

# The Solve ME/CFS Initiative Science and Discovery Plan

Taking a Comprehensive  
Approach to Solving ME/CFS



**“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



**Solve ME/CFS Initiative**

*Making ME/CFS understood, diagnosable and treatable*

# the Discovery Process

Solve ME/CFS Initiative's comprehensive Science and Discovery Plan spans every phase of the discovery process. Our goal is to advance innovative research and identify the underlying causes of ME/CFS, develop safe and effective treatments, and find a cure.



## FILLING KNOWLEDGE GAPS THROUGH ORIGINAL RESEARCH

We design and invest 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.

- **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 the 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**.

- **CLINICAL TRIALS INITIATIVES** Clinical interventions efforts using proprietary compounds, repurposed drugs or newly identified screening targets using our drug discovery platforms for rapid clinical applications. Program conducted by trusted clinical sites with committed partners.
- **CELL-CYCLE ENERGETICS and IMMUNO-SENESCENCE STUDIES IN THE PATHOPHYSIOLOGY OF ME/CFS** Research into the characterization of the disturbances in *enzymes*, *receptors* and *cell-cycle regulators* that control cell function using applied basic science principals and techniques. Partners in this targeted initiative include experts at **Washington University** in St. Louis, the **University of Cambridge**, UK and other partners around the world.
- **DIET AND NUTRITIONAL SCIENCES IN ME/CFS** Studies are aiming at characterizing nutrient sensing and signaling mechanisms in ME/CFS as well as dietary intervention, microbiome homeostasis and host-gene interaction with leading nutrition experts.

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## ESTABLISHING A PATIENT SCIENTIST PARTNERSHIP PROGRAM FOR DIAGNOSTIC TESTING AND CLINICAL APPLICATIONS

This program facilitates patient participation in decision-making and defining research priorities.

- **ESTABLISHING THE ME/CFS FUND AT BRIGHAM AND WOMEN'S HOSPITAL** This fund will support the cardiopulmonary and neuro-signaling research of Dr. David Systrom, focusing on the *autonomic, peripheral neuropathy, and cardiovascular* features of ME/CFS.
- **ESTABLISHING THE CATHLEEN J. GLEESON PH.D. FUND FOR DIAGNOSTIC TESTING** Studies focus on using non-invasive technology to measure tissue *metabolites* in ME/ CFS patients for diagnostic testing. This study is part of a collaborative partnership with the **University of Washington** and others.

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## INVESTING IN INNOVATIVE IDEAS AROUND THE WORLD

This 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.

- **RAMSAY AWARDS IN CLINICAL, PRECLINICAL, AND EPIDEMIOLOGY RESEARCH** Through seed grants and support for pilot studies, our international Ramsay Awards Program promotes original, bold research using a rigorous peer-review process. The portfolio of funded projects includes gut microbiome, autoimmunity, bioenergetics, pathogenic interaction, inflammation, brain imaging and metabolomics studies. The research teams represent 6 universities, 4 countries and 3 continents.

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## 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 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.

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## CREATING RELIABLE ELECTRONIC HEALTH 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 (e.g., onset, duration, triggers, progression) of this disease, and include built-in options for data sharing and collaboration among patients, researchers, and other disease organizations. This includes, beyond the health data, a repository of physical samples from patients to support the work of qualified researchers and accelerate discovery.



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## LEADING CONFERENCES, SYMPOSIUMS AND THINK TANKS

SMCI hosts think tanks that 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, including the Precision Medicine World Conference, and the Biomedical Research for ME Colloquium [BRMEC7] and Conference in London, among others.

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## 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 about ME/CFS in prestigious medical publications.

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## 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.



**Solve ME/CFS Initiative**

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## 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 an 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.

**Chief Scientific Officer and Vice President for Research Dr. Zaher Nahle** is an award-winning scientist with interdisciplinary training in administration and biomedical research. He oversees the research and scientific portfolio at SMCI that includes the peer-review grant program for external investigators, specialized biobanking and patient registry platforms as well as numerous medical education initiatives for patients and healthcare professionals. He also directs a specialized investment program with medical centers, government agencies and industry partners to spark innovation and accelerate the discovery process in the ME/CFS disease space. Dr. Nahle is a frequent speaker at international conferences and serves on specialized committees at federal agencies, including the NIH and the CDC. He earned a PhD in Physiology and Biophysics from Cold Spring Harbor Laboratory/Stony Brook and an MPA from Harvard University, where he also completed a fellowship in public policy and management at the John F. Kennedy School of Government.

SMCI's **Board of Directors** includes senior-level leaders in business, law, and science who each have a personal connection to the disease.

Our **Research Advisory Council**, composed of highly respected scientists from diverse fields, shares its expertise and counsel in all research matters.

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