SMCI This Quarter: A Summary of Our Work

In this recurring section of The Solve ME/CFS Chronicle, SMCI summarizes the highlights of our work. Every quarter you see your SMCI team in action and our unceasing efforts to make ME/CFS understood, diagnosable, and treatable.

RESEARCH work in recent months

SMCI seeks to engage the entire ME/CFS community in research and works to accelerate the discovery of safe and effective treatments.

- SMCI announced new ME/CFS research program with Dr. David Systrom at Brigham’s and Women Hospital
- SMCI sponsored the publication of new ME/CFS Pediatric Primer with Dr. Peter Rowe
- SMCI Research Advisory Council members Drs. Anthony Komaroff and Jose Montoya co-authored ME/CFS gut bacteria study with Dr. Ian Lipkin at Columbia University
- Deadline for Ramsay Award closed with applications from 6 countries submitted
- SMCI expanded substantive biotech research partnership with Metabolon, conducted at Cornell
- Dr. Nahle presented at global ME/CFS conference Invest in ME Research, in London

INFLUENCE and EDUCATION work in recent months

SMCI is the go-to source of trusted, up-to-date medical information, current research, and policy work on ME/CFS and seeks to disseminate this information effectively.

- Cort Johnson of Health Rising featured Dr. Zaher Nahle and our SMCI Bioenergetics Research Program
- Dr. Nahle participated in the technical development workgroup (TDW) resulting in the revisions released this quarter to the CDC public webpage on ME/CFS, removing references to controversial treatments
- SMCI leaders hosted ME/CFS Panel at Precision Medicine World Conference at Duke University
- Dr. Nahle teamed up with rare disease legislative advocates at Capitol Hill information session
- Carol Head was nominated for a WEGO Health Award for a Community and Patient Leader Hero awards
ADVOCACY work in recent months

Through government advocacy, SMCI strives enhance programs that serve patients and researchers alike and for an aggressive expansion of funding for research that will lead to a cure.

• SMCI issued an action alert to restore ME/CFS funding with over 1,850 messages sent to Congress by advocates
• SMCI co-hosted a Congressional briefing on ME/CFS with #MEAction and Senator Ed Markey
• 52 ME/CFS advocates met with 80+ members of congress and their representatives in Washington DC as part of ME/CFS Advocacy Week
• SMCI met in DC with the Acting Director of the Bureau of Health Workforce at the Health Resources and Services Administration to discuss ME/CFS education for health care providers
• SMCI collaborated to pass a state-wide resolution on ME/CFS in California and spoke at an ME/CFS rally at the state capitol in Sacramento
• Working with local advocates Rivka Solomon and Bobbi Ausubel, SMCI helped to secure the political collaboration of the National Organization for Women to advocate for ME/CFS.

Senator Ed Markey of Massachusetts delivers opening remarks at May Congressional Briefing on ME/CFS in Washington, DC