



Leading the Fight to Cure ME/CFS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome



What is ME/CFS?

the DISEASE

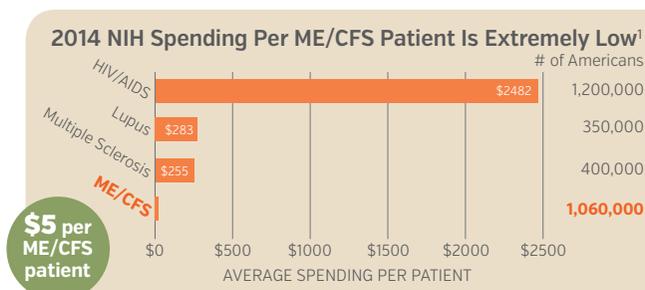
Myalgic Encephalomyelitis [ME], formerly referred to as Chronic Fatigue Syndrome [CFS], is a chronic, complex, neuro-immune disease that profoundly limits the health and productivity of patients. Because of the lack of credibility afforded to this serious disease, many patients try to hide their symptoms which can make it difficult for family members, friends, and the public to understand the challenges of the condition. Many patients are simply not believed to be sick, despite debilitating symptoms, including:

- Profound exhaustion without an attributable cause, which is exacerbated by activity
- Severe headache and debilitating pain
- Diminished ability in concentration and information processing
- Extreme sensitivity to light and sound, requiring complete sensory deprivation 24/7

the FACTS

- › The causes of ME/CFS are unknown and there are no FDA-approved drugs or treatments for the disease.
- › ME/CFS can be fatal.
- › There is no cure.
- › There is no conclusive diagnostic test or biomarker for ME/CFS.

the FUNDING GAP



ME/CFS has been called "America's Hidden Health Crisis" by the Centers for Disease Control and is only beginning to be recognized by medical communities. ME/CFS represents an urgent health crisis.

help us SOLVE ME/CFS

Solve ME/CFS Initiative relies solely on the generous support of patients, family members, and friends to sustain our work. When you support us, you stand united with thousands of like-minded people who understand the devastation of this disease.

To make a secure online donation, go to solveCFS.org/donate.

For mail-in donations, please send your gifts to our street address below. Donations are tax deductible.

How Your Donation Can Impact the ME/CFS Community

\$50,000

Build the You + M.E. Registry

\$2,500

Fund SMCI's Lobby Day in Washington, D.C.

\$25,000

Fund the creation of an interactive SMCI patient support website

\$1,000

Support a Ramsay researcher campaign to secure NIH funding

\$10,000

Fund an SMCI Capitol Hill educational briefing

\$550

Send an SMCI researcher to a national ME/CFS conference

\$5,000

Send an SMCI advocate to meet with members of Congress in Washington, D.C.

\$250

Add 5 patient records to the You + M.E. registry

Gifts to SMCI are not restricted to individual programs.

contact us

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about SOLVE ME/CFS INITIATIVE

SMCI is a non-profit disease organization that accelerates the discovery of safe and effective treatments for ME/CFS, works aggressively toward expansion of research funds, and engages the ME/CFS community in research, advocacy and patient support.

SMCI is the foundational ME/CFS organization, steadily broadening strategic, collaborative relationships with patients, researchers, government officials and other ME organizations across the globe.



RESEARCH

SMCI invests in innovative scientific studies to address knowledge gaps in ME/CFS. We partner with leading experts in the field and work to build new collaborations. SMCI funds a portfolio of research projects at some of the most prestigious medical centers and research laboratories in the United States and abroad.

Investing in Innovative Ideas Around the World: The Ramsay Award Program



Through seed grants for pilot studies, the Ramsay program promotes original research that adds to ME/CFS knowledge and produces preliminary data to support larger grant applications. The Ramsay Awards attract new researchers to the field and ensure they stay engaged. SMCI uses a rigorous peer-

review process that incorporates individuals with ME/CFS into the review panel.

Comprehensive Patient Registry—A Tool for All

You + M.E., the relaunch of our patient registry & biobank for ME/CFS, will further understanding of the natural history of this disease, enable clinical trials and enhance data sharing and collaboration among patients, researchers, and other disease organizations. Our robust data repository includes physical samples from patients to support the work of qualified researchers and accelerate discovery.

Leading Conferences, Symposiums and Think Tanks

SMCI brings together the top minds in clinical care and research, as well as federal health agency leaders to collaborate on key issues facing ME/CFS. In addition to SMCI-hosted events, members of our Research Advisory Council participate and lead panels at prominent international medical conferences.

“ME/CFS is an invisible health crisis, causing suffering for millions. We work fervently at SMCI, with a deep understanding of the research, political and cultural complexities, to solve this debilitating disease.”

—Carol Head, President, Solve ME/CFS Initiative

ADVOCACY

Partnerships with Medical Organizations and Government Agencies

SMCI partners with key medical organizations and government agencies such as the **National Institutes of Health (NIH)** and the **Centers for Disease Control (CDC)** to influence the ME/CFS narrative, advocate for research funding, nurture promising findings, and articulate effective, data-driven policies and solutions.

Driving Advocacy

SMCI acts as an agent for change and unity in the ME/CFS community by advocating for policies, funding, and action. We meet with senior government officials, medical and industry leaders, and scientific pioneers; only a strong and multi-faceted coalition of stakeholders will effect change at the federal level.

Accurate Representation in the Media

SMCI authors opinion and technical pieces addressing current ME/CFS affairs across the science, research, and policy landscapes. Also, we debunk fallacies and misinformation.



our LEADERSHIP



Carol Head, left; Sadie Whittaker, PhD, right

With 30 years of business leadership experience and an MBA from Stanford University, **President Carol Head** leads the Solve ME/CFS Initiative with unparalleled passion as a champion for this disease. Carol has led two for-profit businesses, founded a non-profit organization that empowers impoverished entrepreneurs in the developing world and has served on three boards for national organizations supporting human rights for women. Carol was recognized by *O, The Oprah Magazine* as a “2017 Health Hero.” Carol is a person with ME/CFS.

Sadie Whittaker, PhD, is the Chief Scientific Officer of Solve ME/CFS Initiative. She received her PhD in molecular biology at University of Birmingham, UK, and her BSc in Biochemistry from University of Leeds, UK. Sadie has extensive experience in the biotech industry, in clinical development for biologic medicines, and in strategic leadership roles for advocacy, policy, communication, and external engagement. She brings a deep understanding of the scientific discovery, drug development, and drug commercialization processes, as well as extensive experience in engaging members of the healthcare community. A firm believer in the power of collaboration to tackle difficult public health problems, Sadie has spearheaded several highly successful public/private partnerships and multi-sector coalitions that have resulted in meaningful change.

SMCI's Board of Directors includes senior-level leaders in business, law, and science who each have a personal connection to the disease.

Our **Research Advisory Council**, composed of highly respected scientists from diverse fields, shares its expertise and counsel in SMCI research matters.