



The Solve M.E. CHRONICLE

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

FALL 2021

You + ME Registry Celebrates One-Year Anniversary

The You + ME Registry, one of our strategic initiatives, aims to create the world's largest ME/CFS and Long Covid database and is a vital component of our commitment to identifying diagnostics and treatments.

We marked the Registry's one-year anniversary throughout September by celebrating some accomplishments, announcing the 2021 Ramsay Researchers, reaching a milestone and sharing a few of our 2022 initiatives.

YEAR 1 ACCOMPLISHMENTS

In only one year:

- We grew to nearly 5,000 members and are on track to reach 10,000 by mid 2022, creating a more and more robust resource for researchers.
- We gathered more than 2.4 million data points, more than doubling the number in four months.
- We incorporated Long Covid data to enhance our understanding of ME/CFS.
- We forged partnerships with UCLA, DecodeME and Action for ME.
- We collaborated with Emerge Australia in a landmark effort to establish the first ME/CFS patient registry Down Under.
- We deployed You + ME data to study a potential ME/CFS diagnostic test and for studies supported by our new Stupski Awards.

» to page 2



INSIDE

- 3 Solve M.E. This Quarter: Fall 2021
- 4 Celebrating Funding Victories and Legislative Opportunities
- 6 2021 Ramsay Researchers Announced
- 8 Patient Voices
- 9 We Answer Your Questions
- 10 YOU Make a Difference!
- 11 Reflections from President and CEO Oved Amitay

HEALTHY CONTROL SPOTLIGHT

We also focused on healthy controls during the month, which are vital to medical research.

A healthy control is a person who does not have the disorder or disease being studied – in our case ME/CFS and Long Covid – who can be used as a comparison.

Being a control in the You + ME Registry is easy and one of the simplest things you can do to help people with ME/CFS and Long Covid.

Right now, 10% of people enrolled in the Registry are healthy controls – but we need 30%.

You can help by encouraging a healthy control to join the You + ME Registry.

OUR 2021 RAMSAY RESEARCHERS



Our anniversary celebration also included the announcement of our 2021 Ramsay Researchers. You can find details in “2021 Ramsay Researchers Announced” on page 6.

WRAPPING UP

During the last week of our anniversary celebration, you helped us reach a major milestone – 5,000 enrollees in the Registry – and we’re still on track to reach 10,000 by mid-2022.

And finally, we shared a few of our 2022 initiatives: You + ME | Global, You + ME | Teen and You + ME | Biobank.

These projects will help us achieve our vision of creating the largest ME/CFS and Long Covid database in the world and provide researchers data that makes a difference.

We’ll share details on even more initiatives throughout 2022, and we’ll continue to update you through email, Instagram, Twitter and Facebook.

Your dedication – building the Registry with us, enrolling and encouraging others to enroll, asking insightful questions, engaging us on social media and supporting us financially – has been astounding.

Expanding support for research is critical and one of our most important efforts. You can help. To learn more, please visit solvecfs.org/donate.

Your data makes a difference. Thank you for everything you’re doing to help end the suffering of millions.



The You + ME Registry and Biobank is an online clinical study of individuals committed to identifying a cure for ME/CFS, Long Covid + other post-viral illnesses.

Our community is made up of people with ME/CFS, people with Long Covid + control volunteers collectively providing the research community with critical insight into the lived experience + genetics of ME/CFS, Long Covid + other post-viral illnesses.

Our goal is to create the largest ME/CFS + Long Covid database in the world + provide researchers with the data that will make a difference + end the suffering of millions.

SOLVE M.E. TEAM

Oved Amitay *President and CEO*
Jessica Brown-Clark *Advocacy and Engagement Manager*
Patti Johns Eisenberg *Major Gifts Officer*
Ray Johnson *Development Coordinator*
Jacqueline Kellogg *Operations Coordinator*
Joe Komsky *Director of Development*
Karman Kregloe *Communications and Media Relations Manager*
Kate Mudie *Registry Research Manager*

Leslie Phillips *Consulting Director of Product Management and Operations*
Kira Poplowski *Head of Research Communications*
Allison Ramiller, MPH *Director of Research Programs*
Deborah Saady *Accounting and Operations Manager*
Elle Seibert *Registry Data Manager*
Emily Taylor *Vice President of Advocacy and Engagement*
Ani Vahradyan *Public Relations and Social Media Coordinator*
Sadie Whittaker, PhD *Chief Scientific Officer*

Solve M.E. This Quarter: Fall 2021

RESEARCH: Accelerating the discovery of safe and effective treatments

We are again partnering with the University of California, Los Angeles Iris Cantor Women's Health Center to fund ME/CFS research through their Annual Health Pilot Program. This round of funding follows last year's, which supported a clinical study assessing the effects of repetitive transcranial magnetic stimulation (rTMS) in ME/CFS.

Our You + ME Registry and Biobank is partnering on the world's biggest biomedical study of the causes of ME/CFS with our UK colleagues Action for ME and Professor Chris Ponting of the Medical Research Council Human Genetics Unit at the University of Edinburgh. The DecodeME genome-wide association study will enroll 20,000 individuals with ME/CFS living in the UK using the You + ME platform.

The annual International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis conference featured virtual poster sessions by our leadership. Chief Scientific Officer Dr. Sadie Whittaker presented "One Year of Data Collection with the You + ME Registry," and Director of Research Allison Ramiller and Research Advisory Council Member Dr. Anthony L. Komaroff presented "A Mobile-Device App that Allows People with ME/CFS to Record Their Illness Experience."

Our You + ME Registry welcomed new Consulting Director of Product Management and Operations Dr. Leslie Phillips.

A comprehensive review of ME/CFS and Long Covid research, "Redox Imbalance Links Covid-19 and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome," was authored by

Dr. Bindu Paul of Johns Hopkins, Marian Lemle, citizen-scientist affiliated with Solve M.E., Dr. Anthony Komaroff of Harvard Medical School, and Dr. Solomon Snyder of Johns Hopkins and published by Proceedings of the National Academy of Sciences (PNAS). We facilitated the research by connecting Lemle with her co-authors at Harvard and Johns Hopkins and by funding the project.

ADVOCACY: Strengthening government support, funding, and public awareness

Together with six other organizations, we submitted a proposal to the National Center for Health Statistics (NCHS) to add myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) to the neurological chapter of the International Classification of Diseases (ICD-10-CM). Solve M.E. also hosted a community listening session to discuss the proposal and answer questions.

In response to the Centers for Disease Control (CDC) draft evidence-based treatment guidelines for ME/CFS, we submitted comments highlighting the failure of the CDC to achieve stated goals and strongly discouraged the adoption of the review in any format. In addition to making recommendations to improve patient input, we led a social media campaign encouraging community members to ask their congressional representatives to ensure the CDC is meeting its commitments to Congress and all Americans touched by ME/CFS.

Emily Taylor led the panel "Solve M.E. Update and Federal Advocacy" at the annual IACFS/ME conference. The panel was moderated by Oved Amitay and included commentary by Cynthia Adinig (ME/CFS Patient-Advocate, Long COVID Alliance), Sonya Irey Heller (ME/

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



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Celebrating Funding Victories and Legislative Opportunities

Thanks to your dedication and advocacy efforts, we've seen big successes this year, such as our co-founding of the Long COVID Alliance, hosting a record-breaking Advocacy Week, and ensuring that ME/CFS was discussed in a congressional hearing. Below are highlights of five key accomplishments this year.

1 FIGHTING FOR BIG MONEY FOR ME/CFS IN FY22 APPROPRIATIONS

Thanks to record-breaking participation in ME/CFS Advocacy Week, we secured 53 bipartisan supporters for our \$15.4M FY22 appropriations requests – *that's the largest number of signatures on an ME/CFS appropriations letter in history!* If successful, this increases CDC funding for ME/CFS by 300% and ensures continued participation in the Department of Defense Peer-Reviewed Medical Research Program, which provided more than \$500,000 to ME/CFS researchers last year.

2 CHANGING THE ME/CFS STORY IN THE HALLS OF CONGRESS

A congressional hearing is one of the most highly visible ways members of Congress identify and discuss priority issues. As a direct result of our powerful advocacy efforts, the Subcommittee on Health of the Committee on Energy and Commerce held a hearing on Long Covid, "The Long Haul: Forging a Path through the Lingering Effects of COVID-19."

At that hearing, Rep. Kurt Schrader (D-OR-05) asked about ME/CFS and Long Covid, and the Director of the National Institutes of Health (NIH), Francis S. Collins, M.D., Ph.D., acknowledged the connection and remarked, "My hope would be if we study Long Covid [and ME/CFS parallels] ... we'll learn about both of them."

Long Covid patient advocates Chimère L. Smith and Lisa McCorkell (panelists in our EmPOWER M.E. Roundtable: Elevating Your Voice in Research) gave powerful testimony and spoke to the power of the ME/CFS community in elevating the patient voice and helping new long haulers get the care they need.



Anne Eshoo (top), Chimère Smith (left) and Lisa McCorkell (right) speaking at the Congressional hearing on the topic of Long Covid.

» continued from page 3

Solve M.E. This Quarter: Fall 2021

CFS Patient-Advocate, Solve M.E. & #MEAction), and Shea McCarthy (Sr. Vice President, Thorn Run Partners).

We hosted a virtual legislative café chat on the COVID-19 Long Haulers Act (H.R. 2754) and the COVID-19 and Pandemic Response Centers of Excellence Act (S. 2307, H.R. 4292). Emily Taylor led the discussion and was joined by Alessia Daniele (Weill Cornell Medicine) and Veronica Karam (Houston Methodist).

INFLUENCE AND EDUCATION:

Providing trusted, up-to-date medical information, current research, & policy work

Our President and CEO Oved Amitay was recognized as a Healthcare Visionary by the International Forum for Advancements on Healthcare (IFAH).

Emily Taylor joined the seminar "Understanding Your Patient Rights with a Focus on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)," presented by the Human Health Project.

The Long COVID Alliance, co-founded by Solve M.E., was featured in recent articles in *The New Yorker*, *TIME*, *Fortune*, and *The New York Times*.

3 INTRODUCTION OF H.R. 2754: THE COVID-19 LONG HAULERS ACT

The COVID-19 Long Haulers Act was formally introduced before Congress after being announced during 2021 Advocacy Week at a bipartisan press conference hosted by Solve M.E. The *historic bipartisan act* would authorize \$93M for research, treatment, and disparities of debilitating diseases affecting millions of Americans. The bill contains provisions that will benefit people with ME/CFS, such as nationwide medical education (with ME/CFS specifically identified), expanding prevalence tracking (with ME/CFS included), and research about access to post-viral care and diagnostics (which applies to everyone with post-viral illness). We continue to lead the charge for the COVID-19 Longhauers Act with our advocacy action kit (www.actionkit21.com).



**Representative
Don Beyer (D-VA-08)**



**Representative
Jack Bergman (R-MI-01)**



**Representative
Nydia Velázquez (D-NY-07)**



**Senator
Kirsten Gillibrand (D-NY-20)**



**Representative
Gus Bilirakis (R-FL-12)**



**Representative
Ben Ray Lujan (D-NM-03)**

4 DRIVING SUPPORT FOR S. 2307 & H.R. 4292: THE COVID-19 AND PANDEMIC RESPONSE CENTERS OF EXCELLENCE ACT

We're proud to support this proposal along with the Long COVID Alliance and over 28 bipartisan members of the House and Senate. Led by Senator Kirsten Gillibrand (D-NY-20) and Representative Nydia Velázquez (D-NY-07) this Act and accompanying funding request addresses COVID-19 patient care, clinical research, and medical education through 15 Centers of Excellence chosen and overseen by the Director of Health and Human Services (not the NIH) and an oversight committee, including stakeholders and patient-representatives. With a seat at the table of this new, \$860M research infrastructure, we can help ensure that Long Covid, ME/CFS, and other chronic invisible illnesses are prioritized and funded.

5 PASSAGE OF THE CLINICAL TREATMENT ACT

Lowering the costs and barriers for participation in clinical trials is one of our key priorities. After three years of advocacy, we scored a concrete legislative victory with the passage of The Clinical Treatment Act. This covers clinical trial costs for qualifying 74.8M Medicaid participants – including ME/CFS patients – and reduces the costs for potential ME/CFS clinical trials. Thank you, Representatives Ben Ray Lujan (D-NM-03) and Gus Bilirakis (R-FL-12)!

2021 Ramsay Researchers Announced



The Solve M.E. Ramsay Grant Program is designed to build a workforce, with a special focus on early-career investigators, and to allow researchers to generate data to support larger grant applications.

The Ramsay network now includes more than 60 researchers around the world and has resulted in more than \$7 million of additional research funding.

This year, the number of applications increased by about 130% and they earned the highest ever impact scores from our peer review panel.

We're pleased to share our 2021 Ramsay Researchers.



Sara Ballouz, PhD (Principal Investigator), and Anna Liza Kretzschmar, PhD, from the Garvan-Weizmann Centre for Cellular Genomics

Symptoms, mechanisms and sex: Exploring the sex differences in ME/CFS through integrated computational analyses



Heather Edgell, PhD, York University (Principal Investigator), Riina Bray, MD, Angela Cheung, MD, PhD, Kathleen Kerr, MD, and Farah Tabassum, MD from the University of Toronto

Physiological and cognitive function in patients with PASC or ME before and after inspiratory muscle training



David Esteban, PhD, Vassar College

Microbial aryl hydrocarbon receptor agonists in ME/CFS



Expanding support for research programs like the Ramsay Grants is critical and one of our most important initiatives. You can help. To learn more, please visit

SOLVEME.ORG/DONATE.

Together, we can finally end the suffering of millions.



Alon Friedman, MD, PhD (Principal Investigator), Steven Beyea, PhD, Chris Bowen, PhD, Javeria Hashmi, PhD, and Lyna Kamintsky, PhD, from Dalhousie University and Emagix, Inc.

Blood-brain barrier imaging as a biomarker for ME/CFS



Efthymios Kalafatis, Data Scientist and Predictive Analytics Consultant

Application of machine learning and text analytics in a cohort of people with ME/CFS and people with Long Covid to capture disease severity, potential associations and sequential patterns of events



Aaron Ring, MD, PhD (Principal Investigator) and Jill Jaycox, PhD, from Yale University

Discovery of pathological autoantibodies in ME/CFS and post-acute sequelae of SARS-CoV-2 infection



Jennifer Stone, PhD, Australian National University

ME/CFS and Long Covid: Are they the same condition?



Anthony Komaroff, MD
Simcox-Clifford-Higby Professor of Medicine, Harvard Medical School



Susan Levine, MD
Founder, Medical Office of Susan M. Levine



Maureen Hanson, PhD
Liberty Hyde Bailey Professor, Cornell University



Peter Rowe, MD
Professor of Pediatrics, Johns Hopkins University School of Medicine



Lucinda Bateman, MD
Founder & Chief Medical Officer, Bateman Horne Center



Rochelle Joslyn, PhD
Immunologist, Independent Consultant



Sheila Stewart, PhD
Associate Professor, Washington University School of Medicine



Daan Archer, MBA, MSc
Technology Entrepreneur



John Nicols, MBA
President & CEO, Codexis Inc.



Morgan Fairchild
Actress and Activist

Ex Officio Members



Oved Amitay
President & CEO, Solve M.E.



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

PATIENT VOICES

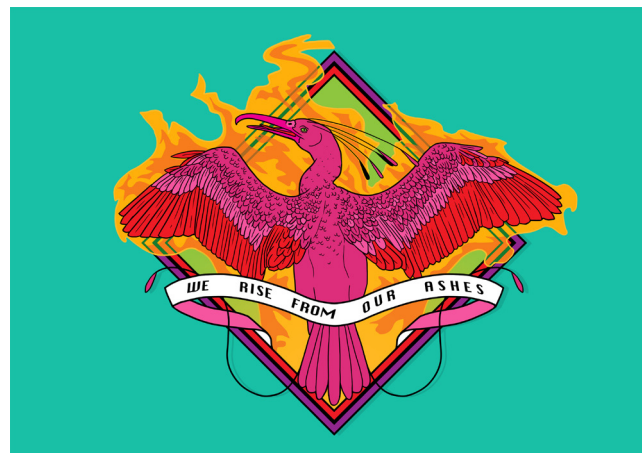
The Solve M.E. Chronicle regularly features the creativity and talent of our ME/CFS community.



Abi Stevens is an illustrator living in Cambridge, UK. She started creating illustrations, enamel pins, and stickers for other chronic warriors after her own health forced her to leave her job as a teaching assistant. She wanted to help other Spoonies feel empowered and remind them that they are not alone. She also hopes her designs will help start conversations about chronic illness and raise awareness.

Abi's Chronic Warrior designs, as well as her other fantastical work, can be found at www.abistevens.etsy.com.

You can also follow her on Instagram @abistevens_illustration and on Twitter @abistevens_art.



We Answer Your Questions



Q: Can I access or download my You + ME data for a doctor's appointment or disability benefits hearing?

A: This feature is a work in progress! The You + ME team aims to "Empower with Information" knowing that it's easier to talk to your healthcare team or loved ones about the impact of ME/CFS or Long Covid if you have data about your symptoms to share. So if you have a doctor's appointment or disability benefits hearing coming up and would like to bring along some of the data you've shared in the Registry, please reach out to registry@solvecfs.org for a data export request. Our team will gather relevant data you've shared in Study Visits or through the Symptom Tracking App so you can bring this information along with you.

Q: I have symptoms from non-ME/CFS conditions. I don't see a place to enter that concept in the Symptoms Assessment survey.

A: We understand why you might think we're only looking for symptoms associated with ME/CFS — a major goal of the Registry is to better characterize symptoms of this disease. But the Symptom Tracking App is designed so you can enter information about the full range of symptoms you experience. On the Track Symptoms screen, you can add symptoms from a pre-populated list or add custom symptoms. It's important that you share as much information as you can about all of the symptoms you experience, regardless of the source. The symptom tracking data combined with information on diagnosed conditions and other indicators of health participants provided to the Registry will allow researchers to look for associations between symptoms and a multitude of other factors aggregated from all app users.

Q: As part of my first Study Visit with You + ME, I'm sharing data on "My Treatments," but I'm not sure if I should list all of my medications or just those I'm taking/things I'm doing only because of ME/CFS.

A: This is a great question! We ask that you include all treatments, including medications and supplements, you are currently taking. We also ask you to provide your history of treatments from the last five years, if possible! When you create a new treatment entry, you will be prompted to indicate if the treatment provides relief for specific symptoms and whether you are still taking it. By providing a complete set of information about your treatments and how well they work for you, you will enable researchers to look for patterns of treatments that work well for people with ME/CFS and other commonalities, such as length of illness or other diagnosed conditions.

Treatment Entry

Name of Treatment

Begin by typing the name of the treatment. You can select the appropriate name from the pre-populated list or finish typing to add a name that is not on the list.

Vitamin C

Route

IV

Dose

2000

mg

Frequency (How often do you take it)?

1

x

month

When did you start (approximately)?

01/2021

When did you stop (approximately)? If you are still taking this treatment, please skip this field.

Don't Know

Did this treatment help, or is this treatment helping with any symptoms?

Yes

LEARN MORE
about the You + ME Registry

SIGN UP at
YOUANDMEREISTRY.COM

YOU Make a Difference!



Solve M.E.
Legacy League

As part of your long-term estate planning, you can provide for your loved ones, meet your tax obligations, and still express your values by giving to your favorite causes through careful estate planning.

Many people, including those living with ME/CFS and their friends and family members, have expressed their commitment to conquering ME/CFS by remembering Solve M.E. in their will and becoming a member of our **Legacy League**.

People like Denny.

Solve M.E. received a letter from Charles Denny White earlier this year indicating that he wanted to pay tribute to his long-suffering wife, Carol, and planned to include our organization in his estate plans.



"She had many doctors over more than 20 years, and most of them tried hard to find solutions for her health issues," Denny told Solve. "Jacob Teitelbaum and Charles Lapp were especially helpful. And yet there were so many questions and so few answers. We were both grateful that Solve M.E. was at the forefront of efforts to improve the lives of patients like her."

We celebrate hearing from Denny, so we can honor him during his life. Denny was one of the first individuals to join Solve M.E.'s new Legacy League.

For more information on the many benefits of planned giving or to join the Legacy League, visit solvecfs.org/planned-giving/ or call our Development Department at (704) 364-0016 Ext 207.

Your legacy can demonstrate the same passion you have shown in your lifetime toward solving ME/CFS and other post-infection diseases.



WHAT YOUR GIFT TODAY CAN DO!

\$1,000 supports sample collection for You + ME Registry and Biobank allowing us to expand into genetic sequencing.

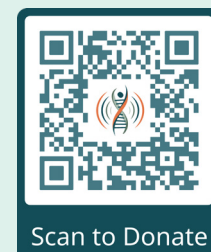
\$500 will help outreach and collaboration with underserved communities to increase engagement through You + ME.

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

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

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

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Scan to Donate

Reflections from President and CEO Oved Amitay

We've learned many important lessons from the challenges of the past year. Among them is the profound impact that the actions of individuals can have on the collective. The community of patients, researchers, scientists, clinicians, and donors we are building – and the insights each of these groups share – brings us closer to our ultimate goal of identifying diagnostics and treatments for ME/CFS, Long Covid, and other post-infection diseases. We are honored to see you sharing our goals and fighting alongside us for a world free of the suffering caused by these diseases.



In just one year since the launch of the You + ME Registry, you and 5,000+ other individuals have joined and contributed over 2.4 million data points to build a robust resource for researchers. Through the Registry, we are creating the world's largest ME/CFS and Long Covid database to accelerate the search for diagnostics and treatments, and we are humbled that you share this vision (and your health data) with us. Only through our shared investment in building this Registry will we begin to better understand these complex conditions.

These stories of collective impact are especially encouraging in the field of ME/CFS research, which is always in need of greater investment and support. At Solve M.E., we catalyze new and ongoing research projects through our Ramsay Research Grant Program. One of our longtime donors, Joyce Stupski, who was the first to underwrite the Ramsay program, passed away this summer. Her generous support made the work of multiple researchers possible, adding to the cumulative scientific knowledge of ME/CFS. Her dedication to advancing understanding of ME/CFS through science will be sorely missed.

This year, we expanded the Ramsay Program by launching the Stupski Awards to support projects that analyze data from the You + ME Registry and honor Joyce's memory. We were again inspired to learn the story of one awardee, Efthymios Kalafatis, a data scientist and person with ME/CFS, who will apply machine learning and text analytics to de-identified data of people with ME/CFS and people with Long Covid to capture disease severity, potential associations, and sequential patterns of events. Efthymios and his fellow class of researchers join the Ramsay network, which now includes more than 60 researchers around the world and has resulted in more than \$7 million of additional research funding for ME/CFS.

We are also moved by the dedication of our citizen-scientists. Marian Lemle is a member of our community who has long been interested in the fundamental processes of cellular energy production. Marian, supported by our research team, connected with world-renowned researchers at Johns Hopkins and Harvard, and their work, "Redox imbalance links COVID-19 and myalgic encephalomyelitis/chronic fatigue syndrome," was recently published in the prestigious *Proceedings of the National Academy of Sciences*!

With fortified awareness of the role each of us plays in moving ME/CFS research forward and improving outcomes for patients – particularly as we are moving into ever-evolving phases of the COVID-19 pandemic – I close with a message of gratitude for you, the members of our community who make our work possible. Your generosity and continued partnership inspire and fuel our action.

Onward, with sincere hope,

Oved Amitay

Oved Amitay

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

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FALL 2021

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.

IN THIS ISSUE

- You + ME Celebrates One-Year Anniversary
- Meet our 2021 Ramsay Researchers
- Five Big Advocacy Wins
- Illustrating Chronic Illness
- Your Questions Answered



Stay tuned for more
information on our all-new
Advocacy MONTH!

Join the You + ME Registry and Biobank and help create the
largest ME/CFS and Long Covid database in the world!

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