

Open Medicine Foundation(OMF)

\$500,000 received!

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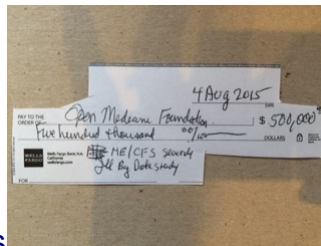
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Unexpected \$500,000 Donation brings total to \$625K for Severely ill Big Data Study

“Build it and they will come” is certainly true of the OMF [ME/CFS Severely Ill-BIG DATA Study](#). We’ve been actively fundraising for this study, which is part of our [End ME/CFS Project](#). When word reached one of our supporters, we were notified that a \$500,000 check was on the way. As you can imagine, when we laid our eyes on it, we were greatly encouraged that we may soon have enough to get this unprecedented study done and bring all of us closer to diagnostic biomarkers and effective treatments.



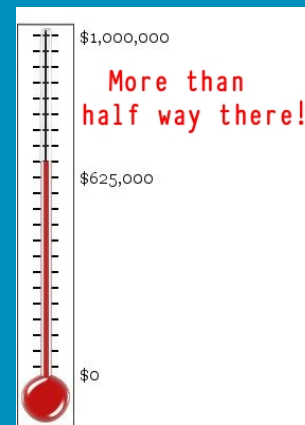
The study budget is \$1 million. With over \$125,000 in crowdfunding already, we’re well on our way to meeting the goal!

Summer 2015 Update

\$500K more received

for

OMF ME/CFS Severely ill Big Data Study



If you love our work then tell the world! Help us raise visibility for our work by posting a review.

Go to

<http://greatnonprofits.org/org>



[open-medicine-foundation](#)

ME/CFS Severely ill-BIG DATA Study Progressing



You've heard about the plan, and now it's in the works. This is truly a unique research study to collect a comprehensive and large amount of data from severely ill ME/CFS patients. We are looking for symptom-driving biological abnormalities in those with the most severe symptoms because the level of the abnormality should be stronger—and therefore more detectable—in these patients.

We've set the testing protocol and are now seeking IRB approval (saying it is safe to do the collections according to our plan) and then we start running the tests. Go to our [ME/CFS Severely Ill-BIG DATA Study webpage](#) to see the following:

- Video of Stanford's Brian Piening, PhD, explaining the data to be collected
- Recording of OMF Director Linda Tannenbaum (with a slide show) explaining the study
- Written explanation of the study's goals and benefits
- A PDF document with a detailed description of testing that will be done

Scientific Advisory Board

Director

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*Genetics & Biochemistry
Genome Technology Center
Stanford University*

Paul Berg, PhD
*Nobel Laureate
Molecular Genetics
Stanford University*

Mario Capecchi, PhD
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Foundation Board

Linda S.E. Tannenbaum,

Reception in Palo Alto Informs People about ME/CFS

At a reception hosted by our own ME/CFS Scientific Advisory Board director, Ronald W. Davis, PhD, and his wife, Janet Dafoe, we introduced the disease and OMF to a mayor, former mayors, scientists and many other political and professional “movers and shakers” in and around Palo Alto, California.

This is part of our effort to gain support for ME/CFS research from those who don't know much about the disease. We were very pleased with the turnout. You can watch three videos from the event:

- [OMF Director Linda Tannenbaum explains the disease and OMF strategy to make quick progress.](#)
- [Janet Dafoe, with help from daughter Ashley Davis, show the impact the disease has when it is severe.](#)
- [Ron Davis explains the scientific process and how OMF research can lead to more NIH funding for ME/CFS.](#)



Executive Director
Kimberly Hicks, *Treasurer*
Patricia J. Linsley, *Secretary*
Tina D. Orkin, *Event Coordinator*
R.P. Channing Rodgers, MD
Deborah Rose, MD
Kenneth Walker, MD, PhD

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ME Action Network Shows What You Can Do in Advocacy

[See #MEAction write up on Ron Davis and why his NIH Proposal was rejected.](#)



Our organization does fundraising and research, but advocacy is needed too. #MEAction has taken an active role in encouraging the ME/CFS community to get involved in taking whatever action that they could.

The federal government has taken some action recently in an NIH report to guide future research through their Pathways to Prevention program and a multi-agency-funded report from the National Academy of Medicine (formerly the Institute of Medicine) that recommended clinical diagnostic criteria and a different name for ME/CFS (SEID). Plus, an FDA Patient Voice report helped government officials understand the illness better. But we all know that's not enough.

Recently, one of the congressional committees made a funding recommendation that, if passed, would bring funding to CDC work on ME/CFS down to zero—nothing. We joined with others in signing a letter urging the funding to continue at CDC, especially since they are currently doing a large-scale biomedical, multi-site study of the

disease.

[#ME Action has a website](#) that serves to bring people together on current advocacy and news and gives an easy platform to do so. You may wish to check it out and get involved online.

Welcome New Board Members

With the generous support from highly experienced and noted professionals, we are setting the bar high to produce ground-breaking results. Four individuals recently joined our team, giving their time and bringing their talent and expertise to benefit ME/CFS research:

New to our ME/CFS Scientific Advisory Board is Paul Berg, PhD.

He is a Nobel laureate in the Chemistry category. He was honored with the National Medal of Science in 1983 and the National Library of Medicine Medal in 1986.



He is a professor emeritus of Stanford University and an expert on the chemical processes involved in cellular metabolism. He's one of the first scientists to show folic acid and B12 are needed for healthy energy production. He is considered one of the fathers of modern genetic engineering. We have Dr. Berg's profile on the [ME/CFS Scientific Advisory Board page](#) on our website. Welcome, Dr. Berg!

Kimberly Hicks joined our Foundation Board and is the current treasurer.

She's been instrumental in developing our financial governance, operating procedures and policies. Kimberly is a finance industry veteran, with over 20 years of



leadership experience across both private and public sectors, and she most recently served as chief administrative officer of the International Securities Exchange. We appreciate and are grateful for Kimberly's expertise and dedication to OMF. [Learn more about Kimberly here.](#)

Dr. Deborah Rose, a psychiatrist in private practice in Palo Alto, Calif., recently joined our Foundation Board. Her interest in serving on our board stems from both her personal experience of having fibromyalgia and then ME/CFS, and also from having patients in her practice with these illnesses. She's been a strong supporter and now officially helps in guiding our organization. [Read more about Dr. Rose.](#)



Tina Orkin brings both medical and event planning expertise to our Foundation Board. She is a certified registered nurse practitioner in OB-GYN, Prepared Childbirth Educator and Parent Educator. Ms. Orkin's interest in serving on our board is personal as well; for the past twenty years she has lived with fibromyalgia and understands the need for research and support. Looking forward to some great events planned by Tina! [Find out more about Tina here.](#)



Website Makeover

As is true with clothes and hair, sometimes a website needs a makeover. We're almost finished with some formatting, design and menu changes to our website. Check the following changes:

- Added a [News Blog page](#) where we post the latest organization news

- Updated our [Current Studies](#) and [Completed Studies](#) pages
 - Added an [OMF in the News](#) page where you will find news media and blog coverage of our efforts
 - Added a new domain url (<http://end-mecfs.org>) that forwards to our current website (Feel free to share it; some are using it on bumper stickers, hats, buttons, and other items.)
 - Added a [Video Library](#) page.
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OpenMedicine Foundation

Tax ID: 26-4712664

Collaborating to Fast Track Answers

Our Mission:

- To support collaborative medical research to find effective treatments and diagnostic markers
- To communicate, engage and inform the patient community.
- To help drive & support scientific meetings for continued global collaboration.

A Word from our Executive Director:

We are extremely grateful to our supporters and donors that are making this urgent research possible. We are elated to tell you that the ME/CFS Severely Ill Big Data study is underway. This study will give us a tremendous amount of information that will lead us to the next steps. Thank you all for reading our newsletter and being a part of the momentum.

To a healthy future for all,
Linda
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We invite the patient community to get involved by sharing with friends and family on Social Media.



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