



# Solve ME/CFS Initiative

Leading the Fight to cure ME/CFS

## *Policy Advocacy Statement*

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Approved by the Solve ME/CFS Initiative Board of Directors on December 14, 2016

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*This Solve ME/CFS Initiative policy statement will drive the organization's efforts to create significant change and improvement for patients. This organization's actions are dependent on resources and board approval to execute an appropriate implementation plan.*

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*Whereas* ME/CFS, also known as Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS), is a complex and debilitating chronic disease with a serious impact on one's quality of life,

*Whereas* ME/CFS devastates the lives of an estimated 20 million patients worldwide,

*Whereas* ME/CFS costs the United States economy an estimated \$24 billion annually,

*Whereas* ME/CFS patients have the lowest median quality of life scores of any disease tested, including lung cancer, rheumatoid arthritis, and brain stroke,

*Whereas* ME/CFS patients have experienced 30 years of neglect and inaction from the federal government, private research, and medical sectors with grossly inadequate funding levels for research and patient care and support,

*Whereas* the low number and size of request for applications (RFAs) published and funded by the National Institutes of Health (NIH) regarding ME/CFS is insufficient to attract researchers who have historically avoided the field because of a lack of funding,

*Whereas* fewer than a dozen recognized ME/CFS clinical care specialists are practicing in the U.S. today which represents a significant crisis in clinical care for ME/CFS patients,

*Whereas* intense stigma and misrepresentation regarding ME/CFS exists in the medical community and general population resulting in the discrimination, dismissal, and harm to ME/CFS patients,

*It is the Solve ME/CFS Initiative (SMCI) advocacy policy to support federal, state, private, and public initiatives that provide desperately needed funding, support, awareness, and education in the areas of ME/CFS research, diagnosis, treatment, and patient care to make ME/CFS medically understood, diagnosable, and treatable and to support efforts to raise awareness and improve understanding of ME/CFS in the general public.*

SMCI advocates for ME/CFS as an immediate priority for government action and scientific research and supports a coordinated, intensive, cross-sector effort to unravel the mysteries of this disease and improve the lives of ME/CFS patients. SMCI envisions four key areas of progress towards this goal.

## **1) Expand and Accelerate Research Investment**

- SMCI calls upon government, academia, the pharmaceutical industry, and other private entities to increase funding for research efforts commensurate with the burden of the disease to better understand the pathobiology and epidemiology of ME/CFS, to identify biomarkers, to conduct clinical trials, develop, FDA approved treatments for ME/CFS, and establish robust prevention strategies
- SMCI calls for an investment in the ecosystem of academic researchers and pharmaceutical companies and calls upon the NIH to immediately prioritize and fund a substantial increase in the size and number RFAs for ME/CFS in addition to stronger financial and strategic commitment to investigator initiated research regarding ME/CFS.
- SMCI calls for increased research coordination, interdisciplinary collaboration, and investment by all members of the research community and expanded opportunities to bring new researchers, clinicians, and scientists into the field of ME/CFS to accelerate progress and improve the quality of clinical care for ME/CFS patients.

## **2) Expedite Government Response to the ME/CFS Public Health Crisis**

- SMCI calls for immediate government acknowledgement of the public health crisis that ME/CFS presents and for the urgent prioritization and effective action to combat this disease.
- SMCI supports government investments, initiatives, policies, public/private partnerships, and programs that will improve the lives and ease the suffering of millions of ME/CFS patients.
- SMCI also calls for governments to effectively engage the stakeholders of the ME/CFS community in planning and executing policies and programs regarding ME/CFS.

## **3) Increase the Quality and Accessibility of Clinical Care and Patient Support**

- SMCI supports programs (such as centers of excellence) and policies by the government, the medical community, and other entities that will dramatically increase the availability of knowledgeable ME/CFS disease experts and care specialists and improves the quality, accessibility, and affordability of clinical care and patient support for ME/CFS patients.
- SMCI calls for the development and aggressive distribution of medically accurate and expert-reviewed education materials and curriculum by governmental, academic, medical associations, other institutions, and other advocacy groups for the purpose of improving the understanding and outcomes, providing patient and caretaker support, and combating the stigma of ME/CFS.
- SMCI supports programs that will improve cross clinician collaboration in clinical care and research, providing an enhanced medical infrastructure to exploit emerging research, drive dramatic improvement in clinical standards of practice, and ensure clinicians across the United States are informed of the latest research findings and diagnostic and treatment protocols.

## **4) Raise awareness and Improve Understanding of ME/CFS in the General Public**

- SMCI calls for dramatically expanded efforts to inform government agencies, employers, schools, and the public that ME/CFS is a disabling condition entitled to all governmental protections and benefits available to disabled persons under federal, state, and local laws and is specifically covered by the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and all other civil rights laws protecting disabled persons.
- SMCI calls for accurate information about ME/CFS to be effectively communicated through multiple methods (e.g. CDC, NIH, SSA, and Patient support and advocacy groups) to combat stigma, change the disease narrative, and foster positive interactions with clinicians, employers, potential donors, and government support agencies.