

# ME/CFS

**Myalgic  
Encephalomyelitis/  
Chronic Fatigue  
Syndrome**

**DERAILS FUTURES  
DESTROYS LIVES  
STEALS INDEPENDENCE**



**“There is an urgent need for more research to discover what causes ME/CFS, understand the mechanisms associated with the development and progression of the disease, and develop effective diagnostic markers and treatments.”**

*—Institute of Medicine, 2015*



**Solve ME/CFS Initiative**

*Making ME/CFS understood, diagnosable and treatable*

# What is ME/CFS?

## the DISEASE

Myalgic Encephalomyelitis (ME), sometimes referred to as Chronic Fatigue Syndrome (CFS), is a chronic, complex, multi-systemic disease that profoundly limits the health and productivity of patients. This disease has long been misunderstood, derided and ignored. 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:

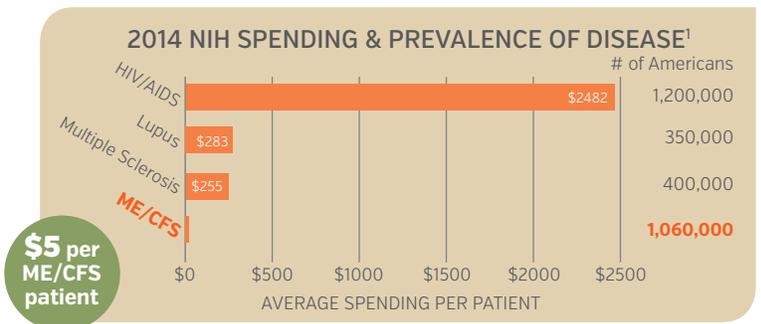
- Profound exhaustion without an attributable cause, exacerbated by activity
- Severe headache and debilitating joint, muscle and lymph node pain
- Diminished ability in concentration and information processing
- Extreme sensitivity to light and sound, requiring complete sensory deprivation 24/7

## 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.
- › ME/CFS represents an urgent health crisis.

## the KNOWLEDGE GAP



ME/CFS is only beginning to be recognized by medical communities in the US and Europe as an urgent health crisis. There is no conclusive diagnostic test or biomarker for ME/CFS. Given the lack of understanding of the cause of the disease, the lack of federal and pharmaceutical investment, the lack of FDA-approved drugs, and that no cure for ME/CFS has been identified, treatment is now only directed at relieving symptoms.

## the PATIENTS

- ME/CFS affects as many as 2.5 million Americans and nearly 20 million people worldwide, but up to 85% are undiagnosed, leaving the true prevalence unclear.<sup>2</sup>
- ME/CFS affects all ages, from children to the elderly. Women are 4 times as likely as men to have ME/CFS.
- Up to 69% of those suffering from ME/CFS are unable to work, and 25% become homebound and dependent on care at some point. Recovery rates are estimated at only 5-10%, and sufferers are more likely to die up to 25 years prematurely from cancer, cardiovascular disease, or suicide.<sup>3</sup>
- ME/CFS patients have a demonstrably lower quality of life rating than patients who suffer from depression, chronic renal failure, lung cancer, type II diabetes, heart angina, breast cancer, and prostate cancer.<sup>4</sup>



<sup>1</sup>U.S. Institutes of Health. "Estimates of Funding for Various Research Condition and Disease Categories (RCDC). NIH, published March 7, 2014.

<sup>2</sup>Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness, IOM 2015

# about SOLVE ME/CFS INITIATIVE (SMCI)



SMCI is a non-profit disease organization that works to accelerate the discovery of safe and effective treatments, strives for an aggressive expansion of funding for research that will lead to a cure and seeks to engage the entire ME/CFS community in research. Through scientific research and advocacy, SMCI serves patients and researchers alike, serving as an information center for the entire ME/CFS community, and enabling SMCI to make an even stronger case for federal government ME/CFS spending, by generating verifiable and large data sets with reliable metrics.

**Filling Knowledge Gaps Through Original Research** SMCI designs and invests in innovative scientific studies to address severe knowledge gaps in ME/CFS. Priority areas include the fields of **bioenergetics, neuroendocrine biology, and inflammation and immunity**. Our partners in these pursuits are leading experts in the field of ME/CFS. SMCI has developed a portfolio of investments at some of the most prestigious medical centers and research laboratories in the United States and abroad.

**Establishing a Patient Scientist Partnership Program for Diagnostic Testing and Clinical Applications** This program facilitates patient participation in decision-making and defining research priorities.

**Investing in Innovative Ideas Around the World: The Ramsay Awards** This international program creates environments to attract, support and retain talent in the ME/CFS research community and helps awardees generate relevant data to compete for long-term federal funding, and facilitates collaboration and cross-pollination among researchers through the sharing of resources and access to additional programming and the organization's network.

**Facilitating Connection and Partnerships: SMCI'S MeetME Travel Awards** SMCI's MeetME Travel Awards fund junior scientists and researchers from underrepresented groups to attend ME/CFS conferences and help build scientific networks by paying their travel expenses for ME/CFS-focused meetings. A goal of this program is to attract new researchers to the field.

**Creating Reliable Electronic Record Systems, Data Management Platforms, Biobanking and Patient Registries** Our new, state-of-the-art national registry for ME/CFS will enable clinical trials, further understanding of the natural history of this disease, and includes built-in options for data sharing and collaboration among patients, researchers, and other disease organizations. This also includes a repository of physical samples from patients to support the work of qualified researchers and accelerate discovery.

**Leading Conferences, Symposiums and Think Tanks** Our think tanks attract the top minds in clinical care and research as well as leaders from federal health agencies, who collaborate on key issues facing ME/CFS. In addition to SMCI-hosted events, Dr. Nahle and members of our Research Advisory Council also participate and lead panels at the most prominent international medical conferences.

**Advancing Medical Education** SMCI is the trusted source for up-to-date medical information, current research, and policy development. We debunk fallacies and restore the narrative through documentation, data and evidence-based presentations. We also lead public medical webinars and educational teleconference meetings that feature influencers in science, medicine, and policy, and publish scholarly articles in prestigious medical publications.

**Partnering with Medical Agencies and Government Organizations** SMCI is a partner with key medical agencies and government organizations that include the National Institutes of Health (NIH) and the Centers for Disease Control (CDC) to influence the 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 focusing our efforts in 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. SMCI authors dozens of opinion and technical pieces addressing current ME/CFS affairs across the science, research, and policy landscapes. Also, we debunk fallacies and misinformation through our "No Spin Zone."

<sup>3</sup> Estimating the Disease Burden of ME/CFS in the United States and its Relation to Research Funding, Mary. E. Dimmock, Arthur A. Mirin and Leonard A. Jason, 2017

<sup>4</sup> Falk Hvidberg, Michael et al. "The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome [ME/CFS]." Ed. Roberto Furlan. *PLoS ONE* 10.7 (2015): e0132421. *PMC*. Web. 13 Sept. 2017