



# Solve ME/CFS Initiative

Leading the Fight  
to cure ME/CFS

## OUR VISION

A WORLD FREE OF ME/CFS

## OUR MISSION

MAKE ME/CFS WIDELY UNDERSTOOD,  
DIAGNOSABLE, AND TREATABLE

**SOLVE ME/CFS INITIATIVE (SMCI)** is a non-profit disease organization that works to accelerate the discovery of safe and effective treatments for ME/CFS, strives for an aggressive expansion of research funding that will lead to a cure, and seeks to engage the entire ME/CFS community in **RESEARCH** and **ADVOCACY**. SMCI serves patients and researchers alike, acting as an information and data hub for the ME/CFS community. Our strategic investments in research move the field forward collaboratively and strengthen the case for increased federal spending.

## our WORK | RESEARCH

SMCI designs and invests in innovative scientific studies to address severe knowledge gaps in ME/CFS. Priority areas include **bioenergetics, neuroendocrine biology, the gut microbiome, genetics, and inflammation and immunity**. We partner with leading experts in the field and have developed a portfolio of investments at some of the most prestigious medical centers and research laboratories in the United States and abroad.

### THE RAMSAY AWARDS

Through seed grants and support for pilot studies, this program promotes original, diverse, and bold research using a rigorous peer-review process and draws new researchers to the field.

### P.E.E.R. PATIENT REGISTRY

Our new state-of-the-art national registry for ME/CFS will enable clinical trials and further understanding of the natural history of the disease. This includes a repository of physical samples from patients to support the work of qualified researchers and accelerate discovery.

### PATHWAYS AND BIOMARKER DISCOVERY

Original research in the areas of bioenergetics, metabolomics, and lipidomics using high-throughput technology. Partners in this SMCI-directed research study include Dr. Maureen Hanson of Cornell University, Dr. Sue Levine of The Levine Clinic in NYC, and biotech industry leader Metabolon.



### DRUG SCREENING AND THERAPEUTIC EXPLORATION

Studies exploring potential drug targets in ME/CFS using advanced technologies and sophisticated drug screening platforms. Partners in this targeted initiative include leading experts at Memorial Sloan Kettering Cancer Center.

### PARTNERSHIPS WITH MEDICAL AGENCIES AND GOVERNMENT ORGANIZATIONS

SMCI partners with key medical agencies and government organizations, including 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, articulate effective, data-driven policies and solutions, and ensure patient representation.

## our WORK | ADVOCACY

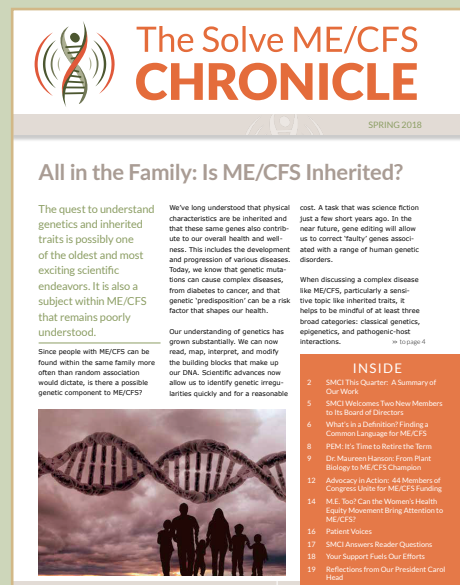
SMCI acts as an agent for change and unity in the ME/CFS community by advocating for policies, funding, and action at a national level. We meet with senior government officials, medical



and industry leaders, and scientific pioneers to foster a strong and multi-faceted coalition of stakeholders. SMCI authors dozens of opinion and technical pieces addressing current ME/CFS affairs across the science, research and policy landscapes.

## our LEADERSHIP

With 30 years of business leadership experience and an MBA from Stanford University, President Carol Head leads the Solve ME/CFS Initiative with unparalleled passion as a champion for this disease. Carol has led two for-profit businesses, founded a non-profit organization that empowers impoverished entrepreneurs in the developing world and has served on three boards for national organizations supporting human rights for women. Carol was recognized by *O, The Oprah Magazine* as a "2017 Health Hero." Carol is a person with ME/CFS.



### All in the Family: Is ME/CFS Inherited?

The quest to understand genetics and inherited traits is possibly one of the oldest and most exciting scientific endeavors. It is also a subject within ME/CFS that remains poorly understood.

Since people with ME/CFS can be found within the same family more often than random association would dictate, is there a possible genetic component to ME/CFS?

We've long understood that physical characteristics are inherited and that these same genes also contribute to our overall health and well-being. This includes the development and progression of various diseases. Today, we know that genetic mutations can cause complex diseases, from diabetes to cancer, and that genetic "predisposition" can be a risk factor that shapes our health.

Our understanding of genetics has grown substantially. We can now read, map, interpret, and modify the building blocks that make up our DNA. Scientific advances now allow us to identify genetic irregularities quickly and for a reasonable

cost. A task that was science fiction just a few short years ago. In the near future, gene editing will allow us to correct "flawed" genes associated with a range of human genetic disorders.

When discussing a complex disease like ME/CFS, particularly a sensitive topic like inherited traits, it helps to be mindful of at least three broad categories: classical genetics, epigenetics, and pathogen-host interactions.

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## our PUBLICATIONS

SMCI produces three publications as a free service to the ME/CFS community:

- *The Chronicle*, a quarterly magazine that provides in-depth articles on SMCI's research and advocacy work and the landscape of ME/CFS research.
- *Research 1st*, a monthly email publication that provides timely updates on ME/CFS research.
- *SMCI This Week*, a monthly email that provides information on our advocacy efforts and organization news.

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