

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.

SOLVE ME/CFS INITIATIVE PROFESSIONAL STAFF

Maryellen Gleason
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Sadie Whittaker, PhD
Chief Scientific Officer

Emily Taylor
Director of Advocacy and
Community Relations

Jody Short
Interim Director of Development

Allison Ramiller, MPH
Director of Research Programs

Elle Seibert
Registry Data Manager

Deborah Saady
Accounting and Operations Manager

Karman Kregloe
Communications and Media
Relations Manager

Shawna Woolridge
Communications and
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Jessica Brown-Clark
Administrative Coordinator

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." ■

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



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