

ME/CFS e-Newsletter

Collaborative Research Update

Open Medicine Foundation (OMF)



OMF Named First Recipient of the VMware Foundation "Group Gigs and Grants" Program to Enhance the Use of Technology in Supporting ME/CFS and other diseases.

The Open Medicine Foundation (OMF) was awarded a generous financial and support grant from the VMware Foundation including VMware products and engineering time. VMware is a global leader in the virtualization and cloud infrastructure industry. Funds from the community-minded donation program will go to support expansion of the Open Medicine Institute's personalized medicine infrastructure (OpenMedNet) to improve patient care and enhance the capacity for data collection. By using this open-framework, the OMI is encouraging collaboration and partnership with patients, physicians and researchers to improve patient outcomes.

We are grateful and thrilled to receive this generous grant and will benefit from VMware's expertise on scaling and hardening the OpenMedNet IT infrastructure. Nicola Acutt, Director, VMware Foundation, commented "This capacity-building grant to the OMF is the result of a group of passionate VMware people who are contributing their time and talents to work with the OMF to help them achieve their mission. Our team found a

May 2013-#2

In honor of
ME/CFS Awareness



[Click above and read today's exciting Press Release posted in the Wall Street Journal, a Grant from VMware!](#)

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kindred spirit with the OMF through its efforts to improve community health care, and we're hoping to provide OMF with a scalable IT environment to help meet its growing needs while making a positive impact on the patient experience. " This grant will directly impact ME/CFS patients as it further supports the registry component of MERIT Project #2 ME/CFS Registry and Biobank.



- Clinical Trials
Rituximab and Valgancyclovir
- Neuro Registry & Biobank-
Partially Funded
- Protein Panels
- Other Mono & Combo Therapy
- Biomarker Exploration Studies
- DNA Genetics-Funded
- Mass Spec/ Environmental
- Viral Testing
- Advanced Biomarker Study
- Natural & OTC
Substances-Partially Funded.

Visit our website for details:
www.openmedicinefoundation.org

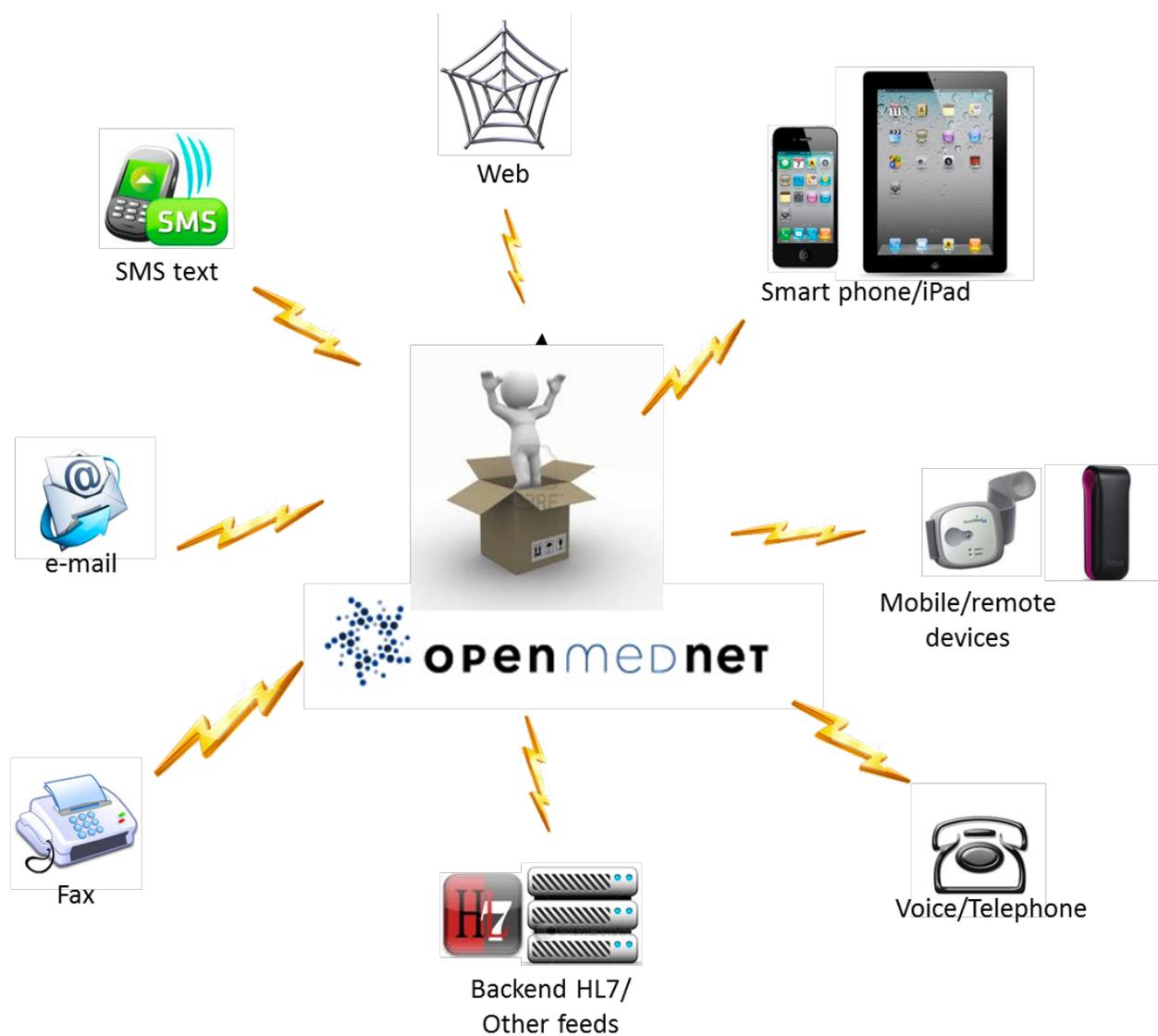
The Challenge:
If every person in the world that is affected by ME/CFS would donate \$1.60, all OMI-MERIT projects would be fully funded!
Research studies start as they are funded.

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!



OpenMedNet facilitates information sharing (patient consented and HIPAA compliant) and optimizes collaboration amongst all participants in the health care continuum. This will soon be available, at no cost, for all patients to log on and enter their own data if they wish to be part of the research and data collection or simply to use as their own electronic medical record. We will announce via this e-newsletter when the OpenMedNet is ready for easy log-on.

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?***

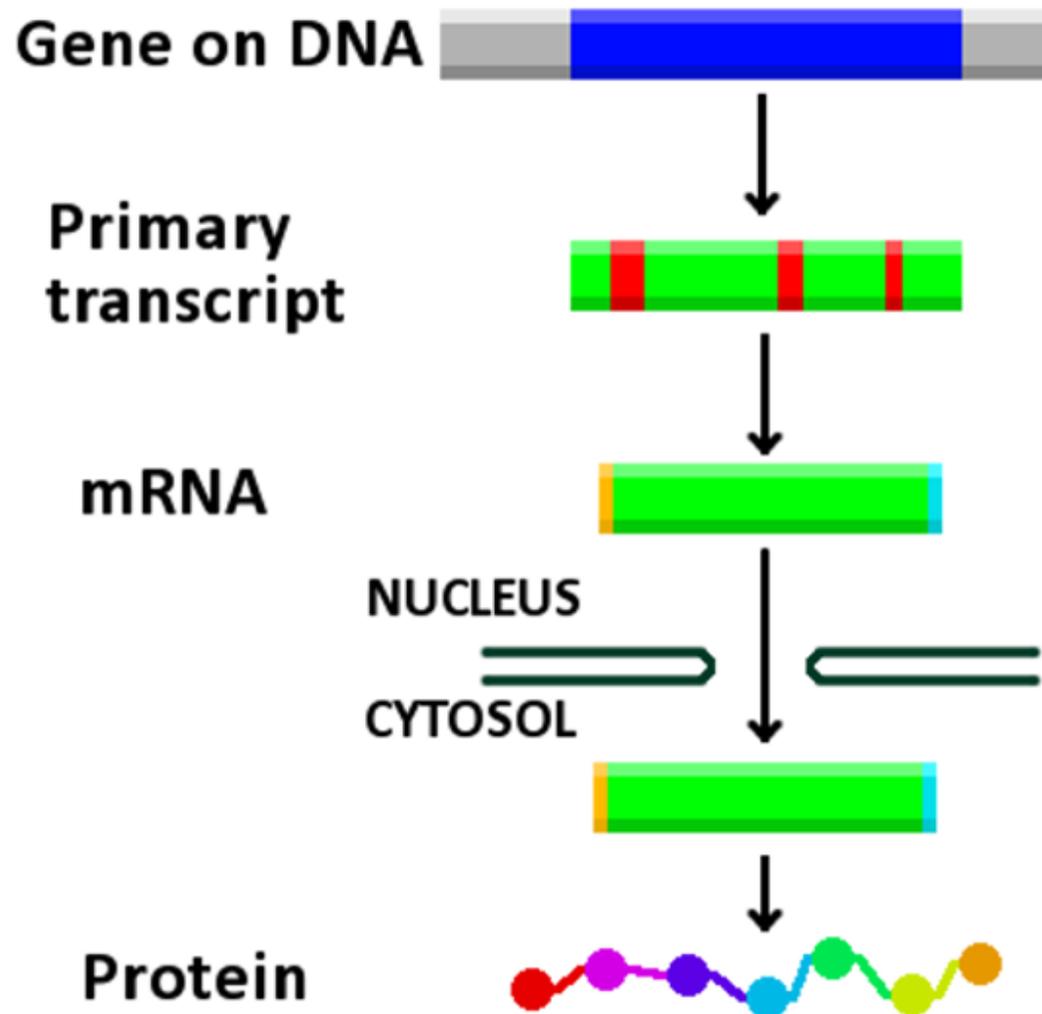
The Open Medicine Foundation in partnership with the Edward P. Evans Foundation has fully funded a ground-breaking grant to the Open Medicine Institute (OMI), Mountain View, CA to determine if genetics plays a role in ME/CFS. This grant will provide answers within the next 12 months.

- **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.

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.



Accelerate this Year of Discovery! Please Donate Now

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

1. Clinical Trials: Rituximab and Valgancyclovir
2. Neuro Registry & Biobank- **Partially Funded**
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**

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

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, along with OpenMedNet increased capacity building, project #2, 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
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**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.**

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