



Solve ME/CFS Initiative

Leading the Fight to Cure ME/CFS



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.

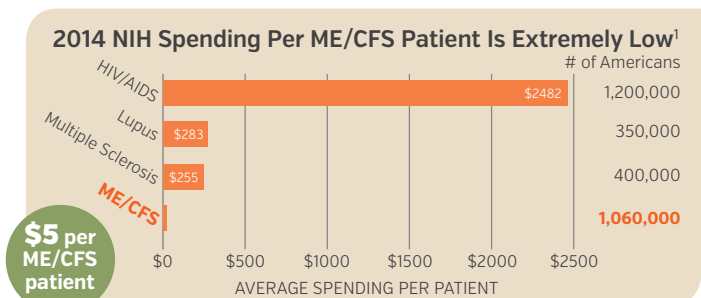
› ME/CFS can be **fatal**.

› 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.

¹U.S. Institutes of Health. “Estimates of Funding for Various Research Condition and Disease Categories [RCDC]. NIH, published March 7, 2014.

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.



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