

ME/CFS

Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome

**The most prevalent, serious disease
you've never
heard of.**



"My illness is excruciating and difficult to cope with. It takes over your entire life and causes more suffering than I can describe."

—Laura Hillenbrand, author of Seabiscuit and Unbroken, and an ME/CFS patient



Solve ME/CFS Initiative

What is ME/CFS?

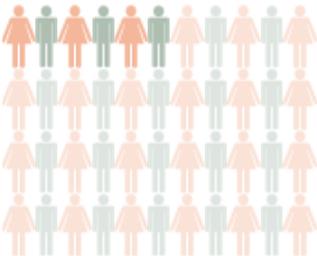
the DISEASE

ME/CFS is a chronic, complex, systemic disease that can profoundly limit the health and productivity of affected patients. This devastating disease has long been misunderstood, derided and often ignored. Symptoms include:

- › Profound exhaustion without an attributable cause
- › Unrelenting, sometimes completely debilitating pain without an identifiable cause
- › Significant cognitive impairment

At least **25% of ME/CFS patients are bed-ridden or house-bound** at some point. Symptoms generally **persist for years**. Most patients **never regain pre-disease health** level. Lost productivity and medical costs contribute to a total **economic burden of up to \$24 billion annually**.¹

the PATIENTS



Read patients' own stories at the Humans of ME/CFS webpage: homecfs.solvecfs.org

Known to affect as many as **2.5 million** Americans and nearly **20 million** worldwide, but **up to 91% undiagnosed**, leaving the true prevalence unclear. ME/CFS affects all ages from children to the elderly.

(Source: CDC)

the CHALLENGES

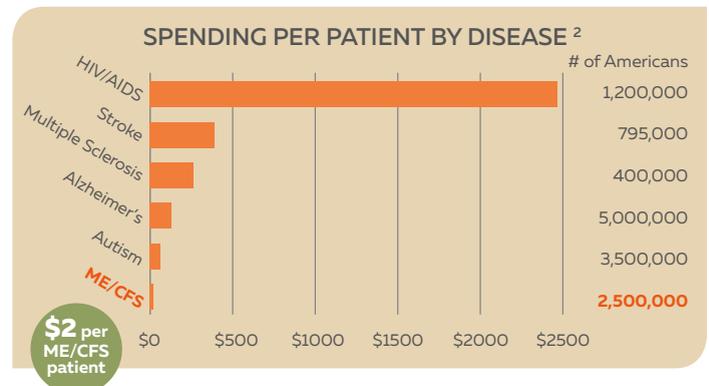
Cause(s) of ME/CFS:
UNKNOWN

FDA approved drugs or treatments:
NONE

Effect of patients' self-medication choices:
UNKNOWN

THERE IS NO CURE

the ANSWER lies in medical research

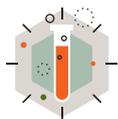


Institute of Medicine Stresses Dire Need for Medical Research

"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."¹

¹ Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness, IOM 2015

Our Program Overview



RESEARCH

Driving toward biomarkers and a cure

BioBank and Patient Registry

Our BioBank is the largest repository of physical samples from ME/CFS patients that supports the work of qualified researchers to accelerate discovery

Seed Grants for Original Research

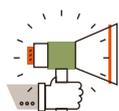
Our rigorous grant program funds promising ME/CFS studies and draws many new researchers to the field

Targeted Initiatives

Our new research program is aimed at closing the knowledge gaps in Bioenergetics, Neuroendocrine biology and Immune dysfunction, where we expect to find the underlying causes of ME/CFS

Deep Dive into Bioenergetics

Our comprehensive, multi-year investigation uses a combination of unbiased, high throughput analysis and in depth mechanistic analysis study design to decipher the crux of bioenergetics deregulation in 500 ME/CFS patients, including those with early-vs late-stage disease



ADVOCACY

Leading the fight for increased federal funding

Engaging with Influential Federal Agencies

We consistently interact with the Centers for Disease Control and the National Institutes of Health regarding funding and research strategy

Raising Awareness on Capitol Hill

Meetings with key members and staff

Chronic Fatigue Syndrome Advisory Council Representative

We advise and recommend to the Secretary of Health and Human Services on issues related to ME/CFS



Solve ME/CFS Initiative

Our Mission:
**Making ME/CFS understood,
diagnosable and treatable**

“Of the many mysterious illnesses that science has yet to unravel, ME/CFS has proven to be one of the most challenging.”

*—Francis S. Collins, M.D., Ph.D., Director,
National Institutes of Health, 2015*

HIGHLIGHTS of our impact

- › Funded ten ME/CFS research studies since 2008
- › Catalyst for new discoveries and seven-fold increases in additional funding from other sources, resulting from our seed studies
- › Created largest ME/CFS BioBank and Patient Registry
- › Important advocate in reinstating the 2016 \$5 million CDC budget for ME/CFS

Who We Are

Founded in 1987, the Solve ME/CFS Initiative is the largest non-profit organization actively supporting research and advocating for increased federal spending on behalf of millions of ME/CFS patients.



President, Carol Head holds an undergraduate degree from Wellesley College and an MBA from Stanford University. Her accomplished career spans major corporations to small entrepreneurial ventures, but it's mission-driven work that fuels her passion as a crusader for this disease. Carol is an ME/CFS patient.

Vice President for Research and Scientific Programs, Dr. Zaher Nahle is an award-winning scientist with interdisciplinary training in biomedical research and public administration. He is a graduate of Harvard University and Cold Spring Harbor Laboratory/Stony Brook University.

“The only way to understand ME/CFS and provide patients with the answers they desperately need is to produce the highest quality medical research.”

—Carol Head, President, Solve ME/CFS Initiative

“Never in the history of this debilitating disease has the opportunity for scientific discovery been as high as it is right now. Unlocking the mysteries of this complex, poorly understood illness is a gratifying, noble pursuit.”

—Zaher Nahle, PhD, MPA, Vice President for Research and Scientific Programs

Solve ME/CFS Initiative Guidance

We are fortunate to benefit from the expertise of these committed individuals.

Our Board of Directors:

Senior level leaders from business, law, science and government who share a personal connection to ME/CFS through a family member or as a patient themselves.

Our Research Advisory Council:

Highly respected experts drawn from diverse fields of science provide deep insight and perspective.



Solve ME/CFS Initiative

Go to solvecfs.org/donate to support Solve ME/CFS Initiative

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