# **Open Medicine Foundation**<sup>®</sup> HYPE Leading Research. Delivering Hope.



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Wenzhong Xiao, PhD

# Open Medicine Foundation<sup>®</sup>

HYPE Leading Research. Delivering Hope.

### ABOUT US

Open Medicine Foundation (OMF) leads the largest, worldwide nonprofit effort to diagnose, treat, and prevent chronic, complex diseases such as Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS), Post-COVID Syndrome, Post-Treatment Lyme Disease Syndrome (PTLDS), and Fibromyalgia. OMF envisions improved health care for patients suffering from chronic complex diseases with collaboration between the patients, clinicians, and researchers.

### O U R V I S I O N

- To change the course of healthcare for chronic complex diseases
- Create a world where people with ME/CFS and other chronic complex diseases return to leading full lives
- Ensure new populations of people are not confronted with the same repeating health challenge

### OUR ASK

Together, we can transform the healthcare and the research landscape, and change how chronic diseases are viewed and how patients are treated. We need to ensure that when the next pandemic occurs, we do not have yet another community of postinfectious long haulers. Help us accelerate this urgent research by donating today!

#### O U R V A L U E S

- Innovation: Research that speeds up progress towards solving these diseases
- Collaboration: Researchers and clinicians willing to work together and share ideas
- Improved Patient Outcomes: Delivering patients better diagnoses, treatments, and personalized care
- Open research model: open to new ideas and ways of approaching how we solve chronic diseases, open to sharing, creating a new paradigm for understanding
- Challenging outdated models so we can understand the broader operating system and molecular fundamentals of diseases
- Fiduciary: be a responsible and transparent overseer of donor funds

### MEDIA REACH











1k sessions per week

67.7k followers 9.8k followers

5.8k followers



# **Fundraising focus**

Our initial focus has been and continues to be on solving ME/CFS so existing patients can resume their lives, new patients can have better outcomes, and other illnesses/diseases don't morph into this type of multi-system host/operating system failure. We believe ME/CFS is at the tip of the iceberg of unsolved and growing, complex health issues. A great research strategy is not enough. To succeed, a foundation must have funding. With optimism and creativity, we are determined to reach our aggressive funding goals, filling a huge gap in the history of these often misunderstood and under-funded diseases and the millions of underserved patients they impact.

This is an opportunity for donors to help us change the landscape of complex chronic illnesses, create a lasting global impact, and save lives and livelihoods. We aim to fundraise a minimum of \$20 million per year to target initiatives vital to providing answers quickly.





## WWW.OMF.NGO

#### OUR FOUNDER'S STORY

LINDA TANNENBAUM, FOUNDER & CEO/PRESIDENT

Linda Tannenbaum is the Founder and CEO/President of Open Medicine Foundation. Linda founded OMF after her 16-year-old daughter came down with sudden onset ME/CFS in 2006. She was told there was no diagnostic test or treatment for the devastating disease preventing her daughter from leaving her bed and living her life.

After researching options, Linda realized that open, global collaborative research into the disease was terribly lacking, as was research funding. Hence, she established OMF in 2012 to fundraise and facilitate large-scale research in search of diagnostic tools, treatments, and ultimately prevention for ME/CFS and related chronic complex diseases.





"Collaboration to fast-track a cure for ME/CFS and related complex diseases is at the core of OMF's mission." -Linda Tannenbaum Linda is a clinical laboratory scientist with a degree in bacteriology from UCLA. She ran and was part-owner of a clinical laboratory for over 20 years. Her passion today is finding a cure for these chronic complex diseases — giving the millions suffering their lives back — and improving clinical care for patients.



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CF is a life-altering, complex multi-system disease.



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex, life-altering, multi-system disease with many symptoms that may change over time and differ from patient to patient. The most common symptoms of ME/CFS are post-exertional malaise (worsening of symptoms upon even minimal exertion), unrefreshing sleep, profound fatigue, cognitive impairment, orthostatic intolerance, and pain.

The cause of ME/CFS is currently unknown, but a combination of genetic and environmental factors appears to be relevant. There are no specific diagnostic tests or FDA-approved treatments available.

What's it going to take to eradicate this disease? **Research!** 

Today, the ME/CFS research landscape is growing, and the outlook for people with ME/CFS is brighter than ever.

The End ME/CFS Project encompasses OMF funded and facilitated research conducted at the ME/CFS Collaborative Research Centers across the globe. OMF's guiding strategy focuses on open, collaborative research so that precise diagnostic tools and life-changing treatments can be available to people with ME/CFS and related chronic complex diseases as soon as possible.



# GLOBAL COLLABORATIVE RESEARCH



#### **OMF's Collaborative Network**

OMF funds a collaborative network of research centers at prestigious academic institutions across the globe. OMF's guiding strategy focuses on open, collaborative research so that precise diagnostic tools and life-changing treatments can be available to people with related chronic complex diseases as soon as possible. We are bringing together thought leaders and innovators from various related fields to apply their knowledge collectively in tackling this problem.

Funding an internationally-based research network instead of single researchers ensures the stability and collaboration essential for an outcomes-focused, transparent, and multi-pronged approach to finding answers. The Collaborative Research Centers are working together to build a repository of data about ME/CFS and related chronic, complex diseases such as Post Treatment Lyme Disease Syndrome, Fibromyalgia, and Post-COVID-19 Syndrome. This data is essential to develop diagnostic technologies, understand the molecular basis of the diseases, and uncover effective diagnostic tools and treatments.

# THE RESEARCH PLAN

Ronald W. Davis, PhD

#### The Research Plan Going Forward

All the OMF-funded Centers & Collaborations follow research themes of direct biological measurements, innovation, and systems thinking. Direct measurements of body tissues and biofluids for cell and molecular functioning provide unaltered insights into the disease model. Conducting these direct measurements in new and meaningful ways requires innovative technology tailored directly to resolve the biological issues in ME/CFS. Building upon these themes in a timely and cost-effective manner would be impossible without collaboration. The research we fund, therefore, focuses on the following work:

- Clinical studies/systems biology/multi-omics studies
- Innovative diagnostic technologies
- Longitudinal patient analysis
- Big Data Analysis and use of AI/CAT/Machine Learning

# PRESS COVERAGE

Researchers warn covid-19 could cause debilitating longterm illness in some patients



OMF's work has proudly been featured in many large news outlets, including:

- <u>CNN</u>
- <u>VOX</u>
- <u>The Washington Post</u>
- <u>Medscape</u>
- <u>Time Magazine</u>
- <u>Politico</u>
- <u>Stanford Medicine</u>

# AWARDS

Open Medicine Foundation is proud to have been recognized in 2020 by Great Nonprofits and received a Platinum level recognition from GuideStar for our commitment to organizational transparency and a score of "100 Encompass Rating" from Charity Navigator in Finance & Accountability.

## **TESTIMONIALS**

**PPPPP** Client Served 08/16/2020

#### \*\*\*\*

An amazing organisation giving hope to millions who have been left behind. All my fundraising and donations go to them.

> MichielTack Professional with expertise in this field 01/11/2019

#### \*\*\*\*

The Open Medicine Foundation funds top scientists to study one of the most neglected diseases of our time.



Christopher W. Armstrong, PhD



CEO Linda Tannenbaum & CRC Directors



Ronald W. Davis, PhD

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