

Solve ME/CFS Initiative



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Leveraging patient-centered
research to cure ME/CFS
FORMERLY KNOWN AS THE CFIDS ASSOCIATION OF AMERICA

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Mission

The Solve ME/CFS Initiative's (SMCI) mission is for chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME) and chronic fatigue and immune dysfunction syndrome (CFIDS), to be widely understood, diagnosable, and treatable.

Strategy/Approach

SMCI's strategy is to stimulate research aimed at the early detection, objective diagnosis, and effective treatment of ME/CFS through expanded public, private, and commercial investment. The organization focuses its resources on research, policy, and engagement/communications that will advance understanding, diagnosis, treatment, and prevention of ME/CFS.

- The **research program** funds laboratory and clinical studies, strengthens collaborations with investigators from around the world, recruits new talent to the field of ME/CFS research, and builds a repository of blood and tissue samples from ME/CFS patients.
- **Policy efforts** in Washington, DC, focus on expanding public investment in ME/CFS research, validating the burden of illness of ME/CFS, and shaping public policy to help ME/CFS patients.
- Finally, SMCI focuses its efforts on **engagement and communication** by providing opportunities for patients and those that care about them to be directly involved in ME/CFS research and distributing information about the illness.

Research Portfolio

Since 1987, the Solve ME/CFS Initiative (formerly known as the CFIDS Association of America) has been the largest private funder of ME/CFS research. SMCI has directly funded or leveraged more than \$10 million in ME/CFS research studies, all aimed at accelerating progress toward accurate diagnosis and effective treatment of ME/CFS.

The current priorities of SMCI's research program are to create a patient-center participatory research infrastructure in order to accelerate progress toward finding the cause, gaining accurate diagnosis and effective treatment of ME/CFS by directly supporting research studies, facilitating collaboration among investigators, and pursuing increased investment in ME/CFS research by public, private, and commercial institutions.

In addition to the critical research funding, SMCI works to foster a collaborative growth environment for ME/CFS research by hosting scientific symposia and co-sponsoring meetings to identify promising areas of investigation. To meet the

unequivocal need for a more robust scientific enterprise for ME/CFS, SMCI created the "Research Institute Without Walls" in 2012; built on a foundation of three core concepts, fostering research that is:

- Participatory research puts the patient at the center of ME/CFS discovery
- Predictive measures come from "Big Data" we gather
- Personalized treatments result from patient-centered research
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The SolveCFS BioBank is a popular way for ME/CFS patients to actively participate in research from anywhere in the world. Unveiled in March 2010, the BioBank as a repository for blood samples, tissue samples, and clinical information to advance biomarker discovery. It is part of the Genetic Alliance BioBank, a biobank infrastructure that allows nonprofits to build their own biobanks.

The SolveCFS BioBank is the foundation of SMCI's research infrastructure. This system is built on a foundation of standards including common data dictionaries, standard instruments, and assessments. The SolveCFS BioBank is designed to allow investigators to share and collaborate. Patient information and samples have Global Unique Identifiers (GUIDs) so the data can be shared while meeting current privacy standards; GUIDs allow results generated on individuals to be linked to other discoveries on the same samples. The SolveCFS BioBank is a cost-effective and robust resource to investigate ME/CFS.

Partnership Practices

SMCI realizes that collaboration is important to advancing scientific research for ME/CFS and encourages collaboration with academia and other nonprofits. For example, the SolveCFS BioBank was created in collaboration with Genetic Alliance and numerous research institutions such as Columbia University, DePaul University, Harvard Medical School, New York University Medical Center, and University of California at San Francisco.

SMCI partners with biotech and pharmaceutical

companies. In 2010, SMCI partnered with a pharmaceutical company on a research study, recruiting a strictly defined group of ME/CFS patients and matching controls samples from the SolveCFS BioBank. Results of the study will be published in an upcoming issue of BMC Research Notes.

Financials

The Solve ME/CFS Initiative, Inc. is a 501(c)(3) tax-exempt nonprofit organization. The most recent financial information available is from 2013.¹

Year ending 12/31/13:

- Revenue: \$2,281,889
- Assets: \$1,803,772
- Grants paid: \$208,700
- Gifts received: \$2,261,366
- Expenditures: \$1,470,852

Key Accomplishments

- Invested nearly \$33 million in initiatives to bring an end to the pain, disability, and suffering caused by ME/CFS since 1987.
- Invested more than \$10 million in research since its founding.
- SMCI is the second largest funder of ME/CFS research, behind the federal government.
- Launched the only repository for blood samples, tissue samples, and clinical information to advance biomarker discovery exclusively for ME/CFS.

Leadership

The Solve ME/CFS Initiative is led by a Board of Directors and a Scientific Advisory Board and supported by a permanent staff.

- **President and CEO:** Carol E. Head
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- **Scientific Director:** Suzanne D. Vernon, PhD,
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- **Chief Financial Officer:** Kristina P. Hopkins,
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¹ Information obtained from 2013 Audited Financial Statements. Available upon request by emailing SolveCFS@SolveCFS.org.