

OMF's End ME/CFS Project Update and more...



THE END ME/CFS PROJECT

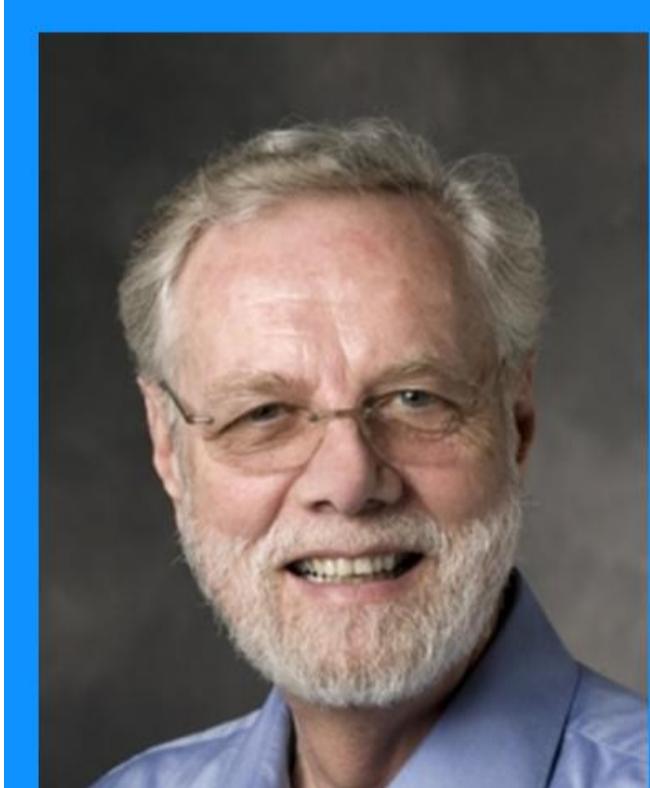
THE END ME/CFS PROJECT

THE OMF End ME/CFS Project Update

Severe ME/CFS Patients Will Be First Subjects

The first OMF Scientific Advisory Board meeting in October concluded with a clear direction toward ending ME/CFS. Whatever biological abnormality causes the disease would most likely be stronger in those who are the sickest.

This first study will enroll 15-20 severely ill ME/CFS patients (largely bed/home bound). We will check many areas: genetics, genomics, pathogens, proteomics, immunology, gastrointestinal, metabolic/endocrine and brain/cognitive function. We are looking for the biological abnormalities that would explain the symptoms and debilitation. A recent Medscape article ([Chronic Fatigue Syndrome: Wrong Name, Real Disease](#)) highlighted this stu



As part of OMF, "Dr. Davis [hopes] to begin studies that will entail making home visits to conduct sophisticated testing on the most severely affected bedridden ME/CFS patients, such as his son."

- Jan. 8 Medscape article titled "Chronic Fatigue Syndrome: Wrong Name, Real Illness"

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expected to cost approximately \$1 million (about \$65,000 per patient). If you would like to donate toward this study and the End ME/CFS Project, you may do so at [our website](#).

What is the End ME/CFS Project?

You can't get anywhere without having a goal. Our foundation includes individuals personally touched by the suffering caused by ME/CFS. Ending that suffering is our goal, and we aim to do so through the End ME/CFS Project.

Started in 2014, the project is modeled after the successful Human Genome Project and the Consortium on Inflammation and Host Response to Injury (Glue Grant) Project. Two features make it different than most other research in the disease: a multidisciplinary approach and collaboration among disease experts and other top-notch scientists.

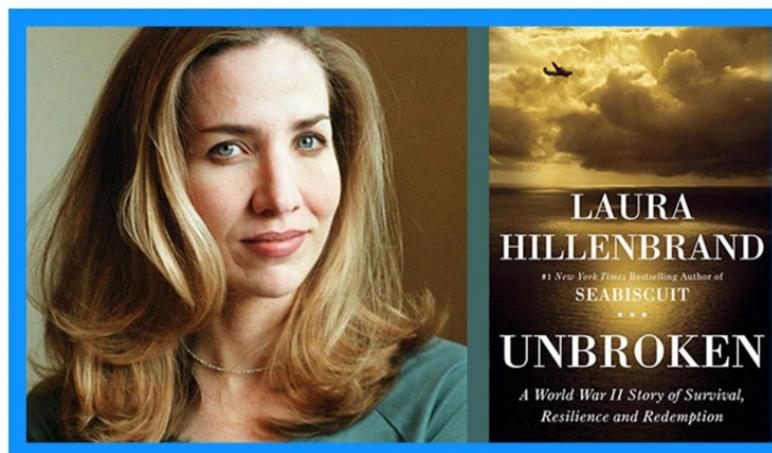
Different studies will be included, the first focusing on the severely ill. The expected End ME/CFS Project outcomes are an understanding of the disease on a molecular level, diagnostic tests, identifying effective treatments, and enhancing the understanding of other neuroimmune diseases.

We know we will have to be aggressive and creative to succeed. The collaboration starts with patients and their families: those who participate as subjects, those who help with administration and ideas, and those who help raise funds. The [End ME/CFS Project](#) has a goal of raising \$5 million a year. We invite you to join our collaboration to end ME/CFS.



ME/CFS Revealed in Famous Author's Story

Many ME/CFS patients have longed for celebrities to speak publicly about their ME/CFS experience to bring credibility and understanding of the disease. In news media interviews, a New York Time's best-selling author, Laura Hillenbrand, has consistently and courageously revealed her personal struggles with the debilitating disease.



The recent release of a movie version of her very popular book, *Unbroken*, has brought a new wave of media attention to her as an author, but also as an author with ME/CFS. In describing how she fought against vertigo and bone-crushing exhaustion and weakness to do some writing each day, the public comes to realize this is a serious disease.

Your friends and relatives have surely heard of the movie. Using that interest, patients can share [this interview](#) with them to help them understand the disease better. Laura Hillenbrand has turned out to be a superb celebrity representative.

2014 OMF Accomplishments: Progress at a Rapid Rate



In addition to welcoming Ronald W. Davis, PhD as Director of the OMF ME/CFS Scientific Advisory Board and in turn, Dr. Davis inviting a remarkable team to join him and launching the End ME/CFS Project, we have other 2014 activities to report:

- Andreas Kogelnik, MD, PhD President and Founder of the Open Medicine Institute (OMI), comments on projects funded by OMF. ([Go here to see this report.](#))
- Through Crowdfunding, and with your support, we raised the funds needed (\$150,000) for the MTHFR/B12/Folate study that is about to begin.
- OMF Scientific Director Ronald W. Davis, PhD served on the

Institute of Medicine (IOM) ME/CFS committee. Report will be released Feb. 10.

- Three OMF representatives attended the National Institutes of Health P2P meeting on ME/CFS: Linda Tannenbaum, Dr. Andreas Kogelnik, and Dr. Ronald W. Davis.

You Can Support OMF Research with Amazon and iGive Purchases



You shop. Amazon gives.

Shoes, electronics, clothes, and many more items are purchased online by neuroimmune patients and their relatives. You can make some of that purchase price go toward research with no additional cost to you.

AmazonSmile is operated by Amazon and lets customers enjoy the same wide selection of products, low prices, and convenient features found at Amazon.com. If you shop Amazon through this link, the AmazonSmile Foundation donates 0.5% of the price of eligible purchases to OMF.

iGive.com is an Internet company with the goal of harnessing the economic power of individuals to benefit their chosen charities and communities. iGive has 1,559 participating stores, many of which are popular and nationally known. When you shop at your favorite stores online through iGive, they will donate to your favorite cause. Through this link, OMF will receive 5-20% of the purchase amount, depending on the store and item bought.

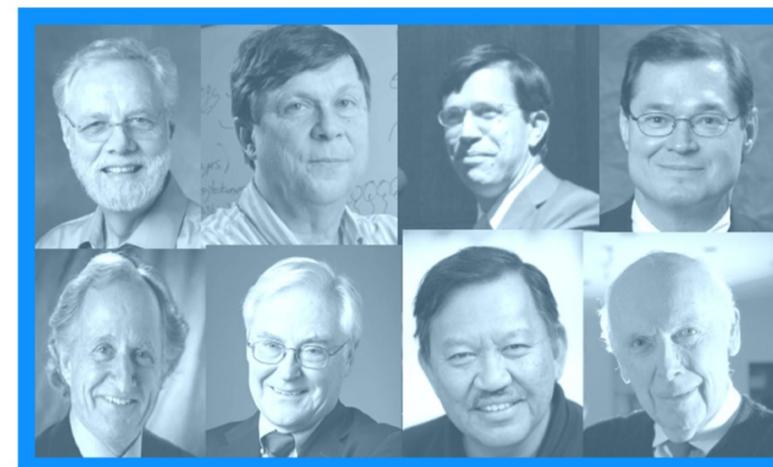


Who Is on the OMF Scientific Advisory Board?

As our foundation moved toward initiating research in addition to funding others' research, we needed scientific guidance. In addition to those with experience with neuroimmune diseases, our Scientific Advisory Board director, Ronald W. Davis, PhD brought in scientists with expertise in genetics, neuroimmunology, exercise physiology, pain pharmacology, trauma-induced inflammation,

bioinformatics, and more.

Moving the science forward faster requires collaboration between ME/CFS experts and accomplished scientists in other fields of study. We are so serious about benefitting from others' experience in success that two Nobel laureates are included on our Scientific Advisory Board.



Get to know our [Scientific Advisory Board](#) members better at [our website](#).

Lots of Great Fundraising Ideas

On Feb. 7, the Arunkumar family will host over 100 people at a fundraiser to be held at an Indian restaurant where they will meet and hear from members of our Scientific Advisory Board and hear personal stories. Could Indian food and the presentations move them to make a donation? We certainly hope so.

The Know M.E. Challenge by the Jarrett Family



Say it. Know it. Cure it!

Most people have never heard of the disease M.E. We challenge you to make a video of yourself (or a friend) saying "Myalgic Encephalomyelitis" 3 times in a row without practicing. We need donations to research for a cure. Post your video and challenge a friend to do the same, with these directions. Together we can change the future for those suffering with M.E.

[Click to join the Challenge](#)

Thank you to Ellinor from Boras, Sweden who generously donated funds to OMF from creating and selling ME/CFS pins and keychains. We encourage others all over the world to

set up their own fundraisers and keep ME/CFS research going!



Many thanks go out to Elenor from Sweden. She and her team are making bracelets to support biomedical research for ME/CFS. It's great to see people all over the world determined to keep research going. Let's keep it up!



On Oct 2014, NIDA (Neuro-Immune Disease Alliance) hosted a fundraiser for OMF at the Chinese Theater in Hollywood, California, where they showed a screening of *Forgotten Plague*, the ME/CFS Blue Ribbon Foundation documentary written and directed by Ryan Prior and Nicole Castillo. Members of the Scientific Advisory Board were in attendance, and Director Dr. Ronald W. Davis spoke at the event.

In 2014, Katie and Al, very generous newlyweds, asked their friends and relatives make donations to OMF instead of traditional wedding presents. Both of Katie's parents suffer from neuroimmune diseases, and this was their gift to them. The same can be done with birthdays, anniversaries or other gift-giving events.

In 2013, Candace, the loving niece of a patient, hosted a volleyball tournament at George Washington University. We've heard of runs and bike rides as fundraisers, but it seems any sport will do. We expect many patients have athletic relatives who would want to do something like this if they knew of the opportunity.

Know someone with musical talent? You could ask them to put on a small or large concert to raise money for ME/CFS research at OMF. It's a worldwide disease, so we encourage patients and their families around the world to join us.

Check out our list of other [fundraising ideas](#) on our website. If you have a fundraising idea you'd like to share or would like to try one of the ones above, please contact us.

Let them Know the State of Medical Care for ME/CFS

The U.S. Chronic Fatigue Syndrome Advisory Committee is considering new initiatives to improve access to expert medical care for those with ME/CFS. They have established a Centers of Excellence Working Group focusing on that goal. But first, they must document the areas of need.

If you are an ME/CFS patient 18 years or older, please fill out this brief survey. While any patient in the world can fill it out, the goal is to assess healthcare for ME/CFS in the United States. All survey responses are given anonymously.

While we make strides in research discoveries, we recognize much has already been revealed that experts use. But, the expert care available to some patients should be available to all patients. Please also share [this survey](#) with other ME/CFS patients in the United States.

OpenMedicine Foundation

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Collaborating to Fast Track Answers

Our Mission:

- To communicate, engage and inform the patient community.
- To fundraise for neuro-immune disease research.
- To help drive & support scientific meetings for continued global collaboration.

A Word from our Executive Director:

We are touched by the support of the International Community as well as the U.S. Neuro-Immune Disease is an International problem and it takes International effort for awareness and for funding research to find a cure .The End ME/CFS Project is the best chance in the history of this disease and all neuro-immune diseases to find answers that will translate to helping those that continue to suffer. With the first focus on the Severely Ill bed-house bound patients, we will be looking for signals, biomarkers, and indicators that may be common among them to set the path for the future collaborative studies.

To a healthy future for all,

Linda

Linda Tannenbaum

Executive Director

OpenMedicine Foundation

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