

ME/CFS e-Newsletter

Collaborative Research Update

Open Medicine Foundation (OMF)



Over \$1 million for ME/CFS RESEARCH!

Major Grants Kick off OMI-MERIT Research Projects

Answering the question: ***Does genetics play a role in ME/CFS?***

The Open Medicine Foundation in partnership with the Edward P. Evans Foundation has fully funded a ground-breaking grant to the Open Medicine Institute (OMI), Mountain View, CA to determine if genetics plays a role in ME/CFS. This grant will provide answers within the next 12 months.

- **Goal:** Use the most advanced methods available to measure DNA sequences in a set of patients and controls, including affected families and unrelated individuals. Utilizing advanced Human Genome Project technologies, this project will undertake whole genome sequencing, gene analysis, DNA methylation studies, HLA and other regional sequencing of areas of interest in a selected group of nearly 1000 individuals.
- **Importance:** Establishing or refuting a role for genetics and potential heritable risk in ME/CFS.
- **Projected length of project:** 9-12 months

Andreas M. Kogelnik, MD, PhD, of the Open Medicine Institute (OMI), will be the Principal Investigator to orchestrate a comprehensive investigation of genetic/genomic factors for ME/CFS through focused whole genome sequencing, large scale HLA sequence analysis and large scale DNA methylation analysis. Ron Davis, PhD, of the Stanford Genome Technology Center will be a key collaborator on the study.

May 2013
In honor of
ME/CFS Awareness



Click above and read the exciting
Press Release!

Quick Links

[Our Website](#)

[Donate Now](#)

[Stay Informed](#)

[Email Us](#)

[Facebook](#)

[Twitter](#)

CLICK HERE
TO DONATE

STAY INFORMED
Sign Up For
e-Newsletter

**Donate Now to
Accelerate Research for
ME/CFS**

Click to see:
TOP 10 ME/CFS PROJECTS:

**-Clinical Trials
Rituximab and
Valgancyclovir
-Neuro Registry & Biobank**

This is the first fully funded research project of the OMI-MERIT Initiative in which scientists and clinicians from USA, Italy, Britain, Germany, Sweden and Norway agreed upon as the priority projects to study ME/CFS. For a list of all the OMI-MERIT Initiative Signators please click [here](#).

The Open Medicine Foundation is tremendously thankful and sincerely grateful to the Edward P. Evans Foundation for their partnership and for granting a substantial and generous donation to study the genetics of ME/CFS. We at the Open Medicine Foundation, look forward to continuing our partnership with the Edward P. Evans Foundation and other like-minded foundations, corporations and the patient-community to move this research forward quickly.

ME/CFS RESEARCH FUNDED

Moringa oleifera pilot study

The Open Medicine Foundation has received a generous grant from Neuro-Immune Disease Alliance (NIDA), for the Open Medicine Institute (OMI) to perform a pilot study of *Moringa oleifera*.

- **Goal:** Examine the potential benefit of *Moringa oleifera*, a natural therapy, in a vetted scientific context.
- **Importance:** This project will be a first application of vetted scientific method and molecular science to non-pharmacologic substances that have had anecdotal benefits reported, thereby setting a standard for mainstream measurement of ME/CFS.
- **Projected length of project:** 9-12 months

Widespread claims of the medicinal effectiveness of the *Moringa* tree have encouraged Jed W. Fahey, Sc.D. and his colleagues at John Hopkins School of Medicine, to do a review of the reports of the medicinal and nutritional properties of this product, available at <http://www.TFLJournal.org/article.php/20051201124931586>.

Andreas M. Kogelnik, MD, PhD, of the Open Medicine Institute, will be the Principle Investigator and will perform a 90-day pilot study on 15 ME/CFS patients. Natural killer cells and other immune markers will be tested before and after and blood will be drawn for additional blood tests and gene expression tests. If *Moringa oleifera* shows positive measurable results, further studies will be done with the blood collected before and after.

NIDA

Neuro-Immune Disease Alliance, Inc.

Do you want to be a part of the solution?
Please Donate Now
to accelerate this year of discovery!

Click [here](#) to see details of OMI-MERIT's Ten ME/CFS Research Projects

-Protein Panels
-Other Mono & Combo Therapy
-Biomarker Exploration Studies
-DNA Genetics
-Mass Spec/ Environmental
-Viral Testing
-Advanced Biomarker Study
-Natural & OTC Substances

Visit our website for details:
www.openmedicinefoundation.org

The Challenge:
If every person in
the world that is
affected by ME/CFS
would donate \$1.60,
all MERIT projects
would be fully
funded!
Research studies
start as they are
funded.

CLICK HERE
TO DONATE

We invite the patient community
to get involved by sharing with
friends.

Through this newsletter, we are
aiming to keep you updated about
the newest developments on the
ME/CFS horizon.

[Forward this email to a friend!](#)

1. Clinical Trials: Rituximab and Valgancyclovir
2. Neuro Registry & Biobank
3. Protein Panels
4. Other Mono & Combo Therapy
5. Immunologic Biomarker Exploration
6. DNA Genetics- **Fully Funded**
7. Mass Spec/ Environmental
8. Viral Testing
9. Advanced Biomarker Study
10. Natural & OTC Substances: **Moringa pilot funded**



Visit our website and review the details of the research projects that are taking off with your support.
www.openmedicinefoundation.org

Post Doc joins OMI to move data collection fast forward.

The OMI is creating an easy-to-use, patient-friendly interface for web and mobile applications for the purpose of gathering data for large research studies and the OMI ME/CFS Registry.

After conducting interviews with ME/CFS patients, Asha Smith, PhD, a Stanford trained Cognitive Scientist and User-Interface expert will be using her expertise in "user experience and implementation" to help create tools to gather data from the patients point of view. Asha received her PhD from Stanford University and has extensive industry experience designing and building user interfaces for different disease conditions. She is currently a postdoc with the Open Medicine Institute.

Invest in ME International ME (ME/CFS)

Infection, Immunity and Myalgic Encephalomyelitis
Mainstreaming ME Research: Clinical and Research
London, May 31, 2013

Invest in ME (IIMEC8) is the eighth annual biomedical research conference organised & hosted by the charity for researchers, physicians and patient groups from around the world.

Multiple OMI-MERIT Investigators to speak:

Drs. Andy Kogelnik, Oystein Fluge, Olav Mella, Sonya Marshall-Gradisnik, Mady Hornig, Carmen Scheibenbogen. Linda Tannenbaum will speak at the pre-conference dinner.



Dr. Andy Kogelnik and Linda Tannenbaum
outside the Open Medicine Institute
Mountain View, California

The Open Medicine Foundation

Tax ID: 26-4712664

Patient advocates advancing medicine.

Our Mission:

- To communicate and inform the ME/CFS community
- To fundraise for ME/CFS and other neuro-immune disease research.
- To help drive & support scientific meetings for continued global collaboration.

The Open Medicine Foundation is investing in wellness for neuro-immune diseases. Starting with the ME/CFS OMI-MERIT initiative, DNA Genetics, project #6 and testing an Alternative therapy, Moringa oleifera, project #10, the Year of Discovery begins! I am personally elated to see this high quality, highly relevant research get started and look forward to reporting the results of the research as they become available.

Best,
Linda Tannenbaum
Executive Director
Open Medicine Foundation
www.openmedicinefoundation.org
Linda@OpenMedicineFoundation.org

Stay Informed

Sign up to our eNewsletter to stay on top of
what is happening.



[Like us on Facebook](#)
[Follow us on Twitter](#)

Please Donate Now

**If every person in the world affected by ME/CFS
would donate \$1.60, all MERIT projects
would be fully funded!
Research studies start as they are funded.**



**We invite the patient community to get involved by sharing with friends.
Through this newsletter, we are aiming to keep you updated about the
newest developments in ME/CFS at OMF and our supported partners.**

Would you like to forward this email to a friend? [Click here.](#)

Share This Email:      

[Remove my name from all future email correspondence](#)

Address postal inquiries to:
Open Medicine Foundation
29302 Laro Drive
Agoura Hills, CA 91301
Powered By

Blackbaud eTapestry™ Delivra