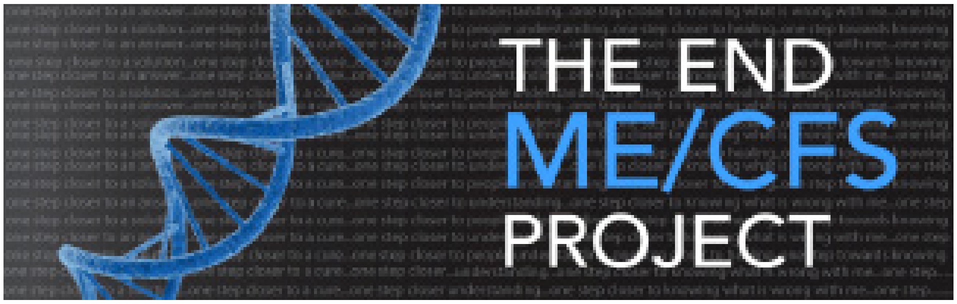
HOPE
OpenMedicine
Foundation



THE END ME/CFS PROJECT

ME/CFS SCIENTIFIC ADVISORY BOARD

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> *"I suffered from bouts of extreme fatigue and sheer exhaustion together with daily pain, horrible headaches, and flu-like symptoms. After eight long and painful years, I was finally diagnosed with Myalgic Encephalomyelitis (ME), but there is no cure."*
>
> — Comment sent to OMF website

Help us decipher a mysterious, yet devastating and life-altering disease that affects up to 2.5 million people in the U.S. alone—ME/CFS, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. It's invisible, it's pervasive, it's under-researched. Patients with ME/CFS have a lower quality of life and higher rates of disability than patients with AIDS, MS, Diabetes and Rheumatoid Arthritis. We are determined to change this.

This is the first time ever that leading world-class scientists will be putting their minds together to solve this massive problem. Led by Ronald W. Davis, Ph.D., considered one of the fathers of the modern era of human genetics, the End ME/CFS Project takes a comprehensive research approach based on collaboration, shared results, and analysis of Big Data. Progress made through this endeavor has the potential to shed light on other complex chronic diseases. ***Help us decode ME/CFS!***

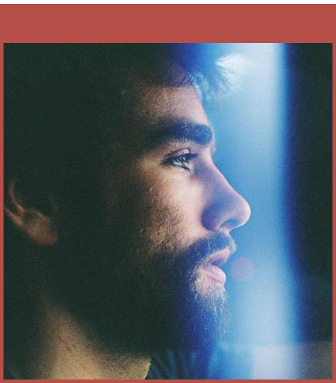
2.5 million people affected in the U.S. alone

80% unable to work or attend school full time

25% entirely house-, bed-, or wheelchair-bound

MANY ME/CFS SUFFERERS FACE...

- Debilitating fatigue that feels like an extreme flu that never goes away
- Severe symptoms including brain fog, pain, unrelenting headaches, sleep problems, and frequent infections
- Symptoms that worsen after even minor physical, mental, or emotional activity
- Inability to do simple things like showering, eating, and getting dressed
- Inability to talk or communicate, stand, or sit up
- Social isolation, fractured relationships, and financial hardships



Whitney Dafoe, **an award-winning photographer, was pursuing his love of art and travel when his health began to deteriorate at the age of 21. Now in his 30s, Whitney has a severe form of ME/CFS. He is completely bedridden and has lost the ability to speak or communicate, to eat, to tolerate any human contact. In the fight for his life, Whitney is slowly, and agonizingly, wasting away.**

What a twist of fate that Whitney's father is world-renowned geneticist Ronald W. Davis, PhD, Director of the Stanford Genome Technology Center. Dr. Davis is considered one of the fathers of the modern era of human genetics. He is also among the millions of ME/CFS family members living with the devastating effects of this widespread and widely misunderstood disease, grasping for hope and searching for answers.

Dr. Davis has joined OMF as Director of the Scientific Advisory Board in order to find answers.

A Personal Nightmare

Living with ME/CFS completely devastates one's life. Patients suffer from a host of symptoms that are chronic, incapacitating, and often last a lifetime. Most patients never regain their pre-disease level of health or functioning, and at least one-quarter of those afflicted are home- or bed-bound as a result of their illness. The long-term prognosis is uncertain. Compromised immune systems can lead to premature death from heart failure, cancer, and infections. No cure exists.

Misconceptions Continue

Most health care providers know little about how to diagnose and treat ME/CFS. Many are skeptical about the seriousness of ME/CFS or dismissive of the patients' symptoms. These misconceptions and lack of knowledge lead patients on a long, frustrating, and expensive path to diagnosis.

> *“I think the most important thing for physicians to know is that while we do not have a diagnostic test or a proven treatment, there is now abundant evidence that in these patients there is an underlying biological process. Their symptoms are linked to problems of their biology and not imagined.”*
>
> — Anthony L. Komaroff, MD

The effects of this disease are different for everyone: for the young, education is disrupted; in the working population, employment is difficult or, for many, impossible. For all, social interactions and family life become severely strained. Many ME/CFS patients are grasping for hope. Dreams for the future—careers, children, travel—are put on hold or dashed as life becomes the mere act of getting through one day at a time. After years of suffering, many patients tragically choose to end their lives.

> *“I feel invisible. People are forgetting me. People are forgetting to call. I lost contact with everyone my age because they are living their lives, the life I am supposed to be living.”*
>
> — Comment sent to OMF website

Open Medicine Foundation (OMF): The Game Changer

The Human Genome Project—perhaps the most groundbreaking project in medicine in the last 15 years—succeeded because world-renowned experts in a wide range of disciplines came together and openly shared their research results. Using this model, OMF has engaged leaders of the Human Genome Project along with researchers from Stanford University, Harvard University, University of Utah and other credible institutions to turn their attention to End ME/CFS.

Directed by Dr. Davis and an extraordinary scientific advisory board that includes three Nobel Laureates, six members of the National Academy of Sciences, and other eminent researchers, the End ME/CFS Project aims to understand the disease at a molecular level. Our first study currently underway is a comprehensive analysis on severely ill ME/CFS patients, with a goal of finding sensitive and distinctive biomarkers—measurable indicators of the severity or presence of the disease. Our openly shared data and lean business model will fast-track research and solutions.

OMF’S APPROACH: BETTER, NEWER, AND DIFFERENT

The Open Medicine Foundation (OMF) supports a fresh collaborative research model to find answers to difficult and complex diseases by...

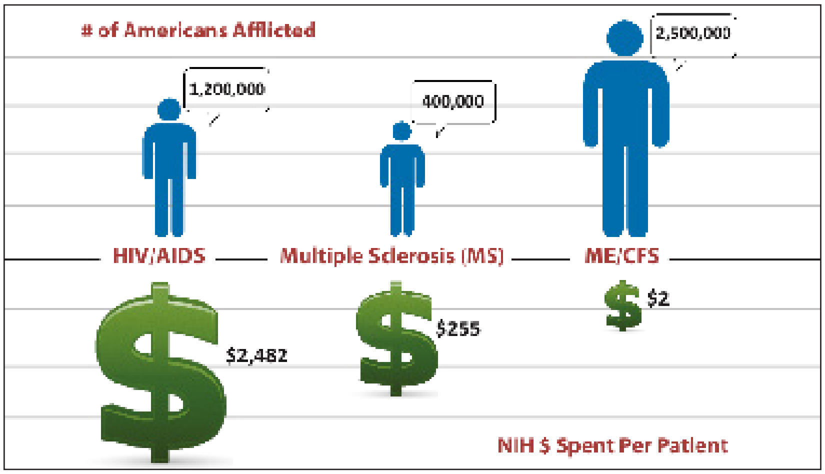
- **Gathering thought leaders from diverse affiliations and disciplines.**
- **Bringing them together in a collaborative open environment.**
- **Engaging the patient community in the research process.**
- **Accelerating research using top scientific institutes.**
- **Sharing the results openly and frequently with all stakeholders.**

> *“You are our only hope. You are the people and this is the research we need. Thank you for not giving up on us and, mostly, for believing in us.”*
>
> — Comment sent to OMF website

Public Health Crisis of an “Invisible” Illness

According to the recent Institute of Medicine report, up to 2.5 million Americans have ME/CFS. At these levels, ME/CFS is more common than multiple sclerosis, lung cancer, or AIDS. And this is just the tip of the iceberg; an estimated 84 to 91 percent of people with ME/CFS have not yet been diagnosed.

Yet, given the number of people afflicted by ME/CFS, remarkably little funding has been allocated by the National Institute of Health (NIH). The NIH spends an average of just $2 per patient per year in research dollars for ME/CFS.



The costs of this disease extend far beyond the patients. Spouses, parents, and other caregivers put their lives on hold to care for their loved ones. The emotional and financial toll can be devastating. All told, the total economic costs of ME/CFS are estimated at $17 to $24 billion annually.

We can’t wait for government funding—which may never come. With your help, we are moving forward. We are grateful that some Early Adopters have enabled us to begin Phase 1: the ME/CFS Severely Ill Big Data study.

Let's End ME/CFS Together

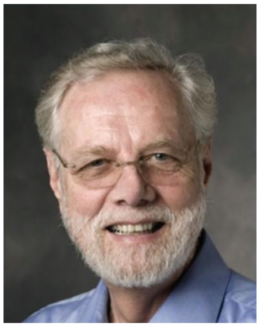
The Open Medicine Foundation has taken on the challenge of filling the gap to fight this under-funded and under-researched, devastating disease. But a great research strategy is not enough. To advance such an ambitious scientific endeavor, the End ME/CFS Project will require a major financial investment from the private sector. We seek contributions from philanthropic individuals, corporations, and foundations—which share our passion and believe in our mission—to raise $5 million annually for this urgent research.

ESTIMATED ANNUAL BUDGET SUMMARY	
Sample collection and testing through esteemed laboratories such as Stanford University, Harvard University, University of Utah and Open Medicine Institute	**$3,100,000**
Computational data analysis with an open access platform	**540,000**
Research project management	**530,000**
Thought-leader consortiums to share data and gather input, the key element of the collaborative OMF model	**320,000**
Patient engagement and communication, fundraising and financial governance	**510,000**
End ME/CFS Project Annual Requirement	***$5,000,000***

We are determined to reach our goals and with your support, the best minds in their fields will come together in collaboration and groundbreaking research to understand ME/CFS. Your support will promote cutting edge research, create global collaboration, and engage patients in research, while keeping them informed.

Be part of this unique effort and spread hope by joining our TEAM of HOPE!

> *"If you want to make a difference in the world, this is where you can do that. This is the last major disease that we have little understanding about. If you want to get involved on the ground floor and help us learn what is going on... this is it."*
>
> — Ronald W. Davis, PhD, Director,
> OMF ME/CFS Scientific Advisory Board



Please join us in our fight for the cure. For more information on OMF or to donate to the End ME/CFS Project, visit our website:
www.openmedicinefoundation.org

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