



Solve M.E.

2021 Donor Impact Report

Your gift to Solve M.E. enables us to galvanize critical research into diagnostics, treatments, and cures for our community that is growing bigger, stronger, and louder!

Measurable progress – all thanks to you!

The last time I sat down to write you a note in 2020, I could not have imagined what an extraordinary year awaited us. The strides we've gained are tangible, measurable, and encouraging. This was possible because of YOUR sustained support!

You + ME Registry

Our vision for the You + ME Registry is to create the world's largest ME/CFS and Long Covid database and accelerate the search for a cure.

In one year, nearly 5,000 of you enrolled in the Registry and we're on track to reach 10,000 by mid-2022. You've contributed 2.4 million datapoints, and each one makes the Registry a more and more robust resource for researchers searching for diagnostics and treatments. Our goals are ambitious and impossible without your support.

Advocacy

Our 2021 Advocacy Week was the biggest ever. We more than doubled our attendance and dramatically increased direct outreach to policymakers. Our advocacy efforts are creating some of the most substantial opportunities we've seen for federal funding of research and medical education, including specific language related to ME/CFS in H.R. 2754: COVID-19 Long Haulers Act.

Policy

Tragically, our community is growing. An estimated 2.5 million new cases of ME/CFS will be caused by the COVID-19 pandemic. To address this emerging need, Solve M.E. co-founded the Long COVID Alliance (LCA), which is already having a huge impact on federal policy – and that benefits everyone in the ME/CFS community. In July, President Biden issued an executive order for access to Long Covid disability after LCA partners met with his administration's task force. This also earned us national media coverage in *TIME* and *The New York Times* – further shining a spotlight on post-infection diseases, such as ME/CFS.

I close with a reminder – this fight is personal for me. For nearly three decades I have watched ME/CFS ravage my wife, Marcie. It is no exaggeration to say this ruthless disease robbed her (and us) of the life we dreamed of when we met and married in the 1980s.

Please help me as we continue to catalyze the search to solve ME/CFS. For Marcie – and for the millions of others who benefit from the tireless work to increase research, funding, awareness, and hope for this cruel disease.

With deepest gratitude,

John Nicols
Solve M.E. Board Chair





YOUR VOICE IS POWERFUL, AND *CONGRESS IS LISTENING!*

Advocacy Successes

We've seen big successes for Solve M.E. 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. But there is so much work to do! Our work with Long Covid and related disease partners has been critical for those communities and, most importantly, for the ME/CFS community.

Clinical Treatment Act

After three years of advocacy, Solve M.E. 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 provides resources for ME/CFS clinical trials.

Advocacy Week

In April, we hosted the 5th Annual ME/CFS Advocacy Week with record-setting attendance by our community and Congress. As our community grows, we welcomed new partners from the Long COVID Alliance and the EveryLife Foundation for Rare Diseases.

Long Haulers Act

The COVID-19 Long Haulers Act was formally introduced before Congress after being announced during Advocacy Week at a bipartisan press conference hosted by Solve M.E. The historic bipartisan act would authorize \$93M for research and treatment, and address disparities of debilitating diseases affecting millions of Americans.

Stay tuned for a big announcement as we secure additional bipartisan sponsors!



FY22 Appropriations

Speaking of securing sponsors, we have 53 bipartisan House supporters for our \$15.4M FY22 appropriations requests. If successful, this is a 300% increase in funding at the CDC and will also ensure our continued participation in the Dept. of Defense Peer-Reviewed Medical Research Program, which provided more than \$500,000 to ME/CFS researchers last year.

The You + ME Registry Turns 1!

2020

You + ME

We created the **You + ME Registry** because we believe in the power of big data to identify otherwise elusive insights into ME/CFS and **accelerate the search for a cure.**



JUNE

We launched the You + ME Registry and Symptom Tracking App.

SEPTEMBER

We expanded the Registry to include Long Covid data.

JULY

The Registry hit 1,000 participants. We were on a roll!

DECEMBER

We shared our partnership with DecodeME, the largest ever DNA study of ME/CFS.

Research Advancements

You + ME Registry

We launched the Registry a year ago and with your help, we:

- Grew to nearly 5,000 members and are on track to reach 10,000 by mid-2022
- Gathered 2.4 million data points, building a robust resource for researchers
- Incorporated Long Covid data to enhance our understanding of ME/CFS
- Forged partnerships with UCLA, DecodeME and Action for ME
- Established the first ME/CFS patient registry Down Under through our landmark collaboration with Emerge Australia
- Deployed You + ME data to study a potential ME/CFS diagnostic test and for studies supported by our new Stupski Awards

This fall, we announced the winners of our inaugural Stupski Data Awards and are presenting a special Long Covid webinar series. We'll soon be announcing the winners of our lab-based Ramsay Grants, the results of our Covid Vaccine Study, and additional plans for the further expansion of You + ME. Stay tuned for all of this and much more!

Your data makes a difference. Together, we can finally end the suffering of millions.



“My belief as a person with ME/CFS + a bioinformatics researcher is that the key to understanding starts with incorporating symptoms, severities + triggers into carefully designed research. This is possible with the You + ME Registry.”

—Camille, researcher + person with ME/CFS

2021

JANUARY

We reached **2,000 participants** in the Registry!

MAY

Registry reached **1,000,000+ data points!**

We announced our partnership with **Emerge Australia** to open the Registry Down Under.

JULY

The Registry hit **4,500 participants!**

AUGUST

Solve M.E. + UCLA ME/CFS **Brain Stimulation Study** begins.

Winners of new **Stupski Data Analysis Awards** announced.

SEPTEMBER

We're sharing research findings, more Ramsay Grant winners + news about **new initiatives!**

Our vision – to create the world's largest ME/CFS + Long Covid database to **accelerate the search for a cure** – is ambitious and impossible without **YOU**.

Your data **makes a difference**. Together, we can finally end the suffering of millions.

Visit youandmeregistry.com to enroll and learn more.

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WHAT YOUR GIFT 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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