.E. announced a partnership with the **UNIVERSITY OF CALIFORNIA, LOS ANGELES (UCLA) IRIS CANTOR WOMEN'S HEALTH CENTER** to issue an ME/CFS-specific funding announcement through their Annual Health Pilot Program. They have a demonstrated record obtaining large National Institutes of Health (NIH) grants as follow-on to the pilot projects – approximately \$27 million return on investment for \$1 million invested.

Solve M.E. Chief Scientific Officer **DR. SADIE WHITTAKER** presented on the **YOU + M.E. REGISTRY AND BIOBANK** at the 6th Annual Science Conference held by the UK CFS/M.E. Research Collaborative (CMRC).

**BHUPESH PRUSTY (PHD), ROBERT NAVIAUX (MD, PHD)** and an international team published findings in *Immuno-Horizons* that Human Herpesvirus 6 (HHV-6) could be driving cellular energy production problems in at least some people with ME/CFS. **CARMEN SCHEIBENBOGEN (MD, PHD)** published a genetic association study that suggests an association between autoimmunity genetic risk variants and people with infectious onset ME/CFS in *Frontiers in Immunology*. Both of these studies received support from the Ramsay Grant Program.

In February 2020, Solve M.E. welcomed the newest member of the Research Department, **ELLE SEIBERT**, who will serve as Registry Data Manager for the You + M.E. Registry and Biobank.

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

**SOLVE M.E. ADVOCACY WEEK** activities in Washington, D.C. for the month of April were transitioned entirely to remote formats. The Solve M.E. team canceled in-person events to protect and preserve the health of our ME/CFS community in light of COVID-19.

Solve M.E. Director of Advocacy and Community Relations Emily Taylor deployed an urgent advocacy action to secure 36 supporters of the ME/CFS funding requests in less than 18 hours. The co-sign letters, led by **CONGRESSMAN BERGMAN** and **CONGRESSWOMEN ESHOO AND LOFGREN**, called for \$3m for the CDC to conduct a national ME/CFS epidemiological study.

Solve M.E. teamed up with local Florida advocates to launch a lightning advocacy action. **CONGRESSMEN GUS BILIRAKIS** and **DARREN SOTO** agreed to lead a Florida Congressional delegation to sign a letter to National Institutes of Health (NIH) Director Dr. Francis Collins urging more immediate action for research on ME/CFS.



Congressmen Gus Bilirakis and Darren Soto

In January, Solve M.E. celebrated **SIX FEDERAL VICTORIES** for our collective ME/CFS advocacy efforts that will create real outcomes at federal agencies, such as the Centers for Disease Control and the National Institutes of Health.

Thanks to Solve M.E. advocacy efforts, ME/CFS researchers may now compete for five new funding streams and over 100 awards, with up to \$7.2 million per award, from the Department of Defense **CDMRP FUNDING** program. The Program is slated to receive \$350 million in 2020.

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

Dr. Sadie Whittaker was quoted in a nationally-syndicated Associated Press (AP) story on the **NIH INTRAMURAL STUDY**, which profiled ME/CFS patient-participant Zach Ault.

Solve M.E. formally submitted public comments to the **SOCIAL SECURITY ADMINISTRATION (SSA)** strongly urging a rejection of proposed rule in Docket SSA-2018-0026. The rule would create a new category for disability recipients that would increase the number of continuing disability reviews (CDRs).



Zach Ault of Paducah, KY is connected to monitors during an exercise test at the NIH Hospital as part of an intensive study on ME/CFS.



Jamey Tuttle assists ME/CFS patient Deborah Smith at home in Wisconsin.

In partnership with the Minnesota ME/CFS Alliance, Solve M.E. Director of Advocacy and Community Relations **EMILY TAYLOR** was featured in the *U.S. News & World Report* article, "Western Wisconsin Residents Struggle With Chronic Illness." ■

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



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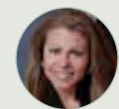
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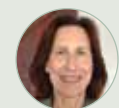
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## Could Improved Testing for Orthostatic Intolerance Lead to Better Clinical Care for People with ME/CFS? (cont'd)

a reduction in total CBF. The authors recruited 429 patients with ME/CFS (Fukuda and International Consensus Criteria classifications) and measured total CBF during a 30-minute head-up tilt test using extracranial Doppler imaging of carotid and vertebral arteries. During the tilt test, 247 patients had a normal heart rate and blood pressure response, 62 had delayed orthostatic hypotension (drop in blood pressure after being tilted upright), and 120 had POTS. Forty-four healthy controls were also assessed. Total CBF was measured before and after participants were placed in the upright position. Participants were also asked two sets of yes/no questions regarding their symptoms, one immediately after being placed in the upright position and another 10 minutes later.

### Q&A 1: immediately after tilt

Did you develop, after being tilted:

- complaints of dizziness or lightheadedness?
- muscle weakness of your legs?
- a feeling of dyspnea or breathlessness?
- pain in the muscles of your neck or shoulders?
- a feeling of nausea?
- a tingling feeling in your right hand?
- a feeling of chest pain or pressure on your chest?
- low back pain?
- palpitations?
- a feeling of a pressure in your head or headache?

Are you, after being tilted, more fatigued in comparison to when you were lying down?

Is your vision less sharp since you have been tilted?

Do you hear me differently, after being tilted, in comparison to when you were lying down?

Are you less concentrated while standing, compared to when you were lying down?

Did you start to sweat after being tilted?

Please visit the online version of *The Chronicle* at <https://solvecfs.org/spring-2020-chronicle-1> to see **Q&A 2: 10 minutes after being in upright position**

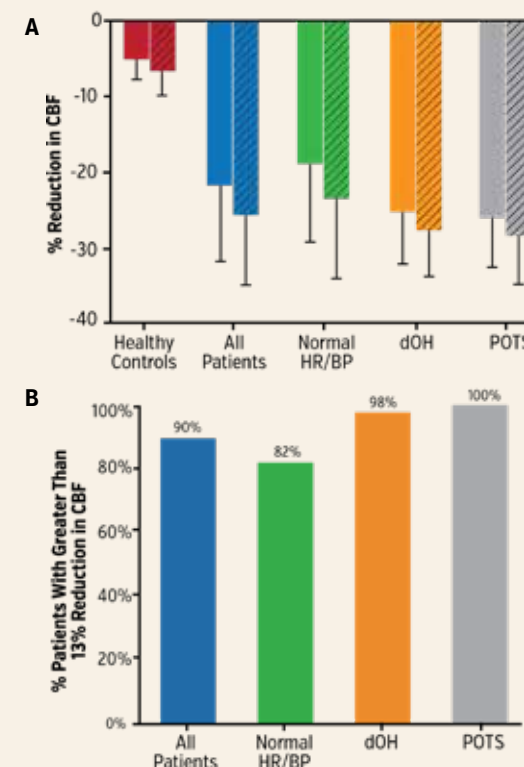
### FINDINGS

- Compared with healthy controls, patients with ME/CFS had an approximate 3-fold reduction in CBF while in the upright position
- Patients with delayed orthostatic hypotension and those with POTS had the largest reduction in CBF
- Almost all patients (90%) had an abnormal reduction in CBF, i.e., a more than 13% reduction in CBF
- Abnormal reductions in CBF were seen in 3 subgroups of patients:
  - » 82% with a normal heart rate and blood pressure response
  - » 98% with delayed orthostatic hypotension
  - » 100% with POTS
- There was a significant correlation between degree of CBF decline and the number of OI symptoms that occurred during the tilt test
- Patients who denied having symptoms of OI in daily life (but who had OI based on clinical signs) had reductions in CBF within the range experienced by patients with OI symptoms
- Patients who had no OI symptoms had similar reductions in CBF to those of healthy controls

**WHAT IS THE SIGNIFICANCE OF THESE FINDINGS?** Van Campen and colleagues have shown that almost all patients with ME/CFS who report symptoms of OI during the tilt test have reductions in CBF. Importantly, this includes patients who report symptoms of OI but who have a *normal* heart rate and blood pressure response to the tilt test—the largest and most often misclassified group—as well as those who stated they had *no* symptoms of OI in daily life.

**“The results of our study may explain why so many patients, including those considered “normal” in the head-up tilt test, cannot maintain an upright standing position and provides direction for treatments for OI. Getting this information out on a broad platform would help improve the way physicians look at OI symptoms in ME/CFS patients—hopefully.”**

**HOW WILL THESE FINDINGS BENEFIT PEOPLE WITH ME/CFS?** The results of this study open the door to more accurate diagnosis and more effective treatments for ME/CFS. For example, treatments that increase blood volume can be tailored to patients who have reductions in CBF. With additional testing, extracranial Doppler during the head-up tilt test may become the gold standard for assessment of OI in patients with ME/CFS. ■



### Reduction in cerebral blood flow in patients with ME/CFS.

**(A)** Reduction in CBF at the end of the tilt test was significantly greater in patients with ME/CFS than in healthy controls: 26% in the overall ME/CFS group [24% in patients with a normal heart rate and blood pressure response, 28% in those with delayed orthostatic hypotension, and 29% in those with POTS] versus 7% in healthy controls. The dotted bars represent mid-tilt; the hatched bars represent end-tilt.

**(B)** Most patients with ME/CFS had a greater than 13% reduction in CBF (abnormal blood flow).

Abbreviations: BP, blood pressure; dOH, delayed orthostatic hypotension; HR, heart rate; POTS, postural tachycardia syndrome.

Adapted from van Campen, C M.C. et al. *Clin Neurophys Prac.* 2020;5:50-58.

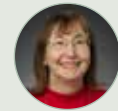
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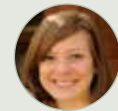
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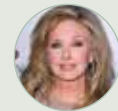
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Sadie Whittaker, PhD  
*Chief Scientific Officer, Solve M.E.*

# You + M.E.: Bringing the Big Data Revolution to ME/CFS

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

The development of the You + M.E. Registry and Biobank has been a labor of love (and at times frustration!) for nearly two years now. When I stepped into the CSO role at Solve M.E., one of my first priorities was to redesign the existing registry and biobank. Our vision: to create the largest possible global data set from people living with ME/CFS and healthy controls. I have spent much of my career working in oncology and have witnessed firsthand the impact that Big Data has had in advancing our understanding of what was once a poorly understood illness. Data has allowed us to understand that cancer isn't a single disease, but rather

a myriad of diseases, each with an individual etiology that can be targeted with a different treatment.

I firmly believe that a global registry and biobank will be the single most impactful driver of progress in ME/CFS, deepening our understanding,

helping us pick apart the heterogeneity, and driving us towards treatments. I believe it will help us answer some fundamental questions that we've all circling around: why do some people respond to some treatments and others do not? Why can some people return to a higher level of functioning while others remain house or bed-bound? Is this a single disease or is it a cluster of different diseases?

But first, we had to create it! We started out by establishing some guiding principles. As big believers in the principles of human-centered design, we knew we wanted to partner with the community to identify what data we should collect, how often, and by what mechanism. We knew we wanted to leverage advances in digital health technology to integrate the ability to track symptoms on an ongoing basis via an app, but what should that look like? The community of patients, care

partners, researchers, and clinicians were invaluable partners in designing all aspects of You + M.E., generously sharing their experiences, their time, and their creative thinking.

Collaboration with others collecting data was also central to our process. Rather than a number of separate silos of data around the world, what if we could create a single Global Data Repository? (It's harder than it sounds!) Together with our lovely partners at **CURE ME** in London we co-created a data capture process that will facilitate data sharing and cooperation between our two registries. Our partnership with **EMERGE** around the creation of an Australian Registry is just beginning, and we are starting to map out how we will collaborate.

None of this would have been possible without our partners at **NIH NINDS**, Vicky Whittemore and Andrew Breeden, who have provided both intellectual and financial support to help us create You + M.E. And I would be remiss not to mention Allison Ramiller, Solve M.E.'s Director of Research, who has been the driving force behind the creation of You + M.E., and for whose determined efforts I am eternally grateful.

Last, many of you have asked about the name: You + M.E. represents the community we hope to build. It represents You + Your Disease; You + Your Healthy Control; You + the hundreds of thousands of others who will contribute their data; You + the network of researchers who will use the data to better characterize this illness. Working together we can revolutionize understanding of ME/CFS. ■

Join the You + M.E. community. Learn more at our website <https://youandmeregistry.com/> and sign up to join us. I would also encourage you to check out our ME Impact Tool <https://youandmeregistry.com/m-e-impact-tool/>. It was designed to communicate a visual gut punch of how debilitating ME/CFS is. Whether it be debilitating symptoms or disengaging from life activities to avoid a crash, ME/CFS crowds everything else out.

# Solve M.E. Welcomes Community Collaboration



**The Solve M.E. Community Advisory Council (CAC)** is a volunteer working group providing guidance and recommendations on Solve M.E. programs. CAC members work with Solve M.E. staff on issues related to ME/CFS advocacy, education, and engagement, and review applications for funding through the Solve M.E.'s community micro grant program.

The CAC had their first meeting in March, where they established working protocols and priorities for upcoming projects. Director of Advocacy and Engagement Emily Taylor said of the meeting, "I simply cannot describe my excitement and gratitude for this amazing group of individuals. There are so many desperately needed education and patient empowerment initiatives that Solve M.E. can now tackle with the CAC!"

## MEMBERS OF THE 2020-2022 SOLVE M.E. COMMUNITY ADVISORY COUNCIL (IN ALPHABETICAL ORDER)

**LISA ALIOTO, JD** is the Vice President of the Minnesota ME/CFS Alliance and runs Realistic Optimism, a website/Facebook page dedicated to helping people with chronic illnesses find realistic optimism in their lives.

**VALENTINA B. COHEN, JD** is originally from the EU and her goals are to raise awareness and secure clinical care for the local community of People with ME living in Los Angeles and around the world.

**MARC COURCHESNE** is a marketing, communications and customer engagement professional and long-time Solve M.E. volunteer.

**SHAKIA GUEST, MAPH** is program developer and manager, and a writer who manages the Instagram account ChronicallyIllWarrior.

**ROBERT JACOBS, MD, MBA** is a retired rheumatologist with a background in laboratory and clinical research.

**ANDREW KANTOR, JD, MBA** is a Disability Insurance Attorney whose practice focuses exclusively on helping individuals whose health, life, or long-term disability insurance benefits have been wrongfully denied.

**SOH-YEON LEE** is a Senior Program Analyst with the State Bar of California and a Volunteer Regional Resource Researcher with Solve M.E.

**SUSAN LEVINE, MD** is infectious disease specialist and founder of the Medical Office of Susan M. Levine, MD. Over the last two decades, she has collaborated with other clinicians and researchers, co-authored a 'Manual for Physicians', served as a reviewer for the IOM report on ME/CFS, and formerly served on the Federal Advisory Committee for CFS.

**LILIANA LIM** has a background in research and communications. She seeks to interweave health content in narrative frameworks to make ME/CFS education more palatable and understandable for a wider audience.

**CAROL MAHONEY** is a nonprofit professional, former member of the Solve M.E. Board of Directors, and current member of the Emeritus Board. Her focuses are in collaboration and helping patients in financial need.

**KATE SANCHEZ, MFA** is an English professor and writer. She is the creator of Vitamin K Mindful, a mindfulness YouTube channel.

**SANNA STELLA** is a long time Solve M.E. volunteer and is currently earning her Master's in Clinical Mental Health Counseling.

**JENNA TAYLOR, MS, NCC, LCPC** is a Licensed Clinical Professional Counselor, educator, writer, and advocate for women and families in crisis.

**DANIELLE WARNER** is an educator and advocate based in Canada. She has experience in communicating with clinicians and researchers to raise awareness about M.E. medical and scientific communities.

# PATIENT VOICES

Every quarter, *The Solve ME/CFS Chronicle* features the creativity and talent of the ME/CFS community. In this edition, we are exploring the extraordinary poetry from members of our community.



by Chris Garcia

## Hope

Remember, the buoyancy in life is found in our enchanted dreams, joyful wishes, and silent prayers.

All create infinite seas of luminous hope. Throughout life we float on hope.



by Bill Clayton

## The Guilt of ME

When the beast descends we know the score  
Strength and hope go through the floor  
We've all been on this road before  
Another day of guilt

Want to take my part in life  
Want to spend some time with wife  
Want to cause no further strife  
Another day of guilt

Said I'd try and meet with friends  
Missed out last time, so make amends  
Woke up to pain, a common trend  
Another day of guilt

Everyone else is doing stuff  
I just can't seem to help enough  
Again I'm feeling just too rough  
Another day of guilt

Want to plan a day away  
Family time, a bit of play  
Woke with head saying not today  
Another day of guilt

We may tell others how we feel  
How symptoms bring us all to heel  
We talk of fog, of how it's real  
We rarely talk of guilt

We blame ourselves for being ill  
For lives and dreams we can't fulfil  
How much more will we hurt until  
We start to banish guilt

Guilt is when you've done some wrong  
Not for trying to be strong  
Guilt with us does not belong  
Let's get rid of all that guilt

It belongs not with you or I  
But with those sitting up on high  
We need to shout with a mighty cry  
Let them bear the guilt

It's with all the powers that be  
Who've chosen to ignore M.E.  
It's been so plain for all to see  
Their hearts should fill with guilt

So let each of us try to shed  
The guilt, and somehow instead  
Understand we do our best  
When daily we are put to test

We beat ourselves up all day long  
Same old singer, different song  
So let's be kind to ourselves, let's not wilt  
And let us banish all thoughts of guilt...

## Solve M.E. Answers Reader Questions



**Q:** *I receive Social Security benefits, and I'm confused about what steps I need to take in order to be eligible to receive the \$1,200 COVID-19 payment from the government. I don't usually file a tax return, but do I need to file one this year in order to get the payment?* -- Lisa

**A:** The Department of the Treasury (Treasury) announced on April 1 that Social Security beneficiaries who are not typically required to file tax returns will not need to file an abbreviated tax return to receive an economic impact payment. The IRS will use the information on the Form SSA-1099 to generate \$1,200 economic impact payments to Social Security beneficiaries who did not file tax returns in 2018 or 2019.

Treasury, not Social Security, will make automatic payments to Social Security beneficiaries. Beneficiaries will receive these payments by direct deposit or by paper check, just as they would normally receive their Social Security benefits.

For updates from the IRS, visit [www.irs.gov/coronavirus](http://www.irs.gov/coronavirus), and be sure to check Social Security's COVID-19 web page at [www.socialsecurity.gov/coronavirus/](http://www.socialsecurity.gov/coronavirus/) for updates, too.

**Q:** *I've read that viral outbreaks like COVID-19 triggered ME/CFS-like illnesses in people who'd been infected. Do you plan to study COVID-19 in order to possibly learn more about ME/CFS?* -- Robin

**A:** We believe our You + M.E. Registry and Bio-bank is well-suited to track both the impact of COVID-19 on people with ME/CFS and the development of ME/CFS-like symptoms following COVID-19 exposure. To that end, we've integrated a COVID-19 questionnaire in the You + M.E. survey dashboard so that we can track the impact of COVID-19 on the health of people with pre-existing ME/CFS.

We've also initiated partnerships with established COVID-19 registries and apps to include questions that ask participants whether they have developed post-viral ME/CFS-like symptoms. If they answer yes, they will be referred to You + M.E. so they can provide more comprehensive information. We believe the combination of these two actions will enhance our collective understanding of the short and long-term impacts of COVID-19.

You can learn more at You + M.E. Registry <https://youandmeregistry.com/>.



## Your Support Makes a Difference

**Caring and determined people like you are building an ME/CFS research infrastructure across the globe by supporting Solve M.E.'s Ramsay Research Grant Program and You + M.E. Registry and Biobank.**

Now more than ever, there is an urgent need to develop a workforce of researchers who can study this disease, which encompasses multiple areas of science including genetics, immunology, neurology, and metabolomics.

Consider the strength that comes from many caring people joining together.



The Solve M.E. Ramsay Research Grant Program does just that. By providing small seed grants and proactively engaging scientists, we are developing a robust workforce of ME/CFS

researchers to uncover the causes and treatments of this debilitating illness. Thanks to supporters like you, in four short years, we have funded 23 studies and a network of over 60 research collaborators, many new to the field and/or early in their careers.

We haven't stopped fighting for you during the Coronavirus (COVID-19) pandemic. Our staff may all be working from home during the quarantine, but that doesn't mean we're lessening our efforts or letting up in any way. We're determined to continue to push toward progress. **When you make an additional gift in any amount today, you'll be supporting these continued efforts.**

Our much anticipated You + M.E. Registry and Biobank will be launched this spring. Patient registries are used to better understand why and how a disease occurs and patterns of disease course, to help identify subsets, to more efficiently facilitate research and clinical trials, and to identify more effective treatments and assess treatment outcomes. The You + M.E. Registry - the first patient registry ever for ME/CFS - will provide the foundation for all of these. In collaboration with the community, we developed a user interface and symptom tracking mobile app that will produce a massive

database of health information from thousands of people with ME/CFS and controls. We've partnered with research organizations in the UK, Canada and Australia as we focus on gathering the largest dataset possible for all researchers around the world.

**When you make your gift today, you're funding critical research and the You + M.E. Registry and Biobank and ensuring that more first-class researchers will focus their careers on ME/CFS.**

Data is key. The data that Ramsay researchers collect through their projects may position them for much larger grants. This means that your support may make it possible for Ramsay researchers to successfully compete for National Institutes of Health funding and advance promising research. Further, the data collected through the Registry and Biobank can be used by ME/CFS researchers around the world in much more systematized ways that can ultimately spur progress.

Your gift, whether large or small, can create change so one day, we will be able to live in a world without ME/CFS. Your support is more important than ever in this time of uncertainty as we all face COVID-19. There are educated projections being made, but the truth is that no one knows for certain how COVID-19 will affect people with ME/CFS or to what degree the number of those suffering from ME/CFS may grow. While it's too early to know exactly how this will unfold, we do know that we must continue to expand available funding for critically needed research. ■

**We are in this fight together!**

**An envelope is included for your convenience, or you can give online at <https://solvecfs.org/donate>**

*Please also consider ways you can maximize your gift, by leaving Solve M.E. in your will, by checking to see if your or your spouse's employer will match your gift, or by joining our monthly giving program. Gifts to Solve M.E. are not restricted to individual programs.*

## Reflections from Solve M.E. Leadership

Dear Friends,

So many in the ME/CFS community are suffering increased hardships as we collectively navigate the unprecedented circumstances brought about by COVID-19. We've created a "COVID-19 and ME/CFS" page on the Solve M.E. website <https://solvecfs.org/covid-19-and-the-me-cfs-community/>, which we regularly update with relevant articles, videos and information from vetted sources about the virus and its impact on people with ME/CFS.

We share your concerns about additional health risks now faced by those with ME/CFS and the impact of economic uncertainty on our already vulnerable community. Some of you have told us of your fears that the research and advocacy gains might be delayed or halted as attention and funding shifts to the current crisis.

But we want to reassure you that all of us at Solve M.E. continue undeterred in our work for you and every member of the ME/CFS community. Our success has not been slowed by COVID-19. In fact, we're redoubling our efforts on every front to defeat ME/CFS. These include:

- **Launching our You + M.E. Registry and Biobank.** Our global registry will collect data and biospecimens from ME/CFS patients and healthy volunteers from around the world. We anticipate it being the biggest driver of progress in identifying causes and treatments for the disease. The You + M.E. Registry also provides a unique opportunity to raise awareness of ME/CFS among clinicians and the general public, creating new hope for better medical care and overall support.
- **Hosting the biggest ME/CFS Advocacy Day EVER!** In order to protect our community, we shifted our annual Advocacy Week in Washington DC to become a completely virtual event. As a result, registrations grew beyond any numbers we've ever seen before, with 320+ registrants from 47 states taking over 250 meetings with members of Congress and asking for \$60 million in new funding for ME/CFS research.
- **Opening our 2020 Ramsay Research Grant RFA** on June 1. The Solve M.E. Ramsay Grants are key to building pilot data, bringing new researchers into the ME/CFS field, and allowing young investigators to lead projects and begin to build a career studying the disease. Previous Ramsay Grant winner Dr. Jarred Younger secured nearly \$3 million in NIH funding based on his Ramsay study pilot data, and we hope to position other Ramsay researchers for similar success.

Despite the obstacles our community has historically faced, and the new challenges posed by COVID-19, we are more optimistic than ever about helping to build a better future for people with ME/CFS. Thanks to you, we have the tools, the people, and the resources to usher in a new era of progress in the fight against ME/CFS. We can't do this work without you, and we're so grateful for your strength, solidarity, and unwavering support.

Onward, together!



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

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

**Solve ME/CFS Chronicle archive:**  
[SolveCFS.org/archive](http://SolveCFS.org/archive)

**Humans of ME/CFS:**  
[HOMECFS.SolveCFS.org](http://HOMECFS.SolveCFS.org)

**You + M.E. Registry and Biobank:**  
[youandmeregistry.com](http://youandmeregistry.com)

## SPRING 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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- Your Covid-19 Questions Answered
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- Poetry by Members of the ME/CFS Community

Join the You + M.E. Registry and Biobank and help bring the big data revolution to ME/CFS!  
Pre-register here so you're the first to know when we launch: <https://solvecfs.org/you-m-e-registry/>

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