

OPEN MEDICINE FOUNDATION

ANNUAL REPORT 2018



Stanford Working Group 2018



FOUNDER STATEMENT

Dear Friends,

I am honored to lead OMF in support of our vision to help people affected by ME/CFS lead fuller lives.

We have assembled a stellar group of scientists who are committed and eager to advance research. Through their support, we are changing the research paradigm by requiring all research results be open. Because of these open communications, collaborations continue to lead to a greater understanding of the mechanisms of this disease.

We are completely transparent as an organization and hold ourselves accountable to the entire ME/CFS community. Every decision we make, whether it is about research or administration, we keep the patient community in the forefront of our planning.

Thank you to each and every person who donated in 2018 to help advance our mission. On the following pages, learn more about our 2018 accomplishments and join us to end ME/CFS and related chronic complex diseases.

With gratitude and hope,

Linda Tannenbaum
Founder & CEO/President



SAB DIRECTOR STATEMENT



A lot of progress has been made in the last year. There is a lot more data and it is now generating testable hypotheses. More exciting collaborations are being established. Excellent new people are entering the field. The future is looking more hopeful.

Ronald W. Davis, PhD
Director, Stanford Genome Technology Center
OMF Scientific Advisory Board

OMF MISSION

Our mission at Open Medicine Foundation (OMF) is to create a world in which patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), post-treatment Lyme Disease syndrome, and fibromyalgia no longer think about or worry about being sick. We aim to cure these diseases and provide the millions of people living with them the opportunity to lead full, productive lives, with effective treatments, individualized high-quality care, and up-to-date knowledge of the mechanisms underlying these diseases.

To achieve our mission, OMF has raised more than \$18 million since its founding, and \$9 million alone in 2018, to fund a team of world-renowned scientists and clinicians to conduct open, collaborative, and groundbreaking research into these chronic complex diseases.

In 2018, we have made significant strides in reframing old concepts of pathogenesis for a broad array of chronic, developmental, autoimmune, and degenerative disorders to provide new models of understanding this disease. We have also launched a new center at Massachusetts General Hospital & Harvard Affiliated Hospitals.

We hope you will join us again in accelerating our search for a cure.

Leading research. Delivering hope.

“For someone like me who is severely ill with ME/CFS for decades, it is incredibly comforting knowing that there are people taking this disease seriously and doing the appropriate biomedical research. You have no idea how grateful the patient community is for OMF.”

- Andy M, Patient

ME/CFS Collaborative Research Center at Stanford

The OMF-funded ME/CFS Collaborative Research Center at Stanford is pursuing projects related to understanding and treating ME/CFS by developing and using cutting-edge technologies. This work is built on previous projects that OMF has supported. The projects funded by OMF include:

T CELLS AND IMMUNOLOGY

Examining the role of T cells and immune-related genes may address whether ME/CFS is an autoimmune or infectious disease, or simply an activation of the immune system.

EXTENDED BIG DATA STUDY IN FAMILIES

By comparing patients to healthy blood relatives, we are more likely to understand what genes cause or contribute to the development of ME/CFS.

DIAGNOSTIC AND DRUG-SCREENING TECHNOLOGY DEVELOPMENT

Four technologies are being developed that could provide a biomarker for ME/CFS. Dr. Davis's team is dedicated to developing these into inexpensive tests that can be easily used in a doctor's office.

1. NANONEEDLE

The nanoneedle biosensor platform has shown promise as a blood-based diagnostic able to distinguish ME/CFS patients from healthy controls.

2. MAGNETIC LEVITATION DEVICE

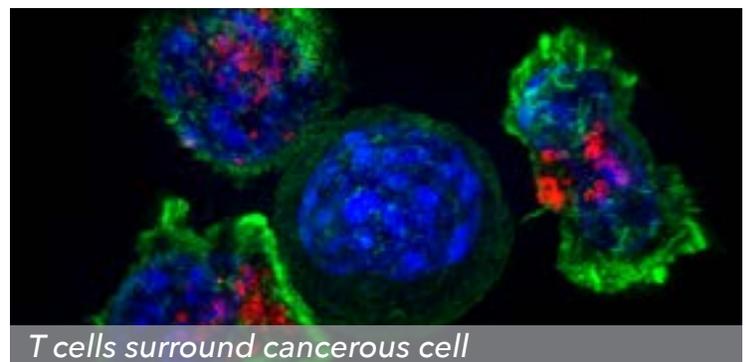
This device allows for white blood cells to be seen in a density gradient, where it was discovered that ME/CFS white blood cells are less dense than healthy controls.

3. RED BLOOD CELL DEFORMABILITY TEST

The red blood cells of ME/CFS patients and healthy controls differ in their time of entry into a capillary, rate of movement through the capillary, and the extent of deformation of the cell in the capillary. Developing a micro-fluidic device that measures blood flow and deformability of red blood cells.

4. MITOCHONDRIAL FUNCTION TEST

This protocol measures mitochondrial function to reveal a significant difference between activated T cells of ME/CFS patients and healthy controls.



T cells surround cancerous cell

METABOLIC TRAP

The hypothesis for a metabolic pathway "trap" in ME/CFS patients could lead to a new treatment.

STANFORD ME/CFS DATA MANAGEMENT AND COORDINATION CENTER

OMF is also funding the expansion of the Stanford Data Center for the Severely Ill Patients (SIPS) Study. The clinical results from the SIPS are currently already open to researchers with access via our website. This expanded data center will give researchers quick access to massive amounts of research data.

OMF FUNDED RESEARCH

2018

ANALYZING PATIENT DATA STUDY

This retrospective study aims to analyze the clinical records and test results of thousands of patients from ME/CFS specialists.

HORMONES, PROTEINS, AUTOANTIBODIES

Validating autoantibody findings, as well as measuring proteins and steroid hormones in plasma and cerebrospinal fluid.

METABOLOMICS VALIDATION STUDY

2016 ME/CFS metabolomics study is being expanded to include additional validation studies with the West Coast Metabolomics Center, University of California, Davis.



SECOND ANNUAL COLLABORATIVE TEAM MEETING ON THE MOLECULAR BASIS OF ME/CFS AT STANFORD UNIVERSITY

In 2018, our collaborative team meeting expanded to three days. The first two days were for in-depth scientific discussion of recent ME/CFS research results. On the third day, the team's focus was to establish collaborations and discuss the most effective path forward to expedite ME/CFS research. At this groundbreaking scientific conference, over 50 international researchers shared unpublished data and ideas.

SECOND ANNUAL COMMUNITY SYMPOSIUM ON THE MOLECULAR BASIS OF ME/CFS AT STANFORD UNIVERSITY

The Second Annual Community Symposium was held on Saturday, September 29, 2018. At the Community Symposium, the scientists provided an update to patient and members of the public on the latest research and our progress towards understanding the molecular basis of ME/CFS and our plans for the future.

ME/CFS Collaborative Research Center at the Harvard Center

ME/CFS COLLABORATIVE RESEARCH ACTIVITIES AT MGH AND THE HARVARD AFFILIATED HOSPITALS

OMF has newly awarded a grant totaling \$1.8 million to establish a new ME/CFS Collaborative Research Activities at Massachusetts General Hospital (MGH) and the Harvard Affiliated Hospitals. The new Harvard project is co-led by OMF Scientific Advisory Board members Ronald G. Tompkins, MD, ScD, and Wenzhong Xiao, PhD, and is working synergistically with the ME/CFS Collaborative Research Center at Stanford, led by Ronald W. Davis, PhD, of Stanford University, also funded by OMF.

Additional OMF-funded Research Projects

1. Computer Simulation of the Effect of Membrane Rigidity on the Micro-Flows of Red Blood Cells to create a Diagnostic for ME/CFS.
2. Erythrocyte Biomechanics in ME/CFS.
3. Preliminary study toward a self-contained high-throughput measurement device for Chronic

OMF FUNDED RESEARCH

2018

Fatigue Syndrome based on cell mechanical properties. The longer-term goal of this collaborative effort between these three groups is to produce a low-cost, disposable device to determine the rapid quantitation of deformability of the cells in a single drop of blood.

4. OMF has granted additional funds to expand work on targeted proteomics for neuroinflammatory markers in cerebrospinal fluid (CSF) in ME/CFS patients.

Advancing Research into Clinical Practice

OMF is partnering with parent advocate Mary Dimmock and Bateman Horne Center to develop Clinical Best Practices and Recommendations to train and educate new clinicians to care for patients.

EXPANDED FUNDRAISING OPERATIONS:

May Momentum, a month-long fundraising campaign initiated in 2018, raised \$50,000.

Triple Giving Tuesday raised over \$1.5 million.

EXPANDED GLOBAL PRESENCE:

Worldwide Tour by CEO/President Linda Tannenbaum, visited with and spoke to the patient and medical communities in Italy and the Netherlands.

Recruited 60 translator volunteers to translate OMF communications into 17 languages.

Established OMF Ambassador program with Scottish pop-star, Stuart Murdoch, ME/CFS patient and co-founder of Belle and Sebastian, which tours Europe, Canada, and the U.S.



Linda Tannenbaum with Stuart Murdoch

RESEARCH AND PROGRESS COMMUNICATIONS:

Optimized website with welcoming introductory video by CEO/President and video of first celebrity OMF Ambassador, Stuart Murdoch.

Regular newsletters, science posts, and videos by Dr. Ron Davis, director of the Scientific Advisory Board, to communicate latest research programs.

Optimization of social media channels, including Facebook, where we increased our traffic to over 12,000 followers, and Reddit, where enthusiastic patient support resulted in a \$5 million donation from the Pineapple Fund.

Media coverage of OMF, including worldwide coverage of the \$5 million donation from the Pineapple Fund in U.S. News & World, Thomson/Reuters, and the Chronicle of Philanthropy. OMF was recognized in CNN's "Turning Points" by reporter and patient Ryan Prior. In addition, ProHealth's March 5, 2018 lead story announced OMF CEO/President Linda Tannenbaum as ProHealth's 2017 ME/CFS Advocate of the Year.

OMF FUNDED RESEARCH

2018

EXPANDED NETWORK OF INFORMATION SHARING, SUPPORT, PATIENT CARE

Hiring of public relations consultant to create awareness worldwide. Generated several press releases and developed relations with strategic health reporters in mainstream and science media.

Held 2nd annual research and patient symposium at Stanford with 50 researchers, 300 attendees, and 6,000 Livestream viewers

Participated in ME/CFS symposia in London and Montreal.



GOOD GOVERNANCE AND OPERATIONAL EFFECTIVENESS

Clear strategy on tactics and priorities.

Strong financial oversight and internal controls. Platinum star rated by Guidestar for the fourth year in a row and Top Rated Charity from GreatNonProfits for five years in a row.

Highly engaged and effective foundation board and scientific advisory boards.

Strong operational governance of OMF with clear procedural policies in place; regular assessment of our effectiveness.

Workflow efficiency and effectiveness, making best use of internal resources while outsourcing resources and one-off initiatives when most cost effective.

Recruitment and utilization of over 170 volunteers with special skills to support all phases of operation, including marketing, communications, and technical services, including Statisticians Without Borders.

Ability to operate quickly and effectively as a cohesive team with shared values and commitment to the organization.

MAINTAINING STRONG CREDIBILITY IN OUR OPERATION, OUR RESEARCH/ SCIENCE, AND OUR LEADERSHIP

In March of 2018, CEO/President Linda Tannenbaum was awarded ProHealth's 2017 ME/CFS Advocate of the Year.

"Linda has displayed a constant, magnificent dedication and commitment to patients, and her results have been nothing less than astonishing. In just the last year, she has virtually single-handedly raised almost three times as much money for ME/CFS research than the entire United States government has historically allocated to the disease."
- ProHealth founder, Rich Carson

OMF FINANCIALS 2018

Revenue and Support

2017 / 2018

Contributions

\$1,515,425 / **\$1,624,762**

Grants

\$1,140,613 / **\$7,279,095**

Interest income

\$1,069 / **\$4,938**

Total: \$2,657,107 / **\$8,908,795**

Functional Expenses

Program services

\$1,902,078 / **\$5,494,893**

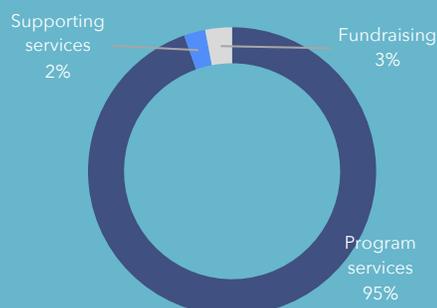
Supporting services

\$116,751 / **\$139,771**

Fundraising

\$127,680 / **\$175,050**

2018 Expenses:



Total: \$2,146,509 / **\$5,809,714**

OMF FINANCIALS 2018

Current Assets 2017 / 2018

Cash and cash equivalents

\$3,061,297 / **\$7,965,136**

Contributions receivable

\$56,667 / **\$6,186**

Total: \$3,119,205 / **\$7,971,322**

Current Liabilities

Accounts payable and accrued expenses

\$19,891 / **\$16,726**

Grants payable

\$1,224,758 / **\$2,980,959**

Total: \$1,244,649 / **\$2,997,685**

Net Assets

Without donor restrictions

\$1,820,449 / **\$2,642,840**

With donor restrictions

\$54,107 / **\$2,330,797**

Total: \$1,874,556 / **\$4,973,637**

At year-end 2018, **\$5,311,756** was set aside for research projects in the following areas:

- Stanford Collaborative Research Center
- Harvard Collaborative Research Center
- Red Blood Cell Studies
- Metabolic Trap Studies
- Physician Education
- Clinician Symposiums

OMF BOARD OF DIRECTORS

Linda Tannenbaum, Founder & CEO/President

Kimberly Hicks, Treasurer

Patricia Linsley, Secretary

Kathryn Bach

Carol E. Jensen

Joseph Morin

R.P. Channing Rodgers, MD

Deborah Rose, MD

Hany Zayed, PhD



**Members of the
OMF Board,
left to right:**

Hany Zayed, Patricia Linsley, R.P. Channing Rodgers, Deborah Rose, Linda Tannenbaum, Joseph Morin.
Not pictured: Kimberly Hicks, Kathryn Bach, Carol Jensen)



Open Medicine Foundation is a U.S. 501 (c)(3) non-profit organization. Tax ID # 26-4712664.

Learn more at www.omf.ngo

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**Dedicated
to patients
around the
world.**