

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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